

Economy and Social Inclusion
Creating a Society for All

William P. Alford
Mei Liao
Fengming Cui *Editors*

An Oral History of the Special Olympics in China Volume 2

The Movement

 Springer Open

Economy and Social Inclusion

Creating a Society for All

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This book and its sequel, *An Oral History of the Special Olympics in China Vol 3—Finding and Keeping a Job*, together with the summary volume, *An Oral History of the Special Olympics in China Vol 1—Overview*, commemorate the 50th Anniversary of the Special Olympics 1968–2018. The three volumes are Open Access books.

To the people and organizations dedicated to promoting the dignity and the social inclusion of persons with intellectual disabilities and a better world for all.

Preface

This volume is a collection of interviews with the families of 18 people with an intellectual disability (ID) in Shanghai who have participated in the Special Olympics movement.

Special Olympics East Asia contacted a number of families and 4 of them agreed to be interviewed. Ms. Meizhen Zhou, from 1 of the 4 families, a Special Olympics family leader, successfully recruited another 13 families, the majority of which have sons or daughters on the drumming team of the Shanghai Hongkou District Disabled Persons' Federation.¹ The remaining family belongs to a Papa John's employee with ID. Because the family has participated in the Special Olympics movement, interviews with this family are included in this volume.

The 18 subjects of this volume, each with ID, participated in the Special Olympics World Games, Special Olympics National Games, or community-level Special Olympics activities. Their experiences reflect the different levels of Special Olympics and its profound impact on people with ID.

At the meeting for parents whereat the oral history project was introduced, I was deeply impressed with the families of the drumming team of the Shanghai Hongkou District DPF. They treated each other like family and were open and optimistic. Sons and daughters from these families have varying degrees of disabilities, and have had different experiences. Some of them have had no schooling, some are attending special education schools, some have been to regular schools, and some have earned an associate degree. Earlier on in life, the parents struggled desperately and shed tears every day. Sports brought these families together, and by encouraging and comforting each other, they have established a small-scale symbiosis. Now the parents have the courage to embrace reality and embrace life, and many of them were willing to use their real names for the interviews.

¹This is the district level's branch of China Disabled Persons' Federation. China Disabled Persons' Federation is a national umbrella organization for persons with diverse disabilities. More information is available on the link: http://www.cdpcf.org.cn/english/About/overview_1793/. Disabled Person's Federation abbreviated as DPF.

Without support from friends and groups, individual families of people with ID are lone boats on a vast ocean. They are entirely on their own, navigating over choppy waters and towering waves. They are lonely, helpless, and despairing about tomorrow. If they can be brought together by the Special Olympics movement to form a community or group, people with ID can become more capable in sports and in life. The pain of each family can be alleviated to a significant extent and the quality of life of everyone involved can be enhanced.

Official or semi-official organizations provide the skeleton whereas private organizations established by families of people with ID are the flesh and blood. Without the skeleton, the flesh and blood won't have support, but without the flesh and blood, the skeleton has no purpose and no life force. This is my takeaway message from my interaction with the drumming team.

Four others with ID covered by this volume have participated in world-level Special Olympics activities. They are now married with kids, or working in a stable job, or studying for an associate degree. They share two apparent traits. The first one is not being deterred by hard work. The young man who climbed the "Great Wall" at the Special Olympics opening ceremony fell in training from heat stroke; the young women who won multiple Special Olympics gold medals started training at 7 a.m. every day; and the child selected as the Special Olympics Global Ambassador walked 40 minutes to school and built a runner's body as a result. They lived the old saying that God will reward the hardworking, because if they had faltered even once in the face of difficulties, they would not have achieved today's results. The second shared trait is their strong desire to be independent and determination to be included in society. Neither they nor their parents are willing to sit at home and wait for the government to hand out subsidies. Instead, they long to earn their pay through hard work and live nine-to-five lives like other people. Today, their wishes have come true for the most part. Hopefully, their stories can motivate more people with intellectual disabilities to venture outside their families and be included in society.

And hopefully, readers from all walks of life can also be enlightened and inspired.

Interviewers for this volume were undergraduate and graduate students from Fudan University and East China Normal University. We would like to thank them for their dedication and for having presented people with ID in print.

Translated by Cissy Zhao

Edited by Andy Boreham and Zijian Chen

Shanghai, China

Mei Liao

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About the Editors

William P. Alford is Henry L. Stimson Professor at Harvard Law School where he also serves as Vice Dean for the Graduate Program and International Legal Studies, Director of East Asian Legal Studies and Chair of the Harvard Law School Project on Disability. A scholar of Chinese law and society, his books include *To Steal a Book is an Elegant Offense: Intellectual Property Law in Chinese Civilization* (Stanford 1995); *Raising the Bar: The Emerging Legal Profession in East Asia* (Harvard 2007), *Can ji ren fa lu bao zhang ji zhi yan jiu* (A Study of Legal Mechanisms to Protect Persons with Disabilities) (Huaxia 2008, with Wang Liming and Ma Yu'er, in Chinese), *Prospects for the Professions in China* (Routledge 2011, with William Kirby and Kenneth Winston), and *Taiwan and International Human Rights: A Story of Transformation* (Springer 2019, with Jerome A. Cohen and Chang-Fa Lo). In addition, he has published dozens of articles concerning China, law, and international affairs. His work has been recognized with an honorary doctorate by the University of Geneva in 2010 and honorary professorships at Renmin University of China and Zhejiang University. He is also the recipient of the inaugural O'Melveny & Myers Centennial Award, the Kluwer China Prize, a Qatar Pearls of Praise Award, an Abe (Japan) Fellowship, the Harvard Law School Alumni Association Award, an award from Special Olympics International recognizing his work on behalf of persons with intellectual disabilities, and several other fellowships and honors. He is a graduate of Amherst College (B.A.), the University of Cambridge (LL.B.), Yale University (M.A. in History and M.A. in Chinese Studies), and Harvard Law School (J.D.).

Mei Liao is an independent scholar at present. Founder of Shanghai Shida Public Welfare Foundation. From 1996 to 2004, she taught as an Assistant Professor and Associate Professor in the History Department of Fudan University in Shanghai. Her research interests include Chinese intellectual history and history of late Qing Dynasty. She has published the book *Wang Kang-nian: From the Civil Rights*

Theory to Cultural Conservatism (Shanghai Classics Publishing House, 2001); the novel *Under the Tower of Ivory* (Jiangsu Literature and Art Publishing House, 2012); and a number of papers. She received her bachelor's, master's, and doctoral degrees in history from Fudan University.

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She Enjoys Idioms and Fables



Yunxiang Zhang

Interview with Miss Li Lin's Mother and Li Lin

Li Lin, female, born in 1976. Only child. Grade III intellectual disability. No schooling. Joined a subdistrict Sunshine Home¹ in 2005.

Interviewees: Chengzhi Wang (Li Lin's mother) and Li Lin

Interviewer and writer: Yunxiang Zhang

Interview date: October 27, 2016 and December 14, 2016

Interview place: A McDonald's restaurant in Xuhui District, Shanghai

An Educated Youth Who Returned to Shanghai and Married Late

Q: How did you get to know your husband?

Lin's mother: It was a marriage arranged by our parents.

Q: Did your parents arrange your first dates?

Lin's mother: No, they didn't, I got to know him through one of my colleagues, but I didn't like him at first. Why did I still marry him? Because I was pushed by my family and other people around me. I wasn't young when I returned from the

¹The Sunshine Home's proper name is the Sunshine Disabled Home, a government-run non-profit institution that serves disabled adults throughout Shanghai. It was set up by the Shanghai government as part of 'the Sunshine Movement for People with Intellectual Disabilities' in 2005. The main aims of the institutes are improving the independence, social skills, and working capabilities of 16- to 35-year-old disabled people in the community by encouraging them to become more involved in community life.

Y. Zhang (✉)

East China Normal University, 3663 Zhongshan Bei Road, Shanghai 200062, China

countryside, I'd been there for several years after graduating from high school in 1968. The truth was, I didn't go to school until I was 10 because I had a birth defect and was a slow developer.

When I came back Shanghai at the age of 28, straight away, I was getting the same questions from everybody: "Do you have a boyfriend? Are you married? You're not young anymore, you should get married soon." At the same time, my mother—she used to be a teacher—developed a mental illness during the Cultural Revolution that developed into dementia. I married my husband even with all these social and family pressures.

Q: When did you get married?

Lin's mother: When I was 30, in March 1976.

Q: What kind of work did you do during that period?

Lin's mother: Li Lin's dad worked with technology. When I came back to Shanghai, I was in a bad state which affected my health, so I looked for an easier job, working in the canteen of a dye factory.

Q: Did you both work at the same place?

Lin's mother: No, we didn't, my husband worked at the Shanghai Color Printing Factory, I worked at the Second Printing and Dyeing Mill. It was a marriage arranged by our parents and we only had one child.

An Infant Born with a Vacuum Delivery

Lin's mother: I was pregnant soon after we got married and I had the baby in December.

Q: The child was born in December?

Lin's mother: That's right. After a ten-month pregnancy, I gave birth on 17 December. I took her to a children's hospital when she was 18 months old and was told she had some kind of a brain problem. Until that time, we hadn't realized she was... People used to call this kind of child an "idiot"; there wasn't a name like intellectually disabled at that time.

Q: Were you told what had caused her problem?

Lin's mother: It all came down to me and my health problems. When I was working on the farm as an educated urban youth, one night I hurt myself badly in a fall.

Do you know about the Cultural Revolution? Have you seen any TV programs about that period? At that time, we had to follow "the early request and late report" rule, and we had meetings every evening. That place only had rough concrete roads; that was the cause of my fall and my tailbone was broken. However, we didn't have a medical service and nobody treated this problem seriously, even me. It healed by itself and my tailbone has been bent ever since then.

This problem affected the delivery. A normal birth usually takes around 10 h, but after my waters had broken my child didn't come out for over 54 h. It was almost dry by that time and the infant got cerebral hypoxia. The doctor used oxytocin, but it didn't work, and finally the doctor found out that my tailbone was bent and

that was causing the problem. The doctors ran out choices and they had to do a vacuum delivery. So my daughter had cerebral hypoxia at first and was injured by the vacuum process; these two things damaged her brain. The vacuum delivery left a big soft swelling on my daughter's head. Anyway, my child had an intellectual disability after this.

Q: How did you feel?

Lin's mother: My heart was broken. I cried every day until my daughter was in her late teens. As you can imagine, people spoke ill of me behind my back and said I was having an unhappy family life and I'd got a disabled child. I was trapped at home and outside. I pulled through this difficult situation. Now people call me the "iron woman", but they don't know the reason or why.

People gave me a lot of advice, for example one colleague who I called auntie used to encourage me: "Xiao Wang, you must be brave and strong in this situation. You should learn something from Ah Q, the character in the Xun Lu novel,² you have to know when to stop thinking if you can't figure out a solution to the problem. It's best to live like Ah Q, a bit crazy but strong; you have to smile all the time, let it be and take it easy."

I was really inspired by her words; if I hadn't listened to her, I probably wouldn't have a family today. In my family, my mother was ill, I didn't get on with my husband, I totally lost hope and cried every day. When my daughter was little, my face was always covered in tears. I used to cry and get upset after I hit my daughter when she had done something wrong.

When she was little, it was difficult to send her to the babysitter's place. There was a direct bus from my work, but I had to go in a different direction to go to the babysitter's home, then take a bus from her place, it was a much longer journey. How hard that journey was. As a small person, for me the worse part of the bus journey was getting my daughter on and off the bus, she didn't have much control over her body. I remember, once, we fell down together, I injured my leg and my daughter cracked her head. Both of us were crying, but I was unable to pick her up at that moment, especially with an injured leg. Who would pity you? Nobody.

I worked at the logistics department at first, but my boss moved me from the office job to a much worse job—a staff canteen cleaner—cleaning and washing vegetables: I didn't even belong to the canteen department. My story was just like Xiaoping Deng's, who dropped down and was then promoted afterwards, several times. Finally, I got promoted too.

Q: Couldn't you tell she had a problem when she was an infant?

Lin's mother: When she was a baby, she just made some noises from time to time; when she was happy, she would jump or kick her legs, but I didn't think that was a problem, because I had been a slow developer too. I was only able to walk when I was seven, so I thought my daughter was probably just like me, a late developer in

²Ah Q is a famous character in modern Chinese literature who came from one of Xun Lu's masterpieces *The True Story of Ah Q* in 1922. As a poor peasant with little education, Ah Q had a difficult life and he had to use his well-known 'spiritual victories'—a kind of mad trick—to lift his self-esteem to an acceptable spiritual 'superior' level from the sufferings and the bullies he encountered.

speaking and walking, more than ordinary children. I never thought she had a mental problem.

Q: When did she start speaking and walking?

Lin's mother: When she was four. She spoke well but with broken up sentences and a small vocabulary. If you blamed her for something she'd done, she couldn't explain herself. Not like today, if something happens to her, she can reason with you and talks all the time. Nowadays, you have to be careful when you judge her.

Q: Did you have any other problems other than learning to walk late?

Lin's mother: No, I was fine. I could walk at seven, but I couldn't go to school the following year, because I hadn't grown up enough. For the same reason, the school registrar rejected me three times until I was ten; my mom was so worried and she said to the teacher: "Please ask her some questions, my daughter knows everything!" When I finally started school, I became known as a good student straight away, because my body was small but my mental age was equal to a fourth year student; so the first 2 years of study was very easy for me. According to superstition, if a man is too clever, it might prove to be a negative for his children's luck and intelligence; a saying that works for me at least: I'm a really competitive person but my daughter is weak.

Q: Did you find out about your daughter's condition from the doctor when she was 18 months old?

Lin's mother: Yes, we found out she had a mental problem, but before then, when she was 10 months old, she started shivering and was kept in the ward for several days. Nobody could say what the problem was, but she was just sweating heavily, her forehead was sweaty, but her chin was cold and she was covered with a cold sweat. I mopped her face with a handkerchief, but it was soaking wet within half an hour. She was sweating all the time, she couldn't say anything of course, but she shivered with cold.

After four days of tests and exams the doctors still couldn't diagnose her problem, but I overheard some of their conversations and they thought my daughter might have a brain disease.

Q: Did she get sick before that?

Lin's mother: No, she was quite healthy before.

Q: Did she have a cold or something like that before?

Lin's mother: Well, she didn't have any sickness when she was very little, but she started getting viruses from time to time when she had grown up a bit.

Bringing her up to what she is now was the best thing I could do for her. When she was born, she was cross-eyed and you could hardly see her pupils, they were tiny; her head was crooked, leaning to one side, and she walked in a very awkward way.

Anyway, when she was born like this and lots of people said to me this girl isn't worth raising any more, but she was my daughter and I couldn't give her up, no way.

Ten Years' Looking for Medicine

Lin's mother: Since I knew she had a brain disease, I started to look for specialists in hospitals through my contacts. There was a relative of a classmate who worked at a hospital of traditional Chinese medicine at the crossroads of Shimen Second Road and Nanjing Road. He helped me find some of the latest medicine for the infant's problem; he used his contacts to help me until he moved to Hong Kong. I tried all kinds of new medicine, whatever I could get for my daughter. My salary wasn't much, but I saved every penny that I could to buy these pills.

Q: How old was your daughter at that time?

Lin's mother: I stopped looking for treatment and medicine when she turned ten.

Q: Do you mean from the time that you first noticed her problem until she was ten?

Lin's mother: Yes, that's right, I never stopped trying new medicine for her during that time. Once we tried acupuncture, during the treatment the doctor put more than 20 gold needles in her head. I only stopped looking for treatment when she was ten.

At that time, through one of my contacts, I saw a very good pediatrician in the Children's Hospital. The doctor told me: "You shouldn't give your daughter any more new pills, there isn't anything that can cure her problem. All of those so-called new drugs on the market can't sort out her problem. The promotional statements on these drugs is just there for the patient's parents, there's no proof that it works. Don't be fooled and waste any more money." It's why I stopped trying new drugs.

Q: Did those drugs do anything good for your daughter?

Lin's mother: Not really. The problem with her eyes was sorted out by surgery when she was six. I wasn't sure if it would work; I thought I was just fighting a losing battle.

Q: An operation?

Lin's mother: Yes, an eye operation for her crossed-eye. Before the operation, many people told me that my daughter didn't need surgery, a pair of special glasses would do the job.

Later, I took her to the hospital at the crossroads of Huaihai Road and Fenyang Road and I happened by chance to meet the Dean that time. He said to me: "Glasses won't be able to cure your daughter's eyesight, she needs an operation." He also explained the condition to me: "Her optic nerves are paralyzed and aren't flexible anymore, only an operation will be able to sort out this problem, not a pair of glasses." So my daughter had eye surgery and after that, I started focusing on her crooked head by telling her off to stop her.

Q: When did she stop tilting her head to one side?

Lin's mother: She was cured after an operation when she was six.

Q: Well, I guess you spent quite a lot of money on her.

Lin's mother: Oh, I wouldn't say that.

A Mother Eager to Do Everything Well

Lin's mother: I spent all my days in tears after my daughter was born and I was always thinking about how I could have a baby like this; how could a strong person like me have a disabled baby?! (A forced smile) I couldn't work it out and I really struggled with the problem.

I couldn't be at ease when I thought about what would happen to my daughter after I died—who would look after her? I heard so many miserable stories about children like her, I couldn't trust anybody. Finally, there was only one thought left—I'll strangle her before I die—we have to live and die together. I couldn't give her to anybody else. This idea came to mind all the time.

Sometimes, I got angry with my daughter when I felt very bad, I even hit her. I used to cry for a long time after I hit her, because I really pitied her. I can't think about how difficult my life had been bringing up my daughter in this situation—a mother who had dementia and a bad relationship with my husband—I can't stop crying when I think back about that time.

All my colleagues looked down on me after I gave birth to this poor child. I was so keen to do everything the best I could but even this didn't help me win respect. Those older female colleagues—we used to call them aunties—they had little or no education and were quite nasty. The truth of the world is that people envy a man when he's wealthier than them and despise him when he has a worse life. Oh, there was an auntie, she liked to talk about other people behind their back so much, and she liked saying bad things about me. I was a fast worker and used to finish my whole day's duty within 2 h. After that, I liked to help one of my colleagues, she was my boss as well. After a while, she was promoted and I got her position.

At the same time, I was doing an adult education degree, because I had only finished my high school study when I left Shanghai and went to the countryside farm during the Cultural Revolution.

I'm a very proud person, some of my colleagues liked to do outside work during their working time, but I wouldn't have been able to pay the price and lose face if I'd been caught doing this, so I told myself I mustn't do this. After I finished my own work, I would either cover for a colleague, who I just mentioned, or read. I was the kind of person who wanted to do better than everybody else.

Q: Did you find a place to study by yourself?

Lin's mother: Yes, I took up a place in the Arts in a high school after I passed the entrance test; I had graduated from a high school before that, but never received a certificate because the Cultural Revolution interrupted everything.

Actually, since I was young, I was good at science subjects but not arts subjects. When I was a high school student, Chinese exams were my weakness. I wasn't good at practical writing or rhetorical writing, so my Chinese score was just above 50% and not enough to pass the exam. Then there was PE; that was difficult. Except for these two modules, I used to get 95% in all my other exams. After Ire-sat this level, I did a technical secondary school level accounting degree.

Q (smiles): Well, you did quite a lot of exams!

Lin's mother(laughs): You're right, I have a lot of report cards and I still keep them, a big pile of them.

Q: You're brilliant.

Lin's mother: But I wasn't able to do anything about my daughter. There is an old saying, "don't lose on the starting line", but I lost all my credits when my daughter was born (laughing).

She Left the Nursery and Primary School

Lin's mother: I'm a very proud person, but I got stuck in a rut after I had my daughter. I had problems with both family and at work. Nobody could look after my daughter while I was at work, my mother couldn't look after a child, and my mother-in-law was a tiny person and she couldn't do it either.

Q: Nobody helped you with babysitting?

Lin's mother: The only choice I had was to put her in the factory's nursery. There was a teacher who treated my daughter quite badly. She was a college graduate and could inject drugs, so I gave my daughter's injections to her—they had to be kept in the fridge until used—and I asked her to inject my daughter when required. While I was there, she put the drugs in cold water and promised me that she'd inject my daughter soon. So I left and didn't insist that she did this immediately because I thought it wouldn't do any harm if the injection was delayed for a short while.

During that period, I was in charge of the food coupons and my office was just next to the nursery.

Q: The two places were very close?

Lin's mother: Yes, both of us worked in the logistics department.

Later that day, I saw an injection bottle in the public bathroom and realized that it was my daughter's drugs. It made me angry. I went back to the nursery and asked the teacher if she had injected my daughter. That teacher said: "Of course I did, you can ask around if you don't trust me." She looked very confident. But I couldn't check further with the witnesses she mentioned, because at that time I was being bullied by my boss; everybody discriminated against me, nobody trusted me.

One temporary worker told me: "Auntie Wang, please don't say anything else, because you can't win this battle with them." He also said he knew I told the truth, but in his situation, he couldn't support me. He also suggested that I should take my daughter to the affiliated hospital for her injections. After that, I stopped sending my daughter to the nursery but took her to work with me.

Sometimes, the gate guards would stop my daughter going into the factory, so I had to leave her at the guardhouse. I didn't care about saving face anymore. After I found out about my daughter's condition, I stopped worrying about any public reputation and stopped all of my other family duties to look after her. That day, I let the guards choose, if they didn't let her inside with me, the only thing I would be able to do is leave her with them. If she came into the office with me, she had to sit

on a stool that looked like a toilet seat, which had a hole in the middle, for 8 h until I finished work.

Q: Did she do anything else?

Lin's mother: No, she would just sit there.

Q: Was she well behaved and sat there for the whole day?

Lin's mother: She was a silly child, there wasn't anything else she could do.

Q: How old was she when she started going to the office with you?

Lin's mother: She went to the nursery until she was 20 months old, later she was looked after by her first nanny, a nursery teacher's mom who retired from work with a large number of workers of her age in 1979. She told me: "Xiao Wang, don't cry anymore, I'm retired now and I can care for your daughter."

Q: When your daughter was over 20 months old?

Lin's mother: Yes, my daughter stayed with her for around 3 years. This auntie had a very introverted son, kind of autistic, perhaps. With the experience of looking after her own son, she said: "I don't think she'll be like this forever, let me try to bring her up in my way."

I told her that my daughter wasn't a clever person, but she was very patient with her. The surprising thing was she taught my daughter to play with building blocks, she could even build some complex buildings. My daughter proved that she was a child worth teaching, right? She certainly did that.

Q: How did you feel when you saw her block buildings?

Lin's mother: I was pleased that she could do such a thing. People called her an idiot, meaning she was totally useless, but this achievement certainly proved that she was better than everybody had thought. Since then, I started to buy her only educational toys that were good for developing her intelligence.

She was a slow learner and couldn't keep still for long. No school wanted her. In those days around the end of the 1970s to the early 1980s, there were no special schools. Even if there had been such a school, I wouldn't have believed it could treat the children well enough. I was worried that it wouldn't do anything for her intellectual development if I sent her to a charity place, especially when she was just starting to develop her intelligence. It was better to let her stay in society.

Q: What do you mean by letting her stay in society?

Lin's mother: Keeping her at home, a place outside school.

Q: Did she go to a primary school?

Lin's mother: She only attended a regular primary school for a month. During that month, her teacher came to me and complained about her behavior all the time. I tried very hard to avoid being confronted by the teacher until I had no choice. Finally, the school forced me to take her out.

Q: What was her school performance like?

Lin's mother: She couldn't sit still in the classroom and she distracted the other students quite often. On the day I enrolled her at the primary school, she was sick and I carried her in my arms, so the teachers of the Baoding Road Primary School didn't see her problem. But in the classroom, when the teacher asked the students to take out their books and pencil boxes, my daughter, after she had taken her things out, would run up to the other students and started shouting: "Take out, take out, take

out your stuff..." Her behavior disturbed the class. She kept doing this kind of thing in that one month at school and I had to hide from her teacher and his complaints. Can you imagine what I felt like at that time? It was a very difficult period for me, and I couldn't stop myself thinking about what would happen to her when I died.

Q: So after that you had to keep her at home and look after her yourself?

Lin's mother: Yes, I've kept her at home since then.

A Girl Enjoyed Care of Many Families

Q: Who took care of the child when you were at work?

Lin's mother: When my daughter was about 7 or 8 years old, there wasn't a single person to look after her, so I had to leave her with my mother. But because of my mother's health condition—she was suffering from dementia—she couldn't look after my daughter properly and even had a damaging effect on the girl. This experience made my daughter even worse. My mother was paranoid and was always thinking that somebody was trying to hurt her, like her food would be poisoned and she had to eat in a locked cupboard with all of the cracks sealed. After that, she had to wear a mask all the time. People kept telling me that I mustn't leave the child with her, but I didn't have a choice.

My mother passed away when my daughter was ten and I had to leave her with my mother-in-law, even though her condition didn't really allow her to take this kind of responsibility. Fortunately, by then, Li Lin was a little older and easier to look after. But my daughter kept making all kinds of trouble when they were together, I couldn't relax while I was at work, I worried about them all the time, thinking she might throw the washing-up bowl on her grandma's head or set fire to the home.

Our old home on Haining Road was a wooden ranch-style building built by the Japanese; a fire was the last thing you wanted—it might burn down the whole area. Once I caught my daughter playing with fire at home, but we were lucky our downstairs neighbors saw her and put out the flames. They were shopkeepers and his family lived on the ground floor. They had come up to use our gas stove. That day, they found a fire when they came up to cook their dinner. The two families were quite close and I used to share some nice dishes with them. As a return favor, they kept an eye on my family for me when I wasn't there.

Anyway, that was how my daughter grew up, she was raised by many different families. After my mother died, one of her neighbors looked after the girl for several months and after that, she stayed with my mother-in-law's neighbor for a while. Actually, my daughter was raised by too many people, I can't even remember how many.

Even though I never felt at ease while I was at the office, especially when she stayed with my mother-in-law, any phone call from the family would drive me mad, and in addition to my daughter, I was also worried about her paternal grandma. If anything bad happened to her, my four sisters-in-law would definitely give me a hard time.

Q: Do you mean your husband's family?

Lin's mother: Yes. During that period, we lived with my mother-in-law, but we had to looker after more people than that. One of my sisters-in-law came often with her husband and their two children and somehow, in addition to looking after my mother-in-law, we had to look after the extended family.

Q: Did this paternal auntie and her family live with you?

Lin's mother: No, they didn't, but they came for meals and stayed for a long time quiet often. At the same time, they looked down on us. My daughter used to complain about her auntie and her family, they would share some special food without her or only gave her a tiny piece.

Q: She could understand this idea of "how much"?

Lin's mother: Of course. I said to her: "Mom earns a salary and we aren't short of money; don't complain to anybody else except me if you think you've been treated unfairly by somebody, I'll buy you what you want." At the same time, my husband wanted me to be in charge of all the family finances, and I refused, how I could take care of so many people? I didn't want to argue with anybody about family issues, especially when I knew my husband's and my salary wouldn't be enough to feed this big family. I played ignorant and let my husband be the boss of the family while I just cared about the money in my own pocket. I insisted on one thing from my husband, he could spend his last penny on his family if he wanted to, but when the money ran out, he'd have to ask his family for help, not me. If they refused to pay anything for their daily expenses, that would be the end of their relationship.

Fortunately, my niece and nephew, his sister-in-law's children, were sophisticated people. They used to give my husband money without my knowledge from time to time. My mother-in-law wasn't an educated person, but she knew these family rules well enough and she used to give money to my husband secretly. In this situation, I just pretended I didn't know anything.

After Li Lin complained to me about being treated unfairly by these relatives, I started taking her out after work if they were there. At that time, I worked in the logistics office and was in charge of the canteen, our working time was from 6 a.m. to 2 p.m. I used to take my daughter out when I got home from work. Our home was on the Haining Road and Sichuang Road—a busy and bustling area—I used to buy her snacks and teach her something while we strolled around the streets.

Q: It was just the two of you who went out together, when the auntie and her family were at home?

Lin's mother: Yes, they weren't my responsibility. I bought my daughter whatever she wanted and taught her as much as I could. I never criticized her at home when she did something wrong, but I'd discussed her problems with her when we were out, I used to say to her: "Today, you were wrong when you talked to your dad in that way, you weren't very nice to him."

Q: Do you mean that you didn't criticize Li Lin in front of your husband?

Lin's mother: No, I didn't. I usually talked about her problems while we walked around the city. The first time, I just pointed the problem in a nice way, but if she made the same mistake again I'd criticize her and question her: "Why did you do that again?" If the same thing happened a third time, I might scold her. I was strict

with her and I would set down the rules for her all the time, criticizing and scolding her quite often when she was young.

Q: Did it work?

Lin's mother: Not really, she was too naughty to keep in line.

Q: What about her father? Did he take care of her?

Lin's mother: Yes, but there wasn't very much he could do except criticize her. He didn't spend very much time with her, because he was busy with his work. He wasn't a patient person with the child. These days, Li Lin is great with housework, but she's still criticized by her dad.

Q: Has he changed his attitude?

Lin's mother: He isn't satisfied with her improvement and he still thinks she isn't smart enough.

Q: Is there a kind of bias in him?

Lin's mother: Well, I stopped worrying about how I look in other people's eyes, or thinking about losing face in public, but her dad has the opposite attitude. Not one of his bosses and colleagues knew anything about our daughter until he retired. He used to give ambiguous answers when his colleagues asked about his child's education or marriage prospects. Some of his colleagues only found out the truth when they got in touch with him after he'd left his job. Very few people in his workplace knew about our daughter.

Q: Was he really afraid of losing face?

Lin's mother: Yes, he's that kind of person. In accordance with the worker's welfare policy, all workers should receive some subsidy and temporary financial support for a disabled child, but my husband was too proud, he cared about his face, not the subsidies.

Q: What about your colleagues?

Lin's mother: Of course, they were biased against my daughter as well. I was a pretty capable employee and I received an important position from the boss, but I was often insulted by the workers about my daughter's condition.

Q: Your daughter stayed at home until she was a teenager?

Lin's mother: Until she was about 20.

Q: She never went to school?

Lin's mother: No, she never went to school.

The Girl Kept at Home for Three Years

Q: Were you the only person who took care of her in your family?

Li Lin: I was very poor in the early days.

Lin's mother: She was locked up at home by me.

Lin: Auntie, you know I was poor, just think about how poor I was.

Lin's mother: What have I told you about interrupting other people's conversations? Stop butting in.

Lin: Hold on one second, hold on, please. Why did I have to go to the Sunshine Home? When I was at home, somebody beat me (talks to her mother), bullied me, when we went out.

Lin's mother: She is talking about a time that a child threw stones at her when she walked past.

Q: Did you keep her company when she played outside?

Lin's mother: I wasn't there that time.

Q: So she went out without you knowing, right?

Lin's mother: Yes that's right. When she was around 20 and my mother-in-law had passed away, there wasn't anybody to take care of her in the daytime, so I had to leave her locked in the apartment when I went to work. This went on for 3 years before I retired, but after that I continued to work at the subdistrict office for another three more years.

Q: Didn't you worry that she might have an accident?

Lin's mother: Our place was quite safe for her, the plug sockets were high up, even I can only reach them when I stand on a stool. My daughter wasn't able to touch them at all because she's shorter than me. We locked the cooker and gas as well, we only unlocked it when my husband or I arrived home. Basically, we locked the door, the gas, and any dangerous stuff. I came back home and cooked for her during the lunch break.

Q: What did she do at home?

Lin's mother: Watched TV.

Q: Did she only watch TV when she was alone at home?

Lin's mother: Well, except for the TV I didn't give her anything else to play with, just in case she had an accident. Back then, we fixed the electric circuit box on a very high wall to make sure my daughter couldn't reach it; even I couldn't reach it easily. Her dad was good at DIY, so he made a wooden box for the gas cooker. She could only use the water tap, we kept her away from all the dangerous things like the electric circuit box and the fire.

Q: What did you do with her after work?

Lin's mother: I'd work for 3 h each morning and afternoon as a subdistrict official, I had a lunch break, so I cooked her lunch during my break and took her shopping after work.

I had an accounting certificate, secondary school diploma, high school diploma, and lots of other qualifications, but because of my daughter's condition, I couldn't take other jobs, so I worked at the local subdistrict office. I locked all of my certificates and qualifications in a trunk.

Q: You had to work locally to make sure you had time to look after your daughter?

Lin's mother: That's right. Also, for the same reason, I eventually quit this late job to look after her at home.

Q: How old was she when you stopped working?

Lin's mother: She was in her twenties.

A Participant of Mother's Community Services

Lin's mother: I retired in 1996, but carried on working as an official for the subdistrict office for another 3 years, until I became a housewife in 2000. After that, I gave all my time to my daughter. I started doing exercises in the community park every morning.

Q: Did your daughter go to the exercise with you?

Lin's mother: She went everywhere with me. I was a volunteer/teacher in the community. I used to teach lots people gardening, bead making, shoe crocheting. I had a big group of students in the community. Some of them invited me to join their morning exercise, so my daughter would go there with me. She did this group exercise without any real structure or rules for 5 years, until she joined the Sunshine Home. After that, I didn't need to do as many activities as before, but carried on with the morning exercise.

Q: Did she go to the free community classes with you? Did you teach her as well?

Lin's mother: No, she didn't go to the classes.

Q: Did she watch you when you were teaching?

Lin's mother: I taught my classes at home.

Q: At your home?

Lin's mother: Yes, at that time, community activity was a new thing and we didn't have a place to go, so the students would come to my place for their classes. Actually, it was a kind of handicraft club. I got on well with all of my students and they liked to come to my place. Everybody knew I didn't charge anything and I even provided food and materials. I'm a very good cook and I can cook all kinds of dishes, like drunken shrimp, fried dumplings, wonton. I used to cook some delicious things for them.

Q: Auntie, you seem a very capable person to me, very good with your hands.

Lin's mother: Well, I was cooking and teaching them for free, I never asked them for anything. I liked to help others rather than charge them in any way.

Q: So, you used to have activities at your home or in the park and your daughter stayed at home while you went out to the park events, right?

Lin's mother: We didn't go to a park, it was the community garden.

Q: Li Lin didn't go to the community garden with you, she stayed at home?

Lin's mother: Yes, she only went to the morning exercise group with me. But she didn't really know what to do, she would do the set-up exercises at the wrong time and pace. She used to crouch down when everybody else stood up. What a mess! She just didn't understand anything.

She Is Very Interested in Learning Idioms

Lin's mother: After I left the subdistrict office, my daughter started going everywhere with me and all the people around us got to know her. We live on the East Yuhang

Road and everybody who lives around the street up to the food market knows my daughter, even though some of them don't know me.

Her face is so easily recognized by people, that's why they know her. Anyway, I liked to take her out when I was free—this was also a time she could learn—I used to teach her stories, traditions, and culture.

My writing has never been great, but I was a good student and I could teach her all kinds of Chinese knowledge, classical Chinese essays, ancient Chinese, and *pinyin*.

Q: Did you teach her Chinese and math at home?

Lin's mother: Math is not for my daughter, she was unable to learn this, so she just learned Chinese from me. If you ask her about the things that I taught her during that period, she might still remember something. We didn't just recite the idioms, but gave her the context and the relationship with other idioms. If you ask her about the meaning of "Wo Xin Chang Dan",³ she might not remember all the details, but she could certainly tell you the brief narrative behind it.

Q: Was it difficult to teach her?

Lin's mother: Not at all, she's really interested in the idioms, she doesn't need the same thing explained twice. But if you try to teach her some numbers, her face will turn blank straight away, like a fool, and she stops talking to you.

Q: Did you teach her some simple numbers? Can she count?

Lin's mother: She can't count at all. In this respect, she's just a silly thing. She usually misses numbers here or there and can't count, math is her weakest subject.

Q: But she's good at literature and she really can recall the stories you tell her. When did you start teaching her idioms?

Lin's mother: When she was in her teens, I realized she had a special interest when she was around 15.

Q: You mean she took the initiative in developing an interest in idioms?

Lin's mother: Yes, it's why I started teaching her. I noticed her interest when she started repeating idioms that she'd heard on a TV program. Of course, she couldn't recall them properly, but the interest was certainly there. I started teaching her some simple phrases when I realized her interest. I only explained some of the more complex phrases in more detail when her desire to learn got stronger. Also, I found out she had a special talent for idioms—there was no need to repeat the same phrase twice—but she could never remember numbers.

Q: So, she learned to repeat idioms from TV programs before you taught her, that's right?

Lin's mother: Yes, she was able to repeat them, but she didn't understand how they were used, she could just naturally recall some of the words, and my teaching was based on her desire to learn.

³Wo Xin Chang Dan is a famous Chinese idiom. It literally means to sleep on brushwood and taste gall; the extended meaning is to endure hardship and to accomplish an ambition. The background story is historical and took place in the Spring and Autumn Period after the state of Wu had conquered the state of Yue. King Goujian of Yue was sent to King Fuchai of Wu's palace as a hostage. Goujian served Fuchai as a most obedient and loyal servant until later Fuchai came to trust him, then Fuchai released him. Later, Goujian spent a long and difficult time preparing for revenge, and finally he defeated Wu.

Q: She didn't understand the meanings of the idioms until you explained them to her?

Lin's mother: Only after I'd taught her.

Q: She started repeating some idioms before you taught her?

Lin's mother: Yes.

Q: It looks like she knows quite a lot of idioms?

Lin's mother: When she was young, perhaps in her early teens, she learned a new phrase "Feng Zhu Can Nian"⁴ without understanding the context and she said this to my dad who lived in Nanjing: "Grandpa, you're Feng Zhu Can Nian." My dad was very angry. He was a Chinese and English teacher, and this misuse of the phrase on him made it even worse.

Q: Her meaning was her grandpa is old and weak.

Lin's mother: That's right, but as a person of that age, he didn't like to hear something like that. He was angry, but he also taught her the right way of using the idioms: "You mustn't say this phrase to anybody, especially your family." You can understand her grandpa's feeling, right? There's nothing wrong with the idioms and stories on their own, but she shouldn't say them to members of her family.

Q: She used the phrases in the right way after you corrected her?

Lin's mother: Um...

Q: She still makes mistakes?

Lin's mother: Yes, she's probably around 70% accurate, that's good enough.

Q: She's pretty good, we all misuse phrases from time to time.

Lin's mother: I agree with you. She's getting better now; years ago, it took me several attempts to explain the meaning of "Wo Xin Chang Dan" to her—her verbal ability wasn't as good as it is today. I mean, she could only explain part of the meaning, but now she understands the context and also the meaning of the phrases much better. If I point my finger (points her finger at the table).

Lin: Mei Mu Chuang Qing.⁵

Lin's mother: If I draw a dragon and point at...

Lin: Drawing a dragon, Hua Long Dian Jing.⁶

Q: She knows them very well.

Lin's mother: If I draw a pancake.

Lin: Hua Bing Chong Ji.⁷

Lin's mother: You can see she knows lots of phrases and idioms, at least several hundred.

Q: How did you teach her?

⁴Feng Zhu Can Nian literally means a man who is old and ailing like a candle fluttering in the wind; the underlying meaning describes a man who has one foot in the grave.

⁵Mei Mu Chuan Qing means somebody is sending silent messages using his eyes.

⁶Hua Long Dian Jing literally means to bring the painted dragon to life by coloring in the pupils of its eyes; the underlying meaning is to add some simple words to confirm a vital point.

⁷Hua Bing Chong Ji literally means to draw cakes to allay hunger, the underlying meaning is to comfort oneself with fantasy thoughts without solving the real problems.

Lin's mother: I taught her the phrases by telling her stories. I used to tell her the background and context of the phrase if I knew it. I also taught her some fables in the same way. I was a big reader, and never forgot the things I read, but over 70% of well-educated people can't recall things after they've finished studying. A good memory also helped me with exam credits, even when I sometimes crammed for exams. As a big reader, one real benefit was I could teach her all kinds of things.

Q: How long did it take her to learn a new idiom?

Lin's mother: She could remember whatever you told her. But trying to teach her numbers was the total opposite, she could never remember anything.

Q: Could she learn and remember the idioms quickly?

Lin's mother: Certainly. She used to laugh away when I told her some funny ancient fable or a two-part allegorical saying. I used to explain the fable "Jie Gan Ru Cheng"⁸ through a story she could understand: there was a stupid boy, one day he had to take a long bamboo stick into a room, he tried to hold it horizontally the first time, but couldn't get in; then he stood the bamboo upright, and he couldn't get into the room either. Having failed twice he cut the stick in two. After I told her the story, I also tried to inspire her further with some questions; would he be able to take the bamboo inside if he carried it long ways? I explained the modern fable "Four Men Sleep on One Shoulder Pole" in the same way. My daughter was laughing away after she heard it, because she understood the story straight away.

Q: Now you realise she has a gift for literature?

Lin's mother: Yes, she's really good at Chinese. I can't say she never makes mistakes, but she's fine once you've corrected her.

Q: How did you feel the first time you realized she had this special talent?

Lin's mother: It was strange, because I couldn't work out how someone could have totally opposite abilities with literature and math. Her literary skill isn't perfect, her biggest problem is she can't work out the right context when using some idioms.

Q: Are you proud of her ability?

Lin's mother: Not really, after all, she doesn't have a sense of numbers and this problem affects her everyday life; she can't use money, for example. I can't leave her the money that I worked so hard to save to her, because if she can't look after it somebody might steal it from her. When my daughter was young, there was no disabled person's allowance, so I would worry about her future and saved every penny I could for her—add 1 yuan to 9 yuan and then I'd have a 10-yuan note; I kept collecting the coins to change 90 yuanto a 100-yuan note. Even though I had to spend most of my salary on my daughter's treatment—and at that time, my salary was only around 40–50 yuan a month—I never stopped saving a quarter or fifth of my income every month.

Q: It must have been very difficult.

Lin's mother: Everything I saved, I did it in this way. I'm not interested in illegal money. I made my fortune in my own way by saving from my daily expenses. If you

⁸Jie Gan Ru Cheng is an old ironic fable about a man trying to bring a very long plank through the city gate, but he fails twice by holding the plank vertically and horizontally. Later, an old wise man tells him to cut the plank in two to make sure he can carry it into the city.

ask my daughter who eats delicious food in our family, she'll tell you it's her and her dad. I rarely eat with them. Even though sometimes I might be a bit greedy with one of the dishes, I only allow myself a couple bites. Today, our family is better off than we ever used to be, but the most delicious food is reserved for them, not me.

Q: You give all your attention to your daughter.

Lin's mother: I used to tell my daughter: "I eat grass squeezed out of milk. I save all the best things for your dad and you."

She Is Independent and Loves Her Family Deeply

Q: How well can she look after herself?

Lin's mother: She can do some housework.

Q: What kind of housework?

Lin's mother: She started helping with the housework when she was quite young, but sometimes I have to clean up after her, things go wrong occasionally. For example, she used to go downstairs to drop off the rubbish, but she wouldn't come back home straight away and liked to wander around the yard; that's when sometimes she'd be bullied by the other children. Usually, if she spent too long a time downstairs, I had to go and find her to bring her back.

She's good at all kinds of housework, washing up, cleaning vegetables, using the microwave, and the rice maker. I only give her a blunt knife to work with just in case she cuts herself.

Because she can't read, we bought the simplest type of microwave oven and rice maker to make sure she can use them: smart machines are too complex for her. Recently I bought an intelligent microwave oven, a very simple and old model. We only taught her one way to use the microwave, switch on the machine for 2 min at a time. If the milk or food isn't warm enough, then she just needs to repeat this process. With the rice maker you only need to press it once, it's very easy to use.

The really smart household machines aren't suitable for our family. When people see our old-fashioned appliances they think we're too frugal, until they understand our daughter's condition. She can't read at all, it's impossible for her to use a smart machine. We didn't choose the cheapest stuff on purpose, but it's the right type for her.

Q: Can she clean her own teeth and dress herself?

Lin's mother: She's slow, but she's independent. She often wastes time or food. Once, I told her to wash a pair of apples for me, then I saw a huge bowl of water in the kitchen! She used a whole washing-up bowl of water to wash just two apples! What a waste! She might be responsible for a bigger part of our water, gas, and electricity bills. Actually, she'd still be wasting water today if I didn't save and recycle what she'd used in different way. We have a water bucket for the used kitchen water to flush the toilet afterwards, for example.

Q: You're right.

Lin's mother: A big washing-up bowl of water just to wash two apples!

Q: Does she know how to save the used water in the bucket for recycling?

Lin's mother: Yes, I taught her to do that. These days, her dad is older and he is showing some early signs of dementia, he messes up the toilet from time to time. I have to tell my daughter to clean up the toilet with a special cloth before she uses the bathroom. I also told her to wash this cloth with soap when she takes her shower every evening. She has no problem with this kind of job, she washes the dishcloths quite often as well.

She's a very tidy person, she even checked the bowls that I washed for her when she returned home from her 4-day summer camp.

She's pretty independent these days, she can stay at home by herself, but usually my husband and I will be at home with her, especially after her dad retired. She stayed at home on her own once when I had to go to Changzhou for a factory event and her dad had a business lunch on the same day. She was on her own for about 5 h and we were worried and almost canceled one of our appointments. Our daughter encouraged us to go: "You don't have to worry about anything, just go, I'll pass the time playing with my Apple and handwriting."

Q: She was okay staying at home herself, then?

Lin's mother: She was that day. I cooked her lunch in advance to make sure she only needed to heat up it in the microwave using the 2-min routine—heat the food for 2 min every time until it's cooked through.

Q: She certainly does what you've taught her.

Lin's mother: Well, her development is from all of our efforts. We've planned for everything for her, knowing her condition and characteristics.

Q: Has she ever done anything that moved you or made you happy?

Lin's mother: I can't say...

Lin: Of course I did...

Lin's mother: Okay, could you tell us something you did that made your mom happy?

Lin: Uh, once, Mom wasn't careful... Somehow, not on purpose, a careless mistake, one time... (She's talking about one time when her mom was sick) What could I do for her? I... Mom had taught me to cook all kinds of dishes, she needed to eat, so I had to cook something for her. I cooked a soup to go with something else for her.

(The mom smiles.)

Lin: I take care of Mom all the time, when Mom had a bad stomach that day, my dad couldn't cook, so I had to cook a meal for her. I cooked an egg dish, something else and a soup; I did all the work myself.

Lin's mother: She can't use the deep fryer or cook fried dish, but she can cook some complicated meat dishes like boiled duck, sliced cold chicken, or other dishes that don't need frying. She also can cook some vegetable dishes like egg custard, cucumber salad, and stewed ribs. She can cook lots of different things, to be honest.

Last time I had a fever for a month and couldn't cook for them, and for a while they had to eat some pretty tasteless boiled food. Later, I had to cook for several days even when I was sick.

Q: Your daughter looked after you when you were ill?

Lin's mother: Yes.

Q: Did she do all of the work by herself?

Lin's mother: Yes, she worked very hard that month. The taste wasn't always perfect, the rice might be too dry or too wet, the dishes can be a bit salty or too plain sometimes, but I eat anything she cooks for me.

Lin: Once, once... Mom I made a direct⁹ mistake when I was cooking the eggs. They were under cooked.

Lin's mother: You didn't boil it for long enough.

Lin: Mom used the microwave oven to cook them for a little bit longer, and the stuff in the microwave oven was... the egg was flying everywhere.

Q: But she knows how to look after her mother.

Lin's mother: Well, she took good care of me. She's the opposite of her dad in this way. He'd say that he's sick all the time to avoid doing housework, sometimes he even feigns illness. My daughter has never done anything like that, she'll only say she's very sick when she is. Even then, she'll get up and help me with the housework when she feels a bit better. She wouldn't avoid her duty even if she cuts her hand. If it was her dad, he wouldn't be able to leave his bed for days. She wouldn't stop working, it's one of her good characteristics.

Q: She seems like a very sensible child.

Lin's mother: She is, she's definitely a good child when it comes to things like this. When she injured her finger, I wouldn't ask her to help me with anything, but she worried about me and insisted on helping with the housework. Fortunately, her wound healed soon. She never uses illness as an excuse.

She Would Buy Birthday Gifts for Her Parents

Lin: Once, I bought Mom a skirt.

Q: Really, you bought her a skirt?

Lin's mother: What skirt are you talking about?

Lin: A purple skirt, maybe coffee colored, but you never wore it.

Q: Did she buy you a skirt?

Lin: I bought it once.

Lin's mother: You bought one for me?

Lin: Of course.

Lin's mother: Oh yes, she's right, it was actually a one-piece dress and she spent all of her savings on it. On my birthday when she gave it to me, she said: "Mom, I have a skirt for you."

Q: She bought it for your birthday, she's very generous.

Lin's mother: She was quite sensitive about my birthday.

Q: Did this happen when she was in her twenties?

⁹It's Li Lin's word, it's her way of speaking.

Lin's mother: She was over 20 at the time. She knew the dates of our birthdays because we used to tell her before the actual day. These days, when she's at the Sunshine Home, she tells her classmates about my birthday. Then the children would send me "happy birthday" WeChat messages on the day. One time, they even said they wanted to come to visit me. Such a pressure, I had to go down to the Sunshine Home and say to them: "I appreciate your kindness, but please don't spend your money on me. I'm your teacher, and I like to do all kinds of things for you, but I don't want anything in return."

I was just being honest with them. I didn't want to lose my reputation by taking gifts from the children.

Q: Does Li Lin remember your birthday every year?

Lin's mother: She does, because it's very easy to remember, it's the day that follows the Dragon Boat Festival. Her dad's birthday is the day before Spring Festival eve.

Q: Both of your birthdays are very easy to remember.

Lin: Mom's birthday is in the Spring Festival; and dad's birthday is on first day of February.¹⁰

Lin's mother: You see she knows.

Q: What does she do for your birthday?

Lin's mother: She's stopped buying things for us these days, but once she bought her dad a gift, a pair of trousers if I'm right. But she usually remembers my birthday; she's the same as the other children who are usually closer to their mothers.

Q: Did she buy a gift for you?

Lin's mother: I told her not to buy gifts, she doesn't have that kind of money. I hold on to most of her money, she has some savings from the red envelope gifts that she receives at Spring Festival. I don't want her spending her money on us, but these days she likes to use this "lucky" money to buy DVDs, even a new television, for the family.

Lin: Mom, Mom, Mom, Mom... I'm sorry, last time I did...

Lin's mother: She bought a television for us, she also bought herself a computer—actually, it's a tablet. It's a 9-inch iPad; it cost around 3,000 yuan and she paid 1,500 yuan.

Q: She used her own money to buy these things?

Lin's mother: She did, she gave me 1,500 and I paid the rest for her "big Apple".

Q: Do you give her pocket money?

Lin's mother: Sure, but she doesn't usually spend the money, she has a problem using money. I usually make sure she has a 5-yuan note with her just in case the Sunshine Home plans a spontaneous outdoor event. It's money for an emergency bus ticket or some steamed bread if she gets hungry.

Lin: I'm not... I don't buy things myself on purpose.

Lin's mother: Nowadays, she knows how to spend her money on some small things. If she sees a pretty notebook, she might spend 2 yuan to buy it herself. She

¹⁰Li Lin gave different information about her parents' birthdays; it's probably just a simple error of speech.

always tells us how much she spent afterwards and why, after she spent 2 yuan on the notebook, I topped up her pocket money to 5 yuan again.

Q: So she always has 5 yuan in her pocket, right?

Lin's mother: Yes.

Lin: I just carry the money with me, but I don't spend it very often.

Lin's mother: She doesn't use money very often, but to be honest, she doesn't know how to use it either. Anyway, she only buys small things like a notebook, pen, or other things that costs less than 5 yuan.

Q: What does she do if she sees something she likes that costs more than five?

Lin's mother: Then she'll ask me to buy it for her.

She Never Neglects Study or Play

Lin's mother: We don't let her play with some ordinary toys or games, but the computer is good for her, we bought it deliberately. She can't read and the computer can't speak to her, so we had to find a way for her to use the computer. We downloaded some emoticons: "hello", "bye-bye" and others she can use, this means she can talk to her cyber-friends using the pictures. For example, she can send an "I'm here" emoticon when she wants to say hello to somebody.

She likes to play with the computer around midnight after my husband and I go to bed. She uses the iPad too much, it's a bad habit, and it affects everything else she does. But she won't change even when we tell her. She will play with her iPad for a while if she wakes up earlier than us, she will only put the machine away when she hears us waking up.

She really lacks self-discipline and I can't handle her. Sometimes, it's hard to tell if she's clever or not, she seems to understand some things but not much, for example she knows how to turn down the sound right down if she's playing iPad at midnight, so I don't hear her. You can see this contradiction in her studies, she can't understand *pinyin* even when I try to teach her, but she can read some *pinyin* and idioms. When she is using the computer or smart phone to chat, she can type some words but not many—she can type my name using the Sougou *pinyin* software—my name is Wang Chengzhi, the character Zhi means wise, it's simple for the software to create the whole word when you type in the first character.

Q: So the software recognizes how to complete a word?

Lin's mother: I taught her how to make a keyboard shortcut, "WCZ" for my name, so she can find—Wang Chengzhi—in an easier way. So you see, she can't read, but she knows some characters even if it's not many.

Q: Can she switch on the computer?

Lin's mother: Her computer skills are probably better than yours. She connects to the Internet first, then she'll switch on the computer when the Internet is running.

Q: She can surf the Internet? What does she usually do online?

Lin's mother: Plays games!

Q: Plays games?

Lin's mother: Yes, we play a popular online farming game together and she likes to steal vegetables from her friends' farms. I usually tell her off when she makes some wrong decisions. In this game, players have to grow the right kind of crops to certain levels. If she plants the wrong stuff, it might affect her harvest. It's quite funny, I have to be patient and correct her even when she's playing a game. Sometimes, if we're going on a trip, I tell her how to plant the right crop in advance: "If you plan those quick harvest crops that only take several hours to grow, after we've been away for several days they'll go to waste. But if you plant some that take 3 days to grow, they will be ready to harvest when we come back home." I don't play this game anymore, but she still enjoys it.

Q: Apart from playing games, what does she usually do on weekends?

Lin's mother: She practices the side drum on Saturday and Sunday.

Q: She has to practice every weekend?

Lin's mother: She doesn't have a day off, she has to go to the Sunshine Home, and the district Disabled Persons' Federation center. She does all kinds of things except for reading and math. I tell her: "What a shame you couldn't study for a longer time, if you'd behaved better when you were younger you might have got a primary school diploma".

Q: Is she obedient?

Lin's mother: She usually listens to me. It's why I take her out all the time. She understands well enough after I've repeated these things to her again and again. Sometimes, she tells people, if her mom doesn't deal with her bad behavior...she might...

Q: She won't do what you told her not to do, right?

Lin's mother: She understands why I complain or criticize her.

Q: Does she understand that you criticize her for her own good?

Lin's mother: Yes, she knows that. When she was younger, she walked with her feet pointing out, it was awkward, easy for her to fall over when she straightened her back too much. I told her to walk with her feet straight and slowly, keep her chest out and stomach in.

Nowadays, she's big girl, but she doesn't push her belly out too far like some other children in their class. Some children are much bigger than my daughter, very big, perhaps over 15 stone. Now, she walks in a very decent way and she's started criticizing other people who don't walk in the right way: "Well, have a look Mom, that guy doesn't walk well."

Now you know that some people don't walk well, but when I corrected you, you said I was too tough and even said you might not be my daughter (talks to her daughter).

Q: Did she complain that you were too tough to her when she was younger?

Lin's mother: She said I was nasty to her, anyway, I used to correct and criticize how she walked constantly, but at least the way she walks is better these days, right? What a nice thing for her to walk with an open chest and straight back.

Q: I think she's lucky to have you.

Lin's mother: You're absolutely right, she's a very happy and lucky person.

Q: Does she have a phone?

Lin's mother: Yes, she has one.

Q: Does she use her phone to chat with her classmates on WeChat?

Lin's mother: No, I won't allow her to use WeChat. One of our downstairs neighbors who is a mildly intellectually disabled child, and this child got an 8,000-yuan phone bill on the first month of his contract, and 6,000 yuan for the second month. Altogether, the child wasted 14,000 yuan for 2 months. So I thought she'd better not use it.

Q: She doesn't need a phone.

Lin's mother: I told her that it's better not to use a phone network, the phone is just for me to keep an eye on you.

Q: Is she able to walk somewhere on her own? I mean from home to...

Lin's mother: No, she doesn't. She doesn't need to go to any places by herself, because I usually go with her when we go out.

Q: You always keep her company all the time?

Lin's mother: Not always, she walks back home from the district DPF center with another boy, a classmate who lives across the road. This boy comes back home with her on school days as well. If this boy can't walk home with her, then my daughter has to wait until I finish my meeting.

Q: Do you go home together?

Lin's mother: Yes, we have to if there's no other choice. Nowadays, she can go to and come back from the Sunshine Home without me, but with one of her classmates, who lives in the same community. She calls me when she's leaving, then I know when she'll be arriving home, if she's late, I might give her a ring. It's about a 15-min walk, but I usually give her an extra 15 min to play on her way back.

The mobile phone amuses her a lot, she likes to call me when she's out. I worry about her when they're out together, because they have to cross several roads. I'm always telling her, your phone is the way to keep in touch and let me know where you are, don't forget to give me a ring when you arrive or leave the home. Anyway, I'll call her if she isn't back within half an hour.

Q: You just said you had to walk her, don't you need to take her to or collect her up from the home anymore?

Lin's mother: No, I haven't needed to pick her up from the home for the last 2 years.

Q: Just these 2 years?

Lin's mother: Almost 3 years now.

Q: She usually gives you a ring or sends a message when she's on the way back?

Lin's mother: She only calls me on the way back or when she arrives at the home in the morning to say: "Mom, I arrived."

Q: Can she walk to the home by herself?

Lin's mother: Well, she's pretty good these days, she can get home from the district DPF center on her own as well.

Q: Can she go to district DPF center by herself?

Lin's mother: She can come back home from there, I've let her try four or five times already.

Q: Do you feel okay about letting her go somewhere on her own?

Lin: Nowadays, there's a thing Mom can use to find me, the phone. She calls me: "Where are you?" I say: "I'm here, I'll be home very soon, don't worry. I've left the Sunshine Home and will be home soon. I'm on East Yuhang Road... Zhoushan Road... Baoding Road... I'm arriving."

Lin's mother: I can't really relax when she isn't with me even if she has some friends with her. She doesn't know or care about anything—her personal stuff or the station—when we take the bus journey to the district DPF center. I keep telling her when we go out together that she has to take care of her own stuff, because I have to look after the group, and I don't have time to check her stuff as well.

I criticized her several times when she lost her stuff, now she can look after her own things. I also told her to keep an eye on the route and check the bus stop information, as if she's on her own. Sometimes I tell her that she's in charge of the group trip and needs to remind us when the right bus arrives at the stop if anybody asks.

I had to do this because she never took any notice of the bus journey over the past 10 years. I kept telling her to remember the names of the stops: "You can't read but you can hear the automatic announcements, at the same time, you'd better try to remember the familiar buildings near the stops." I used to "threaten" her: "If we miss the stop, I'll slap you afterwards."

Q: Did you threat work?

Lin's mother (laughs): More or less, but I needed her to remind me when I forgot the stop sometimes.

Q: You travel together, but she has to be the one in charge of the journey?

Lin's mother: That's right, I let her lead the journey. Sometimes, she'd forget to get off at the right stop if she was chatting with somebody. So, because of this, I would say: "If you forget to get off and need me to remind you, I'll slap you later."

Lin: Nothing hard, just a couple of gentle taps.

Lin's mother: Sure.

Q: Did she make the mistake that you just mentioned?

Lin's mother: Of course, it's easy for her to miss the stop when she's talking. When I was testing her, I realized she wouldn't make a mistake if I wasn't talking to her, it's all about concentration. Can you understand?

Q: She needs to concentrate on the journey and mustn't be distracted.

Lin's mother: You're absolutely right.

Q: Is she able to open the front door?

Lin's mother: At first her hands would tremble when she was trying to open the old lock, but nowadays she doesn't have any problems with the new lock. The old door lock was an easy one, but the new one, has a safety lock that has taken her a long time to get used to.

Q: How long did it take you to teach her that?

Lin's mother: More than a week, perhaps around 2 weeks.

Q: Well, that's pretty quick.

Lin's mother: Sometimes her key gets stuck in the lock; when that happens, I won't say anything but let her dad criticize her. It's the difference between my husband and me, I'm more patient with her than her dad.

She's okay with the phone, because she doesn't need to use the keypad, we've set up a contact list for her already. When she needs to make a call, she only has to type "mom," "dad," or other names. A phone call costs 10 pence, but a message only needs 5, so we taught her to write some very simple messages like "I've arrived" or "I'm leaving."

Q: Did her dad teach her to use the phone?

Lin's mother: Um.

Lin: Dad isn't as attentive as mom, he tells me off sometimes.

Q: What was the relation like between Li Lin and her dad when she was younger? What did her dad do for her development?

Lin's mother: When our daughter was younger, under my led... her dad taught her how to hold a drumstick in the right way, because she was too nervous she might drop them and used to hold the sticks too tight.

Q: Your husband and you used to teach her to play the drum together, didn't you?

Lin's mother: Um, he told her the right way to hold the sticks, hold them with relaxed fingers, and tap the drum gently for a better sound.

Q: Did her dad teach her some idioms when you were teaching her?

Lin's mother: Occasionally, he corrected a mistake, but it's mostly about his mood.

Q: Did her dad take her to the park or morning exercise?

Lin's mother: Sometimes. Once when she was very young, a teenager, I made my husband take Li Lin with him when he had to go to Nanjing for a business trip, because her maternal grandpa lived there. He didn't take her out often because he didn't want his colleagues to know about her, but that time was a business trip and it was just the one time. I told him to leave the girl with her maternal grandpa when he went for a walk. Before that, my daughter went to Nanjing with me several times and knew the area a little bit, so she could recognize her maternal grandpa's place. Finally, my husband agreed to take her with him, and she led her dad to her maternal grandpa's home.

Q: Did she know where to go?

Lin's mother: She knew, because compared to Shanghai's lanes, Nanjing's lanes are much easier to remember. She surprised her dad, he was happy and told me: "She took me to her maternal grandpa's place, even though I knew the way less than her."

She Can Read and Write Simple Characters

Q: Can she write her own name?

Lin's mother: Yes, she can write her own name, but her handwriting is terrible. Her family name is "Lin,"¹¹ the character is two "woods" combined; she writes the character in two separate parts, it looks like two separate "woods" characters to other people (laughs). I told her to write the characters closer together, but she doesn't listen to me.

¹¹Lin, the Chinese character is '林', which includes two '木' (wood).

She also has other problems with the structure of characters, sometimes the character might be too far apart or too close together. When she receives her meal or travel allowances from the district DPF office occasionally she has to sign the documents. Her handwriting is ugly but I won't sign for her, I just let her sign them however she wants.

Q: Can she write any other characters, in addition to her name?

Lin's mother: She can write most of her classmate's names at the Sunshine Home. I didn't know she could write these words until she pointed out some characters to me when we were out together. Now I know that she knows some simple characters on advertising boards, but she has to ask for my help with complex characters.

She doesn't know *pinyin*, but she knows some radicals and some characters that include the radicals.

Q: When did she start learning characters?

Lin's mother: Well, in the last few years. But she still can't tell the time, she doesn't understand the 24-hour clock. She'll be confused if you tell her 13:00 or 14:00, now, at last, she knows 14:00 is 2 p.m.

Q: When exactly did she learn that?

Lin's mother: In the last 2 years.

Q: Who taught her to tell the time, the Sunshine Home or you?

Lin's mother: She learned it at the Sunshine Home and from her classmates at the district DPF center. Sometimes, the children need to write articles, but my daughter can't write long paragraphs. One of the boys usually helps her with her writing and homework. He's a boy from our drum team; he likes to please me by teaching my daughter because I'm their teacher.

Q: What do you mean by "child"?

Lin's mother: It's what we call the students. Most of the mildly intellectually disabled children are educated. If she needs to write something, my daughter would ask somebody to help her and then joked with me: "I have a secretary!"

Q: She lets somebody write things for her?

Lin's mother: Yes, I teach those students and in return, they help my daughter.

Travel Has Been an Eye-Opener for Her

Q: Does she like to stay at home or go out?

Lin's mother: She likes to go out.

Q: Do you let her stay at home sometimes?

Lin's mother: Yes, she can, but she likes go out as well. Well, she likes to go on trips!

Q: Does she tell you when she wants to go on a trip?

Lin's mother: Yes, it's usually her idea. She hasn't been to Beijing and she told me: "I want to go to Beijing, because I haven't been to our nation's capital yet." It's a trip I owe her, but haven't had a chance to organize it yet.

Q: Do you take her on trips very often?

Lin's mother: Yes, we go on holiday quite a lot! I don't try to save money anymore because I don't want my money to go to somebody else. What's the point of saving money just by cutting down on our daily expenses?

Q: Where have you been with her?

Lin's mother: We've been to a lot of places: Thailand, South Korea, Hainan Island, Zhangjiajie. Traveling is good for her intellectual development.

She Gets a Lot Out of the Sunshine Home

Q: You said when she was little, she was a naughty girl. When did she become more sensible?

Lin's mother: When she started at the Sunshine Home in her thirties. She was quite a naïve young woman before that.

Q: The Sunshine Home had a real impact on her.

Lin's mother: Yes, she's made great progress, and her development was perhaps the best of all the children at the Sunshine Home. She's learned idioms and fables, but she doesn't understand numbers. With this poor sense of numbers, if you ask her where she lives, she couldn't tell you the exact address, because she forgets part of the information every time. For example, if she told you the apartment number, she might forget which floor, or the other way around.

Q: She can't remember the complete address?

Lin's mother: That's right, she can't remember the name of the street or the phone number. She used to get very nervous when she answered the phone.

Q: She didn't like answering the phone?

Lin's mother: She didn't know what to say, anyway, she didn't know how to use the phone.

Q: How many years has she been at the Sunshine Home?

Lin's mother: Ten years.

Lin: Which month did I start there? Was it December or June?

Lin's mother: She joined the district DPF center on 9 February 2006; and she joined the Sunshine Home in July 2005.

Q: You know these dates very well.

Lin's mother: I'm not good at dates, but I remember these things so I can teach her. My daughter made me remember them (smiles).

Q: She asks you about these dates?

Lin's mother: I tell her without her asking.

Lin: Do you know how I found this place? Once day a member of staff at the Sunshine Home visited us, I didn't want to go at first, then...

Q: What does she study at the Sunshine Home?

Lin's mother: To be honest, the Sunshine Home has a lot of problems; for example, they overprotect the children from accidents. They just keep the children in the classroom from early morning to 3 p.m., when they finish.

Q: Don't they have any activities?

Lin's mother: Now and again they have some activities. Normally, they don't do any active things other than the People's Radio Calisthenics, because the home is located in a residential building. They might get complaints from the elderly people if the students are too noisy.

Nobody wants to take responsibility for them, the less accidents the better, and it's the same at the subdistrict office. There are some sensitive parents who might give the home or subdistrict office a hard time if anything happens to their children. For example, we took a taxi to a gymnastics competition today and for safety reasons the district DPF officials divided the students into small groups for each taxi; they would rather spend more money than let them take a bus. Sometimes, when the students need to go somewhere together and they don't have enough officials and full-time workers to look after them, some of the parents, like me, have to travel with them.

This morning, I had to look after three of the children in a taxi. The subdistrict office doesn't want any accidents to happen to these children, and the Sunshine Home teachers are even more afraid of taking on this kind of responsibility. So these children don't do anything more challenging than sit in a classroom for the whole day.

Once, one of the teachers said something bad to my daughter and after she told me about this, I went to the home to talk to the teacher. The teacher denied the whole thing. I was angry with the teacher at the time. I lost face, but I can't blame Li Lin. Sometimes, an articulate child can get into trouble.

Well, after this incident, I didn't talk to this teacher again. Some of her classmates, they are also my students in the drum band, aren't very nice; they overheard the argument between the teacher and Li Lin, but they wouldn't be a witness. Now, I feel they've let me down—they wouldn't help in a crisis—even when I give them so much love. I'm just wasting my time, right?

She Cares About Her Classmates and Likes Making Friends

Q: Does Li Lin like making friends?

Lin's mother: Of course.

Lin: I like making friends very much.

Q: Did she have any friends before she went to the Sunshine Home?

Lin: No. (Here, Li Lin answers the question with English).

Q: No?

Lin: No, not really.

Q: Li Lin was mostly alone before she joined the Sunshine Home and then she got to know a lot of classmates and became part of the class. Did you feel uncomfortable when you first went there?

Lin's mother: She didn't have any problems.

Q: So she was able to fit in straight away?

Lin's mother: Yes. Before she went there, a subdistrict official visited us. After I told him that my daughter had never been to a school, he said he was worried that my

daughter wouldn't survive at the Sunshine Home. Surprisingly, she adapted quickly and could understand most of what the teacher was saying. One of the teachers even said my daughter has a strong sense of justice.

Q: She seems get on with her desk mate very well, they were chatting to each other during break time when I was there.

Lin's mother: Yes, Li Lin is close to her; when this girl was young, she was behind with her studies because she was in hospital so often with tracheitis. Her intellectual development was slow, she also has eye and foot problems; she's a disabled person, but not intellectually disabled.

Q: Does your daughter keep in touch with her classmates during the holidays?

Lin's mother: They do talk to each other, and she's able to understand what they're saying.

Q: Do they go out together after school?

Lin's mother: No, I don't let her go out with them.

Q: Why?

Lin's mother: Well, some of those students are much more developed than my daughter, so I don't like her going out with them.

Q: What's her relationship like with her classmates?

Lin's mother: She cares about her classmates; she likes to bring snacks for them at the Sunshine Home or the district DPF center. These days, I have plenty of money to buy her snacks, but she likes to save some for her friends, whether it's a delicious cake or expensive chocolate. She likes sharing with other people. Sometimes, those children ask her for snacks as well.

In winter, she likes to take some herb teas, like chrysanthemum, Goji berry, or orange peel tea. She never says no to her classmates if anybody asks her: "Do you have herb tea today? May I have some?" Sometimes, when we have some snacks that are too hard for my teeth, or I don't like them, my daughter will take them to the home. She usually asks me before she takes snacks to the Sunshine Home: "Mom, one of my friends wants some of your snacks." She's a caring child.

She has pity for some of the children who have lost their parents. There's one child, his unreasonable dad died suddenly one Chinese Spring Festival. He'd divorced with his wife and had sole custody of the child. Following that, this child had to have surgery to remove a kidney and then received dialysis treatment later. Then his mother had to take him back to look after him, but she couldn't do this properly because she wasn't a well-educated person.

These days, I have a higher moral threshold than before. I don't only think about my own daughter, but also the other children. So, when I tell my daughter to take some extra snacks and food to share with her friends, it's like I treat these children as if they were my own.

Q: Did she understand the teacher's orders like "sit still," when she was first joined the class?

Lin's mother: Of course.

Q: Was she well disciplined? Didn't you say she was a hyperactive girl when she was little?

Lin's mother: Yes, she couldn't sit still for a minute.

Q: Could she sit still when she started at the Sunshine Home?

Lin's mother: No, she couldn't, but she developed a new hobby—handwriting—this kept her occupied and still, it stopped her from messing around.

Q: She's certainly able to enjoy the Sunshine Home experience, because she has a mother like you, doesn't she?

Lin's mother: No, not at all. Nowadays, the teachers who don't have a disabled family can't understand what our life is like—sometimes their management approach can be a little bit selfish—they don't have the same caring character as we do. We have more love than these teachers, we have plenty of empathy for these children who have lost their parents.

Q: You feel upset for those children?

Lin's mother: Yes, so now we're looking to get more attention from society.

Lin: There's another poor girl who comes from a two-child family. She was fine before their mom died, but now the younger child bullies this girl.

Lin's mother: The non-disabled young sibling bullies the girl, that's why we didn't have another child.

Q: You mean that you worry your daughter would have been bullied by a younger sibling?

Lin's mother: What?

Q: You just said that you decided not to have a second child.

Lin's mother: We were worried that we might give too much attention to the second child—if we had had another child, they would have had to be a normal child. During this child's college entrance examination period, I would definitely have focused on his/her study and nutrition and wouldn't have been able to look after Li Lin as well as I do now. Li Lin's a minx and she wouldn't allow this to happen.

Q: She wouldn't allow you...

Lin's mother: No, she wouldn't let us have a second child. She used to say: "Where would you leave me if you get a healthy child? You won't look after me anymore." She won't allow my husband and I to play mahjong or dance, because she worries "you might lose me in a mahjong game, no one else would care for me; if you met somebody else dancing, our family wouldn't exist anymore."

Once, I said to her: "Huang Ling is very poor—should we invite her to stay with us for the Spring Festival, just for a couple days?" She said no. I asked why and she replied: "I can't share my mom's love with anybody." She's quite selfish in that way. Another time, she was crying about the poor orphans who lost their parents in the Wenchuan Earthquake. I said: "You don't need to cry, we can adopt one of them and it'll be a good thing for the government and the child." She didn't want to have another sibling, absolutely not. She would rather donate money to these children than adopt them. She's been insecure in this way since she was very young.

She's also very careful with our money. She doesn't earn very much, but she doesn't like us to use our savings either. She's a demanding child and always begs me to buy her some snacks when we go out together, but sometimes when I don't have enough change or I think the stuff is too expensive, I have a special way of stopping her. I pretend to walk to the bank. Then she gets nervous and stops me by

dragging me back. She doesn't want me to withdraw money from my bank account, and tells me: "Mom, we can ask Dad for some money later."

She controls my money and at the same time, my behavior. Nowadays, she doesn't worry when we go to the bank together like she did when she was younger, because she's sure I won't waste money. She also understands her mom is a good woman and has stopped worrying about me, but she was very anxious when I used to go out dancing, even though I never flirted with other men when I went dancing. She was really worried about losing me.

Q: She was insecure when she was younger, but now, she understands things better?

Lin's mother: She knows me better now, but she still gets anxious with other people; she knows she's a lucky child, compared to other children.

She's Made Great Progress in the Drum Team

Lin's mother: These days, she learns more from the district DPF drum team than from the Sunshine Home. The district DPF plays a very important role in her development. She used to leave everything for me to look after when we went to band practice, but now she can take care of her own personal stuff. My job in the band is to look after the group's belongings, so I have to tell her to keep one eye on her stuff, and she's pretty good at that.

Q: What does she do there?

Lin's mother: When we arrive at my office, she'll wash up cups and pack up some food that's been opened; if somebody leaves a flask in the classroom then she'll take them to the office. And she looks after her own bag; I don't need to worry about her anymore.

In the band, she isn't one of the smartest children because of her disability. I feel guilty about my daughter's poor performance, so I always go to the events with the volunteers and teachers. The band leader, who comes from the district DPF office, told me: "You've taught so many students, why can't your daughter learn like them?" I said: "Because my daughter isn't that clever, otherwise she would have learned it already." "I don't believe you, I'm asking you to teach her again until she knows the new movement." So, we'll go to the center tomorrow, borrow two drums, then together practice the new drum routine "Chinese Kongfu."

Q: Will you do that this year?

Lin's mother: Yes, during the 1-month holiday.

Lin: I'll also learn some new idioms in the Spring Festival, and recite songs as well. Can I recite something for you?

Lin's mother: Do that later.

Lin: I want to recite it for her. (She's talking about reciting one of the famous military songs for the interviewer.)

Lin's mother: Do you really want to recite this? Do it later.

Lin (she looks a bit nervous): I just want to recite a little bit of it.

Lin's mother: Okay, fine, you just do it.

Lin: The troop arrived in Zhaxi in February, the reassembled troop looks well organized. We developed the guerrillas in Southern Sichuan, the company was more than three thousand people. Then, the troop arrived in West-Northern Sichuan in July. What are we working hard for? Fighting the Japanese so we can rescue China.¹²

Lin's mother: Teacher Zhou from the district DPF office, who is in charge of our group, told her to remember the lines of this song; it took her... She's getting there this week.

Q: It only took her 1 week to remember the whole thing?

Lin's mother: No, longer than a month.

Q: It took her over a month to remember it?

Lin's mother: She could only recite it properly for the first time this week. She read it to Teacher Zhou already, and she said: "Li Lin did a good job." I explained to her that my daughter could only do this because she had time to prepare.

Q: She needed several days longer than the other children.

Lin: My classmates taught me as well, it wasn't only my mom who taught me; two boys helped me as well.

Q: So, her classmates and you taught her together?

Lin's mother: Yes, those boys live in the same neighborhood with us, both of them are drum band students as well. I get on with them pretty well, I used to take some snacks for them and they like to talk to me about personal things now and again. If we need to go somewhere, the boys usually go with me for safety reasons. They're obedient children and they usually listen to me; they help my daughter to please me.

Q: So, Li Lin can recite the lines but she can't actually write them?

Lin's mother: She can copy the lines if you write down the characters first, but that doesn't mean she understands the words.

She Practices Hard and Looks Forward to Performing

Lin's mother: I'm so pleased we have a drum team. You might have seen one of our shows on TV? There's an old guy, a high-rank official, who worked at the Security Bureau. His son has epilepsy, and he understands disabled people's families very well. When he retired, he put together a drum team for the disabled children to give them a chance to get out of the house.

Some people told him that these intellectually disabled children wouldn't be able to play the drum, but he didn't give up. Now, all of our children can play. We come to the district DPF center every weekend to practice the side drum and the flat drum, dancing, singing, and learning English. Our children go to the Sunshine Home from Monday to Friday and go to the center every Saturday and Sunday.

¹²*The Red Army Overcame The Long March* is a part of the *Long March Song Cycle*. They are famous Red Army songs, stories of the troops who were involved in the Long March, between October 1934 and October 1936.

My daughter was determined to join the drum band when she saw the children playing. She just thought that it was an interesting thing to do, but she didn't understand how hard the training would be.

Q: Did they have to sign up for the band?

Lin's mother: Yes. I didn't let her go, I told her she couldn't join the band at first, because I thought she's not very good at things like this, and wouldn't be able to learn how to play. Later, after she joined the band, I'd criticize and smack her when she didn't keep up with the practice.

Lin: Um... She hit me so many times.

Lin's mother: You joined the band even when I told you not to (talks to Li Lin).

Q: How did you join the band?

Lin's mother: Not me, she did it.

Q: She did it?

Lin's mother: When she found out that she couldn't play the thing, she said to me: "Who would have known that playing the drum would be so difficult? I wouldn't have joined if I'd known how difficult it was going to be." (She's laughing).

Q: How did she find out about the district DPF band?

Lin's mother: She heard the news from her classmates at the home, because the district DPF officials walk around the subdistricts to recruit new people.

Q: So, she got the information from other children?

Lin's mother: She was encouraged by them, because the band didn't have enough players and they were looking for more children. The recruitment teachers wandered around the subdistricts and the Sunshine Homes and approached the students. To be honest, the man, the founder, was very strict, That's his disciplinary style because that's the way he was with his charges when he was an official.

Q: How's she doing with her side drum?

Lin's mother: We haven't started our home tutorials yet, because we haven't been able to borrow drums from the center; when we get them, I'll have to train her much harder, because that's what the band leader wants. I have to teach her every piece of the choreographed movement this week. Playing the drum is a kind of interactive dance, you have to move the body and the drum from front to back together.

Q: Can you give me more details?

Lin's mother: The dance involves a lot of turning around, but my daughter doesn't understand what a 90° or 180° turn is, that's what I need to teach her.

Q: Do you have to teach her one thing at a time?

Lin's mother: Yes. For a full rotation, you should start with a left turn, then do four left turns together and then you'll be back facing the original way. That's this week's homework (see Fig. 1).

Q: That's the only thing you're practicing this week?

Lin's mother: Yes, she only needs to work out those turns this week and we'll practice more movements for the middle part of the dance later. She's pretty good with the beginning and ending already.

The rotation sequence is the basic movement for the whole dance, we have to start with it, and this means that my daughter has to start practicing 1 week earlier than the other students. I've even drawn a diagram of the dance action for her.

Fig. 1 Li Lin practicing side drum



Lin: Mom says... Mom said: "Walk to one side, turn to that side again, now turn again. The left hand turns back while the right hand turns to the front."

Q: Auntie described the movements in great detail.

Lin's mother: I told her, a 90° turn is turn once to the side, a 180° turn means you turn twice, the body faces the back. I drew the picture to show her what turning right and turning left means, I've tried all kinds of ways to help with this.

Q: Can she understand you?

Lin's mother: She's a little bit more enthusiastic today.

Q: She's enthusiastic, how long have you been teaching her?

Lin's mother: It's taken me a whole week. At first, she didn't understand the idea of turning round at all. I'm under pressure from the band leader, that's why I had to start teaching her a week early.

Lin: Do you know how much pressure it's been? He said, "I'll fire you if you can't learn the routine." That's how serious it is!

Lin's mother: The team leader said he might fire her and she doesn't need come to practice anymore.

Q: How long do you teach her every day?

Lin's mother: It doesn't take that long, because I can't teach her too much at once. I thought about teaching her earlier but I got sick last month.

Q: Do you practice every day?

Lin's mother: Yes, every day, for about 2 h more or less. Before the performance, we used to have a week of intensive practice like this, training every evening for a week.

Q: Every evening?

Lin's mother: Sure. Playing the drum is noisy and disturbing, so I let her practice from 4 to 5 p.m.; this is the best time for everybody, she won't disturb our neighbors. At this time, the second shift workers haven't come home, and the night shift workers are having their dinner, and the early morning shift workers are cooking. Anyway, 4–5 p.m. is our training time.

There are some other students who can't play the drum, they are just there to make up the numbers. I told them the best time to practice at home as well. I said that you have to practice harder because I'll check up on you next time, you'd better practice in the early evening. If anybody complains about the noise, you can just say: "Can you think of a better time? It's the best time I know; I haven't disturbed your dinner or sleep." "You have to remember that this is our only practice time," I told them.

Q: Has she ever been to a performance?

Lin's mother: Yes, she's been to some shows. After she'd just joined, she couldn't catch the instructions from the teacher—standing in line, understanding discipline, "at attention," "hull," turning back—until I taught her little by little. I taught her to turn to the same side with other players because she has to keep in line if she wants to join in the performance, it's what she wanted to do.

Q: So, for example, if your daughter can't understand to turn left when the teacher tells her, you'll give her a lesson at home, right?

Lin's mother: Yes, but even now, she's not great at turning round. She likes to watch the other students while they're dancing.

Q: Looks at other students?

Lin's mother: She's usually slightly slower than the others, so she'll follow her classmates after they move.

Q: How does she know to keep one eye on the other dancers?

Lin's mother: I told her to do it.

Q: So, Auntie taught her.

Lin's mother: Haha, otherwise she wouldn't be able to dance at all! At the time she didn't know anything. I told her secretly that she shouldn't stand in the front row but hide behind the others. Now, she knows the dance better than before, so I said: "You should stand just behind the best dancer and follow her/his actions, but don't stand at the back, because you won't learn anything there."

Q: She'd better imitate the good learner.

Lin's mother: I also told her that she had to move to the back row when the teacher comes to check on them (laughs). Nowadays, I don't teach her as hard as before. She'll be fine if she can learn 70%. For the other 30%, I'll teach her when she's ready and wants to learn. I can't teach her when she hasn't worked out what the new dance or movements are.

In our band, the clever children, the mildly disabled ones, received a free drum from the district DPF center, but my daughter wasn't one of them, so I had to pay 200 yuan to buy her one. It's a luxury toy.

Once the band was invited to perform "Without the Communist Party, There Would Be No New China" at a Happy Sporting Meet. Li Lin couldn't play at all. She would just make up the numbers when they were practicing, but this was a formal

event. Before the show, I had to train her very hard, the side drum wasn't available to take back home, so I'd use duvets to make a surface the same height as the drum and let her use a pair of wooden sticks for drumsticks. Later, I took her to the square for further training; we trained very hard, until a dog walker stopped us and said: "Auntie, she's as good as you now, you don't need to practice so hard anymore." I would only let her stop when I thought she was good enough for the performance.

Q: So, she trained very hard and put a lot of effort into it.

Lin's mother: It was very hard work for her.

But the teachers at the Sunshine Home are just happy to let things stay as they are. They won't teach students the Ninth Edition of the People's Radio Calisthenics, the latest version. When the parents suggested they learn the new one, the teachers just said they can't even do the eighth version properly yet. So, my daughter had to go to the district DPF center to learn the new things or learn it with me. I taught her slowly and made sure she understood the rhythm of the movements; before she learned this, she used to move around too quickly, without the rhythm.

Q: Does she like to attend group events?

Lin's mother: Of course, she likes the events very much. If she didn't, I wouldn't need to do all this work. Can you imagine my situation? My daughter's disability is moderate to severe, the band teachers despise her and they won't allow her to stay in the group to make up the numbers when they have a show. They made me pretty angry and I couldn't work out why. I didn't ask them for anything much, just an opportunity for my daughter to be a part of the performance. Besides, I'm one of nine parent teachers; except for my daughter, all the other eight children have a place in the show... I totally lost face.

I was angry with the band about this, but my daughter is determined to go to the practice and I have to force myself to go with her. I really don't want to go. Why do I have to suffer embarrassment? I have plenty of money, I'm a volunteer, I don't ask for anything in return. I really don't need to suffer this.

But what I can do, my daughter loves it. I have to suffer this for her, for her happiness. It's why I kept telling her, all the social work I'm doing now is just to give you a better life.

I know my daughter is moderately to severely disabled and she can't take part in some of the more formal competitions and events, but she's perfectly able to join some shows with the drum team or radio calisthenics. She can just make up the numbers.

I don't ask too much of her but stay in the position—she mustn't turn to the left when the others turn right, or crouch down when the others stand up—she has to keep the same routine and pace. I told her that she has to stop at the same time as the other people when they shout a slogan. At times like this, she has to keep her head down and don't do something different from the others.

Lin: Once, I wasn't careful...

Lin's mother: I criticized her very seriously.

Lin: I shouted "yeah" too early, just after you said it when we were taking a picture together.

Lin's mother: Later, I gave her a very serious lesson. I criticized her very seriously. I said: "What did I you tell you before? Why did you make the mistake and shout at the wrong time again?" The band leader, that old chap asked me: "Why are you criticizing her?" I said because I told my daughter to be careful with her actions, she shouldn't shout louder or out of rhythm with the group, but she...

Lin: Once Mom said I didn't play the drum well, and I practiced until... that day when we were... I got very upset after she criticized me so many times. I felt I'd been discriminated against by people. Even my mom said something nasty to me... I really wanted to quit at that moment. I felt very bad.

Q: When did this happen? Did she tell you she was upset?

Lin's mother: Something like that, occasionally, but not very often. She wasn't good at expressing herself and used to speak incomplete sentences.

Q: How did you feel when you heard that?

Lin's mother: It was a bit hard to laugh (smiles), because I was exasperated that she couldn't get it right. I was angry and there was nobody else to get angry at. I don't have anything in common with the outsiders who have their own families and children. I don't have anything to say to them.

Lin: And, sometimes, I used to say to mom: "Sorry. If I was an ordinary person, Mom would probably have grandchildren by now."

Lin's mother: At that time, I was working at the subdistrict office. One day I was chatting with my colleagues and suddenly, she said to me: "Mom, I'm sorry you can't be a grandma." Her words surprised my colleagues, they couldn't understand why she would say something like that (laughs).

Q: How did you feel when she said that?

Lin's mother: (She's smiling) I thought she's sensible, more sensible than before. I can't tell you how many times I cried for her when she was little. It was a very hard time, but when she was in her twenties, she started telling me: "Mom, you worked so hard to look after me." She'd heard somebody else say something like that to me.

Working Hard Now for the Life Hereafter

Lin's mother: When she couldn't play the "AAB" tune on the drum—it's not something for everybody—I used to teach her by playing with a pan lid or the washing-up bowl. The leader of the band, the old chap, praised me for teaching my daughter so well. He even found out I'd been an excellent worker before I retired.

To be honest, I always think that having this child has been a punishment for my bad behavior, or I didn't worship God enough in the last life...(she laughs) that's why I have her. Now, I have to do more good things for a better afterlife. I must do good things only. I'm always saying I have to dedicate myself to do good things for a better afterlife, especially after I must have failed in my last life. So, I'm always the good one wherever I work, I never offend anyone. People like me, because I never criticize anyone to their face if they make a mistake, but point out the problem in a gentle way. After the band leader discovered my reputation, he invited me to join the

teaching team, but at that time, my thoughts weren't as pure as they are now. I just thought this will be good for my daughter.

Q: Now your daughter is part of the band.

Lin's mother: It was mostly for safety reasons, when I joined the band as a teacher, she could come with me to the center. I didn't have to worry about her getting back safely with somebody else. At first, it was just for my daughter, but now I've been doing this work for over 10 years.

I teach them to make beads, not just the elderly and the children, but also their parents. As a parent of the Sunshine Home, I don't just teach the children, but also provide beads and other materials for them. During the summer holiday, they used to invite me to give a bead-making class to the children when they organized events. I would bring my own beads and other materials to teach them.

Q: Do you usually teach children?

Lin's mother: Usually they're my main group. In addition, I have three parents' meetings each week, Tuesday, Saturday, and Sunday, and do exercises every Wednesday. I also give computer lessons from time to time. I'm very busy. I have to make free time to look after my family's financial investments (laughs).

Q: You have a full schedule.

Lin's mother: I like to do knitting and make beads when I have time, I made this pretty tablecloth!

Q: Do you teach your daughter?

Lin's mother: No, she can't work with the beads at all, putting one bead on a string, it's the only thing she can do. All the children learned the skill except my daughter. There's a student, called Xiao Yiming, who's a warehouse keeper. The other teachers and I taught him computer skills. After he learned some basic skills, he left the class and joined a computer training program and earned a business administration degree from a college. Now, he's graduated and works at an old people's home. That's pretty good, right? He's a caring child and comes to see us at the festivals. None of us expect a gift, but he always brings one.

Q: He wants to express his appreciation.

Lin's mother: These children are sensible. You might not think so, but they know who really cares about them. He said to us, "We don't like to be criticized by the teachers except Li Lin's mother, because she really cares about us." As you can see, these children, they might be a bit wild or have a bad temper, but they know us, the teachers care about them; they are clever enough to understand this, even though it took them a while to work it out.

I've been moved by these children, everything I've done for them has been worthwhile. They know what I say or do is just for them. Sometimes I'm quite strict. I criticize them when they mess up. Some of them said: "I'm not angry with Li Lin's mother when she criticizes me, because she's doing this for my own good." I'm tough with them, sometimes I criticize them when I'm exasperated by their failure to do well, because there aren't many people who care about them, and I have to take responsibility.

Now the Mother Is in Her Seventies and Isn't in Good Health

Lin's mother: I had a light stroke in November. If I turn too fast, I get dizzy. I've had some problems every year... One year I had headaches, and a numb tongue, this year, the problem is dizziness. I even feel dizzy when I'm in a car, and I'm unsure on my legs. One time, when we were training at the entrance of the People's Park, I had to stop teaching her the spinning dance after I became really dizzy. I couldn't stand up. I gave up teaching her because of the dizziness, also because I didn't have any pressure to teach her at that time. This time, now the weather is getting warmer, I'll start again.

Last week the band leader told me: "I really don't understand why your daughter is the only one who can't learn the dance. I have to tell you that if she can't catch up with the other students, I'm afraid I won't be able to keep her in the band." So I said: "It's not her fault, I'm responsible for it, because of my health problems, I haven't been able to teach her properly."

I can't turn around, especially spin around, with my daughter and she needs me to show her the same actions several times. I have a number of health issues now—can you see how my face is swollen? (points to her face) I've made an appointment at the tumor hospital to have it looked at.

Q: Auntie, please take good care of yourself.

Lin's mother: Before I received the test results, I was under a lot of pressure because I've been told that this type of tumor might be nasty. I'm frightened to death. I'm not worried about myself but for my daughter. The only thing I can do is go to see the doctors. This heavy pressure is making my face worse.

Q: Are you all right now?

Lin's mother: I'm better now, but I still feel it; the swollen lymph nodes can't be cured even if I take medicine every day.

Q: So you usually worry a lot?

Lin's mother: When I was standing in the queue for the test, several people in front of me were given bad news about their tests. This upset me and I felt under huge pressure. That day, I left in the dark, took the earliest bus at 5 a.m., changed from No. 17 to No. 49. I had to stop myself thinking about it too much when I arrived at the hospital. Finally, the result revealed I was fine. I told the doctor I don't have other problems except for cystic oviducts. It was at one side at first, but now both sides are affected. The doctor said the cystic oviducts isn't the cause of the swollen lymph nodes (points to her face).

The rest of the tests went well. After the swelling had gone, I went to a gynecology hospital and took another cystic oviducts test and the doctor said the swelling had disappeared. I couldn't believe the result. I guess the underlying problem is still there, but the tumor has shrunk. I can relax a bit and have a good Spring Festival with the family now. Otherwise, I won't stop worrying about it. I'm 70 this year and I'm worrying that I might not last much longer.

At my age, few people can dance, sing, or play with their children like me, especially when I have such a heavy family burden; it's why I was so upset when my

daughter couldn't do her best for her dance. This year, according to the Chinese lunar calendar age, I'm 70 already, and I'll actually be 70 next June. Can you imagine how tired I am having to do all this for my daughter?

She's Still Concerned About the Future

Lin's mother: For parents like me, our only concern is the future of our children after we die. Maybe you've heard some stories about the old people's home, if we leave the children with them... On our street, there's a child who is in the same situation as my daughter. His parents have some money and decided to move into the old people's home. The only condition was that they could take their child with them. The manager said that they would be welcome, but not their child. So, what happens to our children when we die? Even if an old people's home agrees to take our children after we die, we still have to worry that they say one thing to our face, but do exactly the opposite behind our back. They might treat our children well before we die, but after we pass away, they might only look after the children when the inspector visits. I even don't dare to think about this thing, so, the best thing for us is that our children die before we do.

Q: Has she ever thought about getting married?

Lin's mother: I don't want her to get married, because there are too many two-faced men who would spoil your daughter when you're living together but throw the girl out and keep all of her money after you die. There are too many stories like this. Too many disabled people's marriages end badly. Li Lin's future mother-in-law might look down on her as a disabled daughter-in-law; the situation can be worse than you think.

Right now, whoever is responsible for her when we die is a real family issue. I'll try my best to arrange something for her after I die. The government would be better than our relatives. My older maternal sister who lives in Nanjing used to say to me in front of my daughter: "You're welcome to visit me, but you mustn't bring your daughter with you." She's my relative but even she thinks about my daughter like this. Every time we go to Nanjing to visit my parents' tomb, we have never stayed at her place even though she has a three-bedroom apartment. We used to stay at a hotel and eat out, and I didn't want to eat at her home.

Q: One day she'll be alone...

Lin's mother: Well, it's a family problem, and I've decided to let the government look after her.

Q: The government?

Lin's mother: I want her to join a "house-for-pension" scheme, because I have a property that I can pass down to her later. If there's a day when she loses all her money, she would still have a place to live; anyway, she has an allowance. Her dad disagrees with this plan. He insists: "My nephew, niece, and their children will look after her." How could I trust them? They've never cared about her. I don't think it's possible for them to take care of her.

Q: Her dad wants her to live with his relatives?

Lin's mother: Yes, right now we're in the middle of a "cold war" over this. I'll leave the property and our daughter to the government if he dies first, but if I die before him, the thing might go the other way. We wish the government would set up a special care home for these children with high-quality workers. Otherwise, we would never be at ease leaving the children with the current group of workers. Take the nursing homes as an example. You might have heard some stories about the number of new arrivals who've died there in the last few months to a year. On the one hand, it might be related to the health of these people; but on the other, some cases are down to a lack of care or bad service.

Of course, the government takes this issue very seriously, but implementing policy isn't as good as it should be. We think that because these workers aren't family, they give a poor service. Mildly disabled children have a regular income and affiliated workplaces before they retire. After that, they'll receive a pension. But moderately to severely disabled children only have a minimum allowance and no pension provision. It's why I feel helpless about my child's future; the policy treats the two groups of children unequally.

Q: Do you mean a mildly disabled child has a better income?

Lin's mother: A mildly disabled child, can be affiliated to a company. They'll receive a pension monthly when they reach retirement age.

The biggest problem is that some bad people might steal their money, but they'll get income again the following month. They're very vulnerable when they have to deal with money themselves and without their parents. They won't have anybody to look after them. Most of the children don't have a sense of the value of money, even for the children who are more intelligent than my daughter. They can't work out what change they should get from a 100-yuan note. They can be cheated too easily.

Q: Can't she buy a soft drink herself?

Lin's mother: Not my daughter, but some of the cleverer children can.

Q: Can't she?

Lin's mother: It's not possible, she doesn't even understand numbers up to 10.

Q: What's her degree of intelligence?

Lin's mother: Degree three, she's closer to severe rather than a moderate condition. Being articulate, is her only advantage.

Q: Do they have allowances?

Lin's mother: There are two different kinds; a person who has a mild condition will receive a minimum wage, and there is a minimum allowance for moderately and severely disabled children.

This year has been a good year for them, surprisingly, their allowance increased a little through two new policies. Her minimum allowance was around 900 yuan, but now it's been increased to 1150 yuan. She has also started receiving two additional benefits; a 350-yuan special subsistence, and 150-yuan rehabilitation subsistence. In total, she gets 500 yuan more than before; it's much better than we expected.

Q: The government has quite a big budget for this group of people.

Lin's mother: Well, it's a lot of money, but her allowance is still less than a mildly disabled child's. Our biggest worry isn't about what's happening now, while she's

living with us, whether she has her own salary or not, we're able to look after her. It's about her future, when we die, what kind of social care will there be, who'll take care of her. The central government has no policy about this yet, but we desperately need one as soon as possible. There are two key issues for us; one is that somebody or an institute will look after her after we die, or I would hope for her to die before us to make sure we can give her a secure and happy life.

Lin: I don't want to leave any trouble for mom. If I die... if I die before you, please throw my ashes in the sea.

Lin's mother: Of course, I'll go to rest in the sea as well, because there will be nobody to visit our tombs or pray for us even if we had a tomb.

Q: That's all of the questions I want to ask. Thank you for telling Li Lin's story to us, we appreciate it very much.

Interview with Li Lin's Teacher

Interviewees: Teacher Wang and Li Lin's mother

Interviewer and writer: Yunxiang Zhang

Interview date: June 26, 2017

Interview place: Sunshine Home

Q: Are you Teacher Wang?

Teacher Wang: Yes, that's right.

Q: How long have you been Li Lin's teacher?

Teacher Wang: Six years, more or less, since the two Sunshine Homes merged.

Q: How able is she? And her attendance?

Teacher Wang: Her attendance is pretty good; she hardly misses a school day.

Q: As her abacus teacher, what do you think about her ability?

Teacher Wang: It's not so good. She's quite practical and good at thinking, but she's terribly bad at math. I can't figure out the reason. In class, when you explain something to her, she would say: "No problem, I understand," but if the question is more complex, she'll soon get lost (smiles).

Q: How about her attitude to learning?

Teacher Wang: She isn't bad in this respect; she wants to learn new things, she likes to finish her homework.

Q: What happens if she can't answer a question in class?

Teacher Wang: She'll ask me to explain the question to her.

Q: Is she frustrated when this happens?

Teacher Wang: This thing happens quite often. Let me try to describe her problem... She likes to ask a question if she can't answer it in the first place, but then you'll find out she's asking a different question. Sometimes, when we are talking about one thing, she'll change the question to another one.

Q: Is she quite interactive with the teachers in class?

Teacher Wang: Yes, she's pretty interactive.

Q: Does she like activities outside the class?

Teacher Wang: She's very active in this respect.

Q: Does she get along with her classmates?

Teacher Wang: She's not bad, she likes to help her classmates, especially one student who has bad eyesight. She has the social skills to avoid conflicts with other students, generally speaking, they're quite friendly with one another.

Li Lin's mother: I used to show her how to get along with her classmates, what she should do or not do; never get involved in anybody else's business.

Q: Has there ever been any conflict between her and other students?

Lin's mother: No, there hasn't.

Teacher Wang: She doesn't have any serious problems with her classmates, but sometimes her stubbornness can appear in some small issues. How should I say this, she's an "I'm-always-right" kind of person (laughs). If she thinks she's right about something, she'll insist in this right up to the last minute—she has to argue, she even makes excuses.

Q: You mean if she thinks she's right—even if she's not right—she'll argue her case.

Teacher Wang: You're absolutely right. In her mind, she's always right, always. If she's not right, she has to find a way to make it happen (he's laughing away).

Years ago, the two subdistrict Sunshine Homes, Xingang and Tilian Bridge merged. I was working at Tianlan Bridge Home and the students there were quite laid-back people and got along well with each other. But Li Lin's old cohort, compared to our old students, were more active and used to argue with each other.

One day, after the two homes had merged, Li Lin came to me to say that two monitors—Liqin Liang and Jiawei Sun, who came from different classes—had a confrontation when they were washing their lunch bowls in the public bathroom. So I talked to these two students and asked them what had happened. I said to Liqin Liang: "Did you argue with Jiawei Sun and tell him to wash the bowls?" Liang said: "No, we didn't do any such thing, I just told him to wash the bowls properly that's all. There was no argument." I said: "But Li Lin told me you had a fight." Then I asked Li Lin to come along and tell us what she saw. She insisted: "You guys argued, didn't you? Both of you raised your voices and fought about who should wash the bowls." (He's laughing again). That time, after we established the facts, Li Lin agreed and apologized straight away, but when she went back home, apparently, she told you a different story (talks to Li Lin's mother), her own story, because for her, what she saw was definitely the only truth, and she couldn't have been wrong.

Q: She probably just felt she should apologize at that moment, but didn't change her mind.

Teacher Wang: You're definitely right.

Lin's mother: Li Lin said her classmates were two-faced.

Teacher Wang: She insists on her own versions as the truth (he's laughing).

Lin's mother: When this kind of thing happens, she'll argue with them first, and if she can't win "the battle" with words, she'll even hit them. I will criticize her seriously if I hear she's done something like this. But she'll never admit to a mistake

in the first place—usually, it takes a while for her to apologize if it's her fault—it's how she is.

Q: Now you've been Li Lin's teacher for several years, have you noticed the progress she has made?

Teacher Wang: She's made great progress. Now she looks very independent to me. She can do all kinds of things—she can certainly wash her own bowl very well.

Lin's mother: The cleanliness of the bowls she washes is guaranteed.

Teacher Wang: She's become a highly capable girl and she's able to do everything herself, but some years ago, when I first met her, she couldn't do most of the things that she's good at today. Her mother had to force her to learn.

Lin's mother: She still can't remember phone numbers; she doesn't have a sense of numbers.

Teacher Wang: She's much better than in the past. For example, she couldn't write when she came here, but now, if you give her a copybook she can draw characters even though she's not as quick as other students. Her essay writing skills are getting there little by little. She wasn't able to write this kind of thing—an essay that students write after activities and events—her schoolmates used to give her their work for her to copy. After she copied the essays, stroke by stroke, character by character, her writing has become much better.

Q: She can copy characters and essays, but she can't explain her own feelings and thoughts, can she?

Teacher Wang: That's right, but she's very good at explaining her feelings through language, she certainly can do that very well.

Lin's mother: She never needs to prepare if she's speaking.

Teacher Wang: She's a very good speaker. Once, when we went to summer camp together, she told a story about her great parents, it made all the teachers weep. That's the truth! One of our teachers was swept up with emotion about the difficult life Li Lin and her parents lived. She told us how her mother washed her cloth nappy in the cold winter and other details; the story really touched the teachers' hearts and made us cry. She's a very good storyteller (smiles).

Lin's mother: That was the story how my daughter was born in a cold winter and I had to warm up her cloth nappy before I put it on her in case she felt cold.

Teacher Wang: Li Lin said her mother had to put nappies on her own belly to warm them up before she put them on Li Lin. In those days, people didn't have air conditioners or other heating appliances, so her mother had to warm her nappies in this way. Li Lin's story, well, really... it was touching (he's laughing).

Lin's mother (laughing): Her stories can make people cry, she's a very good talker.

Q: How could she remember these stories from her childhood?

Lin's mother: Well, she has her own ideas.

Q: Can she remember things that happened to her when she was a child so clearly?

Lin's mother: She can remember them well enough after I've told her the stories.

Q: How long does she speak, usually, for example, on a topic about her gratitude to her parents?

Teacher Wang: She can talk on this topic much better than others. On that occasion, the story competition was about 20 min, but she took up to 45 min. She kept talking

about those tiny, subtle details that happened in her life. She could remember all of them!

Q: Did she prepare before the event or just make them up?

Teacher Wang: She hadn't prepared. Even the teachers only received a last-minute note. That evening, we were called to a meeting and one of the host teachers announced that we would have an impromptu competition: every subdistrict home had to name two students for a storytelling competition to share their stories about their gratitude for their parents and teachers. Xiao K and Li Lin represented our home, but Xiao K's story was much shorter than Li Lin's.

Q: Why did you choose Li Lin?

Teacher Wang: I didn't, Teacher Xu Sheng chose her, but both of us agreed that Li Lin was a good talker. In our class, she sometimes speaks more than her teachers (he's laughing). Anyway, she's a very good talker, but she can't write anything down. Also, she can talk about so many details, that's a part of her ability to express herself (laughs again).

Lin's mother: She can keep talking about one thing forever (she's laughing, too).

Q: She has this very strong speaking ability in class.

Teacher Wang (he keeps smiling): She's pretty good, very good.

Lin's mother: And the officials of the subdistrict office didn't think she would be able to join the Sunshine Home.

Teacher Wang: It's about a perspective of policy; the home is for children with medium or mild disabilities; we hardly ever offer a place to a child with a severe condition. The purpose of the home is to provide a place for them to develop their skills through everyday classes. We can't take responsibility in the same way as a nursery, looking after babies and feeding them when they're hungry.

Q: How about her abacus performance in your class?

Teacher Wang: She can work with some simple numbers if she practices with the other students. In group practice she can follow her classmates if she doesn't understand how to do it herself. She'll be fine if I tell her to put "two" on her abacus, but then she wouldn't be able to calculate two plus two. Our addition and subtraction practice is only simple, but she can't do it without watching her classmates. A poor understanding of math is her weakness (smiles).

Q: I noticed that she was struggling with the abacus when I attended your class last time.

Teacher Wang: You're right.

Q (smiles): I also realized that last time, in the classroom, you didn't ask her to answer your questions.

Teacher Wang: On the one hand, the learning progress of the students is uneven; on the other, we have to meet the set teaching programs—when the district DPF office tells us to move on to Book Two, we can't stop for slow learners. We have to finish our set teaching material. If they want to learn something new, they can improve themselves in their break or at lunch time; if they can't reach the class's target, there's nothing we can do for them except to tell them to try to remember those formulas.

Q: Do you offer students who are falling behind extra help during lunch time?

Teacher Wang: We offer this for those students with a stronger learning ability, like Xiao L or Xiao C; if they have any questions, we like to help them.

Lin's mother: These days, she has a stronger interest in Chinese language and literature; she can write characters and *pinyin* with a copybook independently. This is something new she has learned at the home; now she can even copy the English alphabet from a copybook.

Q: She can certainly copy those characters, but does she understand them?

Teacher Wang: I'm afraid she only knows some simple characters, but not the complex ones. She just draws them using the copybook.

Q: What classes do you have except for the abacus?

Teacher Wang: We have English, math, domestic science, Special Olympics training, rehabilitation training, and personal hygiene classes, too many. We usually have two classes, one in the morning and one in the afternoon each day.

Q: How about Li Lin's concentration in class? Does she pay the same amount of attention in both the morning and afternoon classes?

Teacher Wang: She's not bad, usually her performance is better at the beginning than at the end of the class, if her classmates are quiet. If anybody makes a noise, she has to get involved with their business straight away (starts laughing).

Lin's mother: Li Lin concentrates on writing better than anything else; otherwise, she likes to "manage" the other students.

Q: What about her everyday performance, apart from the fact that she's too easily distracted by other students?

Teacher Wang: Generally speaking, she's a good student, she takes her study quite seriously.

Q: Which class do you think is most helpful for her?

Teacher Wang: Perhaps it's the rehabilitation training, this deals with body exercises, like radio calisthenics and dancing—she loves this kind of activity. She also enjoys the singing class very much.

Q: She was very active during the singing event when I was here.

Teacher Wang: She likes to sing; last week the class went to karaoke together where she was singing with several other students. She was humming the tune even though she couldn't read the subtitles on the screen (laughs).

Q: It's pretty difficult to learn a new song if you can't read.

Teacher Wang: Sure, it's not easy to remember the lyrics without being able to read.

Q: Do you teach the music class as well?

Teacher Wang: Yes, I do, we have to teach so many different things. The teaching program requires us to teach them a new song every month, but one song can take much longer than expected. For example, we taught them a new song after the Spring Festival, but some students still can't sing it yet.

Lin's mother: Some students who have that talent learned the song immediately. One of them learned Yue Opera with his grandma; with this kind of musical training, he can sing along with you if you start humming a song.

Q: What is Li Lin's learning ability like in class?

Teacher Wang: She's just about okay.

Q: Is she better than some other students?

Teacher Wang: Yes, some students are worse than her.

Lin's mother: There are quite a lot of students who don't understand a thing. They're not like my daughter, she seems to understand your meaning but only from time to time (she's laughing away).

Teacher Wang: She can certainly understand if you point out her mistakes, but with the worst students, they won't understand you and they can get angry with you at the same time.

Q: It's a difficult balance for you and the other teachers.

Teacher Wang: It's not too bad, I'm fine with whatever they like (he smiles). Basically, they're obedient.

Q: I think all the teachers of the Sunshine Home are very kind and positive.

Teacher Wang: We're okay, we try our best. We haven't charged the students for lunch since 2005. Some homes have to charge 150 yuan because there is a shortfall in students' monthly lunch subsistence—but our subdistrict office and the district DPF office covered the budget gap for us. It's why the students who register with the Tilan Bridge subdistrict office get a free lunch, but we have to charge a little bit of money from some students if they come to our home but have registered elsewhere, because we won't receive their food subsidy. Somebody suggested we charge some money for every student, but how can we do this to them? We can't do it.

Q: Could you tell us one thing about Li Lin that has impressed you the most?

Teacher Wang: She has a very good heart, but sometimes she likes to make things up. Once, when we were on summer camp, she wanted to sleep over in Teacher Sun's room.

Q: Do you mean the summer camp where Li Lin told the story?

Teacher Wang: No, this was another camp. The camp site was in the Songjiang District. Each teacher had to share a room with three students, so Li Lin, Xiao S, and Xiao Z were with me. But suddenly, when I was in the shower room, Li Lin told Xiao S that she was moving to Teacher Sun's room. Xiao S asked her why, and she said because her friend Xiao T was in that room and insisted she had to go, otherwise she would get angry with Li Lin. Then, from outside the bathroom, Li Lin asked me if she could go to Teacher Sun's room.

I said: "You can only go if Teacher Sun says yes. I'm not sure if they have enough space for you, so you'd better ask her first." She said: "There is space for me, and Xiao T will get angry if I don't go." So, I agreed to let her go. Later, after we came back from the summer camp, she told her mother a completely different story; she told her mother that she had changed rooms because Xiao S didn't like her snoring and that I had kicked her out. It was totally untrue. She just made up the story for her mother (he's laughing away).

Q: So, she told two different stories to you and her mother at that time?

Teacher Wang: The story behind it was, Li Lin is very close to Xiao Y and Xiao G, but she'd had an argument with Xiao S in the past—Xiao S can be an aggressive person, she'll beat you up if you're not very nice to her—so these two shouldn't have been together. I didn't know this story when I arranged the rooms until Teacher Sun told me. She said to me I'd better not put these two children together. I replied:

“They’ll be fine this time, because I’ll be keeping a very close eye on them.” But the story about her snoring and changing rooms still happened... She definitely told me, her mother, and other teachers several different stories. She can really make up a story.

Q: But why?

Teacher Wang: I really don’t know, she just enjoys telling stories, she’s clever enough to know which story you don’t like (keeps laughing).

Q: Does Li Lin go to this kind of summer camp often?

Teacher Wang: She goes to summer camp every year because she’s independent enough to look after herself, showering and feeding herself.

Q: Do they need to take a shower and have meals on their own?

Teacher Wang: Of course, they have to be independent to this level; the camp is also a chance to prove their abilities. It’s quite an independent experience for them. They have to spend 4 days and 3 nights with their teachers and friends but not their parents. When the teacher tells them to carry out a duty, they have to be able to do it independently.

Q: The camp has many activities, how often is this event, once or twice a year?

Teacher Wang: There are two camps for eight subdistrict offices every year. They only can offer places to three of the subdistricts each time. If one subdistrict office cancels, the other seven offices take turns in the camps. There’s a special site for the event.

Q: Could you make a final comment about Li Lin?

Teacher Wang (he laughs again): It’s impossible to do that in a single sentence.

Q: You can say more if you like.

Teacher Wang: Let me think about how to describe her. For me, she’s a person who likes help others.

Q: She’s eager to help others.

Teacher Wang: Also, she always the first person to clear up the place. She’s that kind of person, she volunteers for all kinds of responsibilities (he’s keeps smiling).

Q: She’s very enthusiastic.

Teacher Wang: Yes, she’s a very enthusiastic person. There’s anything else... I can’t think of anything (he’s laughing away).

Observation of Li Lin at the Sunshine Home

Observation date: 9:00–15:00, December 14, 2016

Observation place: Sunshine Home

Observer and writer: Yunxiang Zhang

Time	Content	Observed activities
9:00	The early arrivals watch TV while they wait for the other students to come	
9:10	Li Lin opens the gate of the home and walks in. She calls her mother after she sits down and takes out her paper and pen. Then she comes and says hi and shakes hands when she sees the observers	All the students, with the teacher’s help, have to open the gate themselves. Li Lin looks a bit sleepy when she walks into the classroom, she keeps turning back with a smile to look at the observers
9:19	Li Lin stands in the second row during radio calisthenics	Li Lin sorts out her clothes and the clothes and hat of the student in front of her. Her performance is out of tune, but her movements are good. She concentrates on the exercise and seems to enjoy it very much
9:32	After the exercise, she comes back to her seat where she’s left a notebook she took out earlier from her bag and chats with her desk mate. Then, she starts writing	Li Lin is very quiet when she writes
9:36	She leaves the seat and walks to the bathroom	
9:40	When she returns, she puts her notebook in the drawer and chats with her classmates for a while. She starts playing with her abacus	Li Lin tells her desk mate that she can’t write on the abacus with a pencil, that won’t work
10:00	Class begins, the teacher asks the students to practice the abacus	During the practice, Li Lin’s mother is teaching her. When somebody answers the teacher’s question, Li Lin applauds with the other students and says “Great, great, you’re great,” to him
10:06	Li Lin stands up and tries to answer the teacher’s question “Can you add eight on the abacus,” but she has to sit down after the teacher chooses another student to answer the question	Li Lin listens very carefully when the other students are answering the question
10:25	Following the teacher’s instructions for addition and subtraction with her hands	She makes quite a lot of mistakes
10:30	During break time, Li Lin takes out a pen and writes something down, but she erases it afterwards. Later, she drinks some water from her flask and puts it back in her bag	She drinks slowly
10:40	After a rest, Li Lin sits down and sings “Sit Up Straight” with her classmates. Then they open the book and start to practice again	She can’t follow the teacher’s guide even though her mother is next to her helping
11:05	The teacher asks them to clean up the room while Li Lin is out	

(continued)

(continued)

Time	Content	Observed activities
11:15	When she comes back the classroom, Li Lin chats with her classmates	
11:25	Lunch time, she stands in the queue with her classmate	Li Lin takes her bowl to get food from the teacher and thanks him afterwards. The lunch includes rice, egg, and steak
12:00	Li Lin stops one of her classmates looking at an observer's phone, she also reports this to the teacher	
12:25	Handwriting time	
13:25	Bathroom time	
13:30	Prepares for entertainment time	Li Lin cleans her desk and puts the chair onto the desk before she stands up. She claps her hands and taps her feet, she looks very excited
13:45	They play a clapping game together. They clap hands together and count from 1 to 37 while they're marching on the spot	Li Lin looks very happy
13:50	She comes to show the observer how to dance while she's moving to the rhythm	
13:55	A classmate sings on the teacher's stage, she listens very carefully while she taps the rhythm with her fingers and moves her body. Later, she opens her hands wide and claps hard	Her body movement is very exaggerated
14:00	Li Lin taps the desk and talks to her friend while another student starts singing	She enjoys the classmate's song very much; she applauds enthusiastically and is very happy
14:05	She turns back and smiles at the observer, then carries on her dance	Li Lin looks very happy
14:10	Everyone sings "A Grateful Heart" together. Li Lin joins in and uses sign language	Li Lin is excited; she claps her hands and moves around
14:15	Li Lin is chatting with her friends while a student sings "My Happiness Is I Miss You"	
14:20	Li Lin and the two other students come to the front of the classroom and sing "My Happiness Is I Miss You"	Li Lin is very active; she starts to sing even before the teacher asks her
14:25	She moves her arms when one of her classmates sings "Run"	
15:00	The class ends	

*Translated by Huili Meng
Edited by Russell Murray*

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Experienced Employee of an Office Supply Company



Xiaolong Lu

Interview with Mr. Guojun Zhang's Mother

Guojun Zhang, male, born in 1979. Only child. Grade IV intellectual disability. Has worked at a company in Hongkou District of Shanghai since 2008.

Interviewee: Cuixiang Kong (Guojun Zhang's mother)

Interviewer and writer: Xiaolong Lu

Interview date: October 23 and December 12, 2016

Interview place: The Hongkou District Disabled Persons' Federation, Shanghai

From a Beloved Little Daughter to an Iron Lady

Q: Hello, Auntie Kong, could you tell me a little about your family?

Zhang's mother: There are four people in our family, him (points at her son), me, his dad, and his paternal grandma. I was born in 1953 and his dad was born in 1954. I worked in the Xinhua Bookstore until my retirement, I used to be a director and store manager for a while. I needed more time to look after my son, so I applied to take a smaller role and became the business supervisor when the boy was in his early teens. His dad worked in a factory but retired quite early: he had polio disease when he was very young, and has a lame leg. My salary was the only family income at that time.

Q: How did you get to know each other when you were young?

Zhang's mother: Through a mutual friend, one of my good friends who was also a colleague of my husband. One time she invited me to attend an organizational activity at their Youth League branch, and I met him there. We were seeing each other for around a year before we got married. My parents and young sisters were against this relationship because of his lame leg and his poor family background. An old saying says "marry in your own class," but our relationship broke the rule. That's why my family didn't support me. We used to struggle to find a way to meet. I had to

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ask my sisters to go out with us, my parents wouldn't refuse if I was with them. So my sisters used to call themselves "the third wheel" on our dates (she has a sheepish expression).

My son was born in 1979, after we were married more than a year. There was nothing untoward throughout my whole pregnancy. I was looking forward to his birth and having a healthy baby, but I had an accident when I was delivering the baby; my waters broke and amniotic fluid choked his lungs which led to a fever, this damaged his brain. My son was born around six o'clock that day, but it took the doctor until 10 o'clock, almost 4 h, to save his life. My son spent 2 weeks, more or less, in hospital after his birth.

I had to look after both of us when we went back home. We didn't live with his dad because we didn't have married couple housing and had to rent a very small place that wasn't big enough for three people. So his dad used to visit us for a short while every day.

Q: Has his body been bad since birth?

Zhang's mother: He had to see the doctor almost every week with his lung problem and had fever, over 40°. I didn't have any other plan but to fight this disease. This problem always comes back sooner or later. With monthly pneumonia he had to go back to hospital every 2 or 3 days. I was the only person who could look after him. He was sick all the time from when he was born until he was 14 years old. High fever, pneumonia, and tracheitis, all of this was caused when my waters broke. It's hard to tell how many times he went to hospital, but he has been to all of the big hospitals in Shanghai and he's seen all the doctors who could help him. My son has had all kinds of medicine and injections, too many, and he's had so many injections of penicillin and other antichloristic drugs. Penicillin was the most popular medication back then.

When he was 14 years old, he got the fever again and we went to the community hospital. The doctor said: "I can't help you because he is dying." I was so scared. I fell over several times carrying him back, and I ran to another hospital. When I got there, the doctor was very kind and told me (speaks in a grateful tone): "Don't hurry please, I'll check your son out." Later, I was told he had pneumonia again.

How could I not worry? What a life going to hospital every 2 or 3 days! Well, it's really... (her eyes brimmed with tears). During his childhood, he was saved by doctors several times; otherwise he wouldn't be here with me, and probably would have died a long time ago. I got bad news from doctors so many times. Anyway, he had to stay in hospital at least twice a year and I was told that he was dying almost once every year. When I was told he is dying I couldn't do anything but cry. I was absolutely terrified.

There was no cure at that time. When he was 14, people would tell me your son is growing up and he needs extra nutrition to build up his health, especially something for his lungs; so, I fed him all kinds of supplements. Although he didn't grow taller, he did get bigger, and at the same time he became stronger with better immunity. I told myself I should be glad he was healthy. I was very skinny when he was ill all the time; just over 6 stone, after I had my son.

I was the only person who could take him to the hospital at that time; sometimes my sisters would take him if I had to work. My son would never want me to leave

him, so I would go after lulling him to sleep. In those days, we didn't have a private phone or a night public phone service; if he got sick at night, I was the only person who could carry him to the hospital.

I never talked about these things with his dad; anyway, he was nowhere to be found. I didn't mind looking after him myself; his good health was my only concern. I didn't want to dwell on other matters. His dad would come and visit him if he knew he was sick, but if he didn't know, that would be another story. At that time, we'd lived apart for quite a long time already, he would just come to see us after dinner.

He hardly took care of our child. But once I called him about a blood transfusion for my son, the doctor checked my husband's blood type match and let him donate his blood. Anyway, my husband didn't care about the child, so everything depended on me. The child has always lived with me, and he goes everywhere with me, even now.

My husband became kinder to our son when he'd grown up. His attitude towards the boy softened little by little. For example, my son would usually buy a souvenir from a trip or a Father's Day gift for his dad. I told my husband: "Have a look at our son, he is disabled, but still independent, while his healthy peers still depend on their parents." I also told him: "He is your son. Your scorn isn't helpful. It doesn't do anything to solve this problem at all." My husband couldn't hide his feelings, and everybody could read what he thought. He was upset because he wanted a healthy child, but had a disabled one. At the workplace, he always felt bad and wouldn't say a word when his colleagues talked about their children going to college. He turned against my son when he felt bad, but when I was upset, I would love my son even more. He treated our son slightly better after his boss told him to.

Q: Were you under heavy financial pressure back then?

Zhang's mother: Our salaries were 45 yuan for each person while the average salary was 36 yuan in the 1980s. We earned more than most people because both of us were professionals in our companies. In those years, my company, the Xinhua Bookstore gave their workers generous holiday and festival benefits, and this was very helpful for our family.

I never thought about looking for another well-paid job even though I had financial problems, because I'm a single-minded person and love whatever job I do. I saved every penny by cutting down my own meals even when I was well paid. After I had my son, I never had snacks or fruit like the other women. I never felt like fruit and I don't feel bad about that.

I didn't take a bus either even though the ticket was only four pence each way, but I spent several yuan on a raincoat and carried the baby when I walked to work on rainy days. Back then, I really appreciated the kindness of one bus driver, who would give us a free ride. I can't find him now, but if I could I would want to say "thank you." My son still remembers him. I didn't like taking the bus to save money, but this driver told me his timetable and would give us a free ride when he could. I really appreciated his help and kindness when my life was so difficult, especially when he took a risk and could have been punished by his company.

I never asked relatives for financial support and I didn't even say anything to them when I was short of money for the child's treatment. I said to myself, I mustn't ask

for help because I should take the whole responsibility for my marriage, especially when my parents didn't agree from the very beginning. I chose to get married and I have to pay the price. Finally, I made it without other people's support. I used to tell my son: "You must try to meet my expectations and let me be proud of you." I taught him everything a young man needs to know and trained him to be a real man. I hope he can make something of himself one day. I told him: "When people look down on you, be even more determined."

My husband took early retirement around 1989 and hasn't taken up other jobs since then. His colleague and friend invited him back to the company to take a part-time job, but he was too proud and didn't like other people's pity. His pension is higher than sick pay, but more than the minimum wage he received for years before retiring. So our family economics got a little bit easier afterwards.

Q: It sounds as though you took all the family responsibility on your own shoulders?

Zhang's mother: Oh, exactly. I'm the person who holds everything together in the family and it's why people used to call me the "iron woman." I'm not an iron woman at all, I just didn't have any choice (she has a forced smile).

My family was very wealthy when I was young, and my family background was much better than my husband's. Before the Cultural Revolution, our family could afford a maid and nobody needed to do any housework. But during the Cultural Revolution my parents had to send the maid away. At the same time, they couldn't take care of me and six other siblings who didn't have any life skills and needed looking after, so they had to pay neighbors 5 yuan, a huge amount of money at that time, to look after us.

When I got married, I didn't know how to do any housework, even wash my own clothes, but I learned everything step by step after I had my son and I became the one who looked after the family. All my neighbors said I was a good person and I treated my parents-in-law very well, even better than my own parents. I never forgot to buy them a gift for Mother's Day and Father's Day, even though they looked down on me all the time. The neighbors talked to my son and sometimes they'd say: "Your mom is a very good person, but she's had such a hard life since the start of her marriage up to now." I'm very friendly with my neighbors as well and I would never say no to them if they asked me for help. I not only support my own family, but also try to help the people around me. It's why they call me "iron woman." At work I always do my best. I don't care whether the job is only for strong men or too dirty.

Opposite Attitude of Relatives in Two Families

Q: When did you discover your son had learning difficulties?

Zhang's mother: When he was at the senior kindergarten, I found out he couldn't learn like the other children. I had suspicions about this condition, but didn't take him for an intelligence test because I thought he was probably just a slow learner. We only found out about his problem after he did a test at the special school.

Q: Did you ever think about having him adopted when you discovered he had a disability?

Zhang's mother: Never! (Speaks in a firm tone.) I only wanted him to be a strong boy and never thought about anything else; I didn't ask the government for help either. If I had a child in the same situation today, I would definitely apply for help from the Civil Administration and the Welfare House.

I didn't think about having another child either, because I was worried about being able to treat two children equally, especially if the second was a healthy child. People usually prefer healthy and adorable children to a disabled one. So I decided to give all my time and love to this child and try my best to make his life better.

If the second child was a daughter, she'd look after her brother when she grows up, but you couldn't expect a young brother to do the same thing, especially after they get married and have their own family. His wife wouldn't agree to look after him, maybe even scorn the older brother. The young brother might not have a problem with his older brother, but who can tell what his wife would be like?

Q: Did you talk to your family and relatives after you knew about his condition?

Zhang's mother: Both families know what happened to my son, but I didn't explain to them how hard our life had become. I never complained about the problems we had when he was young. For myself, I couldn't accept the situation when I got the news, I didn't understand why everyone else could have a healthy child except me. Why? I didn't dare go out for a long time, because I was afraid of other people gossiping and criticizing me behind my back. I didn't dare to talk to my colleagues, because I worried they might talk about me behind my back. I only revealed my son's condition to my boss when I had to ask him for a role with less responsibility. I don't like people's pity or scorn. I might have a disabled child, but I can raise him without anyone's charity and pity.

My parents showed me more love than all their children because of my son. My older brother said: "I look after you more than my other siblings because they have a normal life and don't need any extra support." I have two older brothers, one older sister, and three younger sisters; all of them support me and never let me down. They understand how much I hurt inside. As my parents got older, my younger sisters helped me more and more. If I couldn't take time off work to care for my son when he went to hospital, my sisters would always help me. We're very close and always ready to help each other. You can ask him (points to her son who is sitting next to her), his aunts compete with each other about who will look after him if I'm too busy. They used to say to him: "You'll be comfortable with us until your mom is free." Their support has always been strong, even today (her eyes are tearful).

In my husband's family, everybody blames me for having a foolish child. For them, I'm solely responsible for my son's problem. They argue all the time about my son's right of inheritance and keep telling my husband not to give the family property to my son. They say: "If we give the house to you, one day you'll pass it down to your son, but why does an idiot need a property?" That is my husband's family! (She looks angry.) In any case, my husband doesn't have a property to give away. The place my husband lives in at the moment is the apartment I bought for my son, while my son and me live in an apartment that his paternal grandpa left to us. They still insist that my husband mustn't give the apartment that we live into my son, because a fool can't look after property and one day I might give it to my family.

Q: When did your husband's family start calling your son an idiot?

Zhang's mother: The year he went school, when we realized my son couldn't keep up with his studies. They started calling him an idiot and blaming me, and they've never stopped since, but we speak much less nowadays. The paternal grandma is the worst; she is always saying bad things about my son. This upsets me very much. I don't mind if she treats me badly, her behavior won't change my attitude towards her, she's a parent; but I'm so angry at the way she criticizes my son. However, because she's my mother-in-law it's my duty to care for her, even though people say to me: "Your mother-in-law totally lacks respect for you."

The paternal grandpa was totally different from her. He didn't say much, but he loved my son very much and treated him so well; a really heartfelt kind of care. Grandpa was never bothered about my son's disability. He liked to take him to all of his factory's events.

When my son was little, his grandpa took him to the staff children's day nursery when I was too busy. This place is only for the staff's children during the summer vacation, where some colleagues take on a teacher's role and look after the young children. It's one of the benefits for workers, but without his grandpa's help, my son wouldn't have been able to go there. My son spent every summer and winter vacation at that day nursery for years; he studied, played chess and other games with the other children, and they were looked after by the teachers. My son was very close to his grandpa, they shared all kinds of stories together.

When he was younger, he had some unpleasant experiences when we went out. I hated being looked down on by others and sometimes I couldn't control myself and argued with them. The only thing I could do is not go out so much. I felt so bad when we went out; I didn't dare lift my head when people pointed their fingers at me. One time, we were on a bus and he was curious of a woman's watch. At that time he wasn't very smart and he was very naughty, and he touched the watch strap without asking. Suddenly, the woman started shouting at him. I tried to explain that it wasn't worth shouting because my son couldn't understand what she was trying to say. She said: "What an idiot your son is." I was so upset and returned the insulted: "My son might be an idiot, but at least I love him. You're young, and maybe one day you'll understand what it's like to have a child." Anyway, this kind of discrimination used to happen on the bus and that's another reason why I didn't like to take the bus and walked.

I rarely took my son out when he was young, because I hated the way people laughed at him. After some years, when I had more free time, we went out more often together. He's had a change of mind too; 5 or 6 years ago, he didn't like to go out with me even if I asked him. In the beginning, he was worried about his problems with speaking and communicating; he hardly talked to other people. But when he could speak better and began to get bored staying at home, he changed his mind and asked me to take him out. Usually we just went to public parks, but if he told me he wanted to take a 2-day journey and spend a night somewhere, I wouldn't let him down. For example, on the National Day holiday, several days ago, we went to Guangfulin Heritage Park in the Songjiang District for a photography trip.

He Wasn't Good at Studying but Good at Doing Things

Q: Could you tell me more your son's experience at the nursery?

Zhang's mother: He went to an ordinary nursery and was the favorite boy of the teachers; they praised him quite often. The teachers thought my son was very cute, especially when he was imitating things. The teachers would applaud or reward him with a little red flower.¹ He was such an active child, he didn't talk too much, but he liked to hug or kiss the teachers and he was sociable with people all the time.

Before he went to school, he was fine, even if he wasn't talkative. Then a first-year teacher hit him, and after that he didn't dare talk and stopped replying to other people's questions. When he was 7 or 8 years old, in the first semester of first grade at the school, he was told to leave by a teacher. A child like him doesn't get any respect from the teachers because he could have a negative effect on the enrollment rate.

The teacher hated my son very badly at that time, because my son was the reason that he couldn't get an award for the class test results. Once the teacher hit my son with a book and gave him a bloody nose. The teacher insisted on throwing my son out because of his bad performance in class: he wasn't clever, he lagged behind, couldn't read, or do maths questions, we were terribly worried about him.

We didn't think he had any intellectual difficulty until he had an IQ test at the special school. Before then, we just thought he was slow-witted and clumsy, because we couldn't see anything wrong from his appearance. The test result revealed he had an intelligence score just slightly below average. The doctor told me his condition was almost the same as ordinary people.

Q: Did you look for legal support?

Zhang's mother: No, we didn't know anything about the law in those days. If we'd known the law, I would have sued the hospital over the accident at birth. A newborn baby choked by water is nothing other than a medical accident! We were different to people today; we were ignorant about the law. Fortunately, I knew an old retired teacher in her eighties, who was a very nice person and member of the district Chinese People's Political Consultative Conference. What a shame she's passed away (there is an expression of loss on her face). She said to me: "Don't worry, let me see what I can do for you." She asked one of her students, who was the Director General of Hongkou District Education Bureau to visit us and listen to our problems with my son. Following that, he advised us to send the boy to a special school.

We didn't know anything about this school before and would never have thought about sending our son there. If I had known my son's condition was more complicated than him just being a slow learner, I wouldn't have let him go to the ordinary school. With this director's help, my son spent two extra years at that school, because I was too busy to keep him at home. The normal length of a child's education is the 9 years, but I asked the school leader to keep him there for a longer time. I didn't mind paying the extra tuition fees and we were lucky the school leader agreed to keep him for another 2 years.

¹ Years ago, in Chinese nurseries and primary schools, teachers would reward a well-behaved student with a red flower or a red flag, usually made of paper.

Q: Did you need to take him to school or could he get there by himself?

Zhang's mother: I took him every day until he graduated. Every school day, I took him to school before 8 a.m. and left after his class started. Then I went back to the school at 3:30 p.m., half an hour before they finished. I took him to my office, and we went home together when I finished work. He would work on his homework or handwriting practice at the bookstore.

Q: What lessons did he study at school?

Zhang's mother: Chinese, math, business, and some extras. At the special school, they don't offer much study of cultural knowledge because they are slow learners, but focused on practical abilities. In addition to the regular classes, they also had some extracurricular activities; for instance, spring or autumn picnics or radio calisthenics competitions. Compared to an ordinary school's teaching, I think the special school's timetable and activities were more suited to children like my son. They use different textbooks at the ordinary school; basically, the special school's textbooks are much easier.

He was very popular at the special school. All of the teachers liked him pretty much. When they went out for spring or autumn picnics and slept out at night, he didn't need to share a room with other students, and he could go to the teachers' place if he wanted. He was very sweet when he was a child; he would say hello to people all the time. Now, he still has a warm heart, but speaks much less. For example, if his teacher visited us, he'd ask the teacher to sit down, give him a cup of tea but wouldn't chat. That's how he is, a quiet person.

Q: Did he make some good friends at the school?

Zhang's mother: I don't think so. He didn't dare talk too much because he was a quiet child. He was worried people might find out about his condition when he started to speak. He was very introverted, so closed off, and he looked like he might have a form of autism. He was like that from the time he was beaten by that teacher until we joined the China Association of Persons with Intellectual Disability and their Relatives² in 2007. He became more relaxed when he joined those children who had similar conditions and became more and more open and talkative. Before that, he didn't dare to talk with ordinary people at all.

When he was a student, he never talked about his school life, even with me although I kept asking. He's just like other autistic children; they won't respond to other people even if you repeat yourself a hundred times. But gradually he became more mature and sensible at the same time. He understands me better and now he does more housework.

Actually, I never treated my son as an intellectually disabled person, and I was determined that he should learn everything an ordinary person would. He was always very good at housework from the time he was very young (speaks in a very proud tone). Why? I realized my son could never be a good student from the time he was in kindergarten when the teacher said to me: "You don't need to push him to study, he

²The English abbreviation is CAPIDR. The Chinese abbreviation is "Zhiqinhui". It is a corporate organization, a non-profit association affiliated to the China Disabled Persons' Federation, founded in 1989. There are grass-roots branches at all levels throughout China.

can do anything he likes, just make sure he's behaved and doesn't disturb the other students." I disagreed with him, and I kept telling my son: "You're not a smart boy, you might not be a good student, but you have to be good at housework and grow up to be independent. I won't be with you forever; you will have to live your own life after I die." (Her voice is choked.)

From when he was nursery age, I let him practice as much as possible and never spoiled him. For example, I didn't allow him to use a spoon to make eating easier. So he used chopsticks from a very early age and never used a spoon. I was very different from normal parents, how they like to let their children start with a spoon—because a spoon is easier to handle—and then learn how to use chopsticks afterwards. I taught my son to use chopsticks from the very beginning. I know, with a child like him, if he didn't learn these skills at an early age, he would never get a chance to pick them up later in life. In our group, some children have never been able to use chopsticks.

I used myself as an example and would say to my son, if your mother, who is much older than you, had to learn everything after I got married, you, a young and clever boy, must be able to learn these things quicker and better than me!

After I had drawn the bath water for him, I taught him to take a shower by himself. He also learned to tie his own shoelaces; I don't care if the knots were pretty or not, but he had to be able to do it himself. He started washing the dishes when he was smaller than the sink, so I gave him a stool. I was never annoyed if he said to me: "Mom, I've broken a bowl," because for me, letting him learn the skill was much more important than buying a new bowl. I even made him a small mop and taught him how to clean the floor every day, before he could use a full-size mop. He was quiet, but always tried very hard to learn the things I taught him. I taught him all sorts of housework bit by bit, until he became independent. These days, he works slowly, but he can bathe himself and wash his own clothes without any problems.

When he was little, he used to fall over so easily, but I never helped him up. This might be difficult for most parents to understand; for them, helping their children get up would be a very natural thing, especially for a disabled child, but I insisted doing this my way. Once, he slipped and was kneeling on the ground, I didn't help him up, but walked to him and stroked his head (pretends to stroke something): "Climb up!" A neighbor who saw us was shocked and asked me: "Wow, what's wrong with you, why don't you lift him up?" The thing I didn't expect was that night my son was in very bad pain. Later, the doctor told me that his leg was broken. The tears were rolling down my face as soon as I heard this news. But I only regretted stroking his head, not about training him to become independent. It was just a very rare accident, he could always stand up by himself after falling down, nothing like this had happened before or afterward.

I was very sad when I watched my son fall over, but I couldn't bring myself to help him (her voice is choked). The only reason I treated him so strictly was because I knew he needed to learn from his own mistakes to be able to grow up. I had to hold back my tears and stand away, telling him to get up even though it was very painful for both of us. That night, after I learned my son had broken his leg, I lost control and cried terribly, tears were running all over my face (her eyes brim with tears).

I don't beat my son very often, except if he's been very disobedient. For example, I would have to teach him a lesson if I told him to get washed and he refused. To be honest, I never feel good after beating him and couldn't help but cry afterwards. He was never punished when he was a little boy, because he wasn't as obstinate as when he was older. In his teenage years, he started to know his own mind, sometimes he would disobey me or even deliberately make me angry. Now, if I want to beat him, he'll hold my hand and stop me, but also, he understands my reasoning very well. I usually say to him: "Mom would never hit you without reason, I'll only do it if you've done something wrong." I care about him very much, I always check if he's swollen or has a red mark after I hit him (covers her face and weeps).

If I've had to hit him that day, when we get back home, I'll usually discuss what mistakes he's made, and let him think about what he did afterwards. If it was his fault, he has to say he is sorry to me, but I don't mind apologizing to him if he thinks Mom was wrong. It's a two-way thing, I would never beat him for nothing, I want him to be a better person.

I also trained him to be aware of social etiquette, for example, when he was very young, I was always telling him not to yell or speak loudly on the bus. When we get off the bus, he can talk to the people he knows, but nicely and gently. These days, if he takes a bus to his maternal grandma's home, I know he won't talk too loudly or behave in a rude way.

Outside, he has a very good sense of behaving in traffic; even my colleagues praise him for that. Sometimes "jay walking" across a traffic light for an adult is easy and happens often, even I crossed on a red light once when we were cycling, but he never does this. A red light means stop, and a green light is go; he never crosses on the wrong light. I have been strict and serious with this training. There can be no alternative. I keep saying to him: "One day, your mom will die and you will have to live on your own. If you learned all the things I teach you now, you'll survive in the future." I've repeated these words since he was very young; I have to set a very high standard for him, always.

Q: I heard your son is interested in cooking, does he cook at home?

Zhang's mother: He can cook, but he doesn't need to cook for me at home. To know how to cook is what I want for him. I ask him the same question from time to time: "You don't need to worry about food when we're together, but what would you do when your dad and mom pass away?" He says: "I'll buy noodles and cook them myself." He can cook some simple dishes, poached eggs or fried eggs, for example. If you let him cook at home, he might say to you: "I'm afraid you won't like my cooking, I'll only cook for myself if I need to."

He Is Efficient at Work and Very Capable

Q: What was your plan after he graduated?

Zhang's mother: After he graduated from the special school, he stayed at home for a while, but it was a difficult time and I had to lock him in the house when I went to work. I prepared some bread and malted milk for him before I left, but I didn't give him any hot food in case he hurt himself. I would come back home to a messy boy and house.

In those days, he was young and couldn't control himself and he usually did some crazy things. He cut up my best clothes and new shoes—it made me cry when I saw this ruined stuff. It had been a gift from my sisters who'd taken pity on me. I'm a very frugal person and reluctant to spend money on clothes. But I didn't have a choice; all I could do was hide the scissors and any other sharp stuff. On a day that he broke things, the only thing I could do was ask him to help me clean up. If you mess up, then you have to tidy up, that's my rule.

Two years ago, my friend opened a private bookstore. She's a friend that I met at the Xinhua Bookstore. One day, she said to me, if you like, I can give your son a job and teach him how to work. I took up this offer for him. My son has grown up in a bookstore, he was always at my workplace after school until I was off duty. So, he was used to a bookstore environment and after years and years of watching he knows how it all works.

When he went to the bookstore, a place opposite to my home, the senior workers taught him how to arrange books and other things and he worked there for around 5 or 6 years. As a part-time worker, he only earned 400 yuan a month; it was only enough to pay for his own food, but there's two aunties who treated him very kindly.

Later, my bookstore needed a cleaner and the boss asked if we wanted this job. It was a job in the Putuo District's Xinhua Bookstore branches and covered three stores. Each store paid him 200 yuan, so he could earn 600 yuan every month. It was only a half day's job, he started at 8:30 a.m. and spent more or less an hour in each store. It wasn't a high standard job for him, but one store was quite far away and he needed to cycle there. For my sake, these stores knew about my son's condition and never mistreated him as long as the place was tidy enough. My son liked to help the other workers after he'd finished his own work, and he did this job for around 3 years.

Then, I talked to my manager—who was good to me—and told her my son had a problem and I couldn't look after him while I worked. She said: "Why don't you let me meet your son?" After she'd met my son, she said: "Your son looks fine to me. If he can pass a 1-month internship at the storehouse, he can certainly work for me." All of the workers agreed that my son's work performance was good that first month and since then until now, he's been employed part time.

Part of the Xinhua Bookstore's business is student textbooks and exercise books; my son is in charge of the exercise books. Here's an example, (she takes out an exercise book which she's carrying with her) we have all types of exercise books, and my son has no problem classifying and arranging them.

There are many kinds of exercise books in different style and color, each grade and subject has its own exercise book, vertical lines, horizontal lines, big grids, and small grids. My son learned from me how to classify and arrange all of them. He wouldn't be a good worker without my teaching! (Speaks proudly.) Actually I always teach him patiently whatever he needs to know. Other people might only need to be told once, but my son might need to be told 20 times.

His work schedule is Monday to Friday, but he can ask for leave if he needs to. The manager is a good friend, so I ask her to do him a favor if he has to take a day

off. Her husband likes my son very much because he works very hard and works quickly and correctly, he never shirks off work with excuses.

In the beginning, he wasn't a sociable boy, he didn't like to talk to colleagues except for greeting them. People asked me why he worked so hard but never talked, because he only focused on what he was doing and never responded to other people, whoever talked to him. He changed little by little after I told him not be so quiet. These days, he's quite close to the driver in his team and he likes to talk to his colleagues, too. His colleagues never leave him behind if they have a company banquet or trip; they treat him as an equal. But he only socializes with them and doesn't invite friends to come back to our place because our apartment is too small.

Q: What does he do with his salary? Keep it or give it to you?

Zhang's mother: He gives his salary to me, but asks me for some money when he needs it. Usually he only carries a 100-yuan note in his pocket which he can use if he needs some small things, but if he needs 500 yuan for something I won't say no.

Basically, he's a thrifty man, he doesn't like to buy bottled water or snacks, even when you tell him to. He always has his own flask with him if he goes out. Another example is if he misses breakfast at home, he won't buy one. He wouldn't do that, but if you bought some food for him, he wouldn't refuse. He only cares about the money in his pocket—"if the money isn't there, it can't be mine"—that's how he thinks. He likes to save money from snacks and other things, but spends it on what he likes.

Q: Do you still remember when he received his first month's salary?

Zhang's mother: The first month, when he worked for my friend who runs the private bookstore, I remember he got 450 yuan. He bought a gift for his paternal grandma, even though she doesn't like him very much. Actually, I was angry with his attitude towards his family; my mom loves him so much, but he never gave her a special gift. It's like he thinks that only my husband's relations are his family. For him, even though his paternal grandma treats him badly, she is still his family, and they belong to the same Zhang family. The paternal grandma lives next to us but rarely talks to my son, even though my son likes her very much. Actually, his paternal grandpa was very nice to him, but he died too early.

A Fanatic Football Fan Who Enjoys Sports

Q: I heard he took part in Special Olympics that were held in Shanghai years ago.

Zhang's mother: Yes, he did, when he was 26. He came second in a running race. It also was his first time to participate in a large-scale athletics competition. He won a lot of medals (takes out six sports medals). This is a gold medal, and this is a silver medal from the Special Olympic Games (describes the medals on the desk)... We have lots more medals at home, some bronze medals as well. He was also involved in the football tournament, bowling, running, and bocce in Special Olympics; all of these medals he won at Special Olympics or related sports competitions that year.

He was active in sports at school as well; he could give up all the other classes but not PE. He was involved with many sports at the school's annual sports meeting: football, basketball, running, long jump, among others; he didn't miss any of them.

This Friday, we went to a Unified Run³ competition, and this time won second place. Each team had 12 people, ordinary people/volunteers and disabled people, half and half. It's quite a difficult game—all the contestants stand in line and tie their foot to the person's next to them. During the game, they have to run with the same rhythm—everybody has to move their left foot when their partner moves their right. My son and I have been involved three or four times since the first Unified Run competition, and we plan to go to next year's game too (See Fig. 1).

The nice thing is, we met his good friend at the sports stadium and they were so close and excited. He is the friend we met last year at a family event in Shanghai; every district sends two families there. During the event, we got to know the boy and his mother, who come from Zhabei District, and found out that both boys love football. Since then, they've become best friends forever and keep touch all the time by WeChat or other ways.

We also have a small group at the district DPF center, which includes eight adults and seven children. We're very close friends just like our children with the other children. We usually hang out together. In our group, my son is a very handy man and can turn his hand to anything when we need him.

Q: Do you prepare for the competition before Special Olympics?

Zhang's mother: No, we don't prepare for the games. The first time, we received a very late invitation and didn't have time to prepare because Special Olympics didn't have enough advance publicity. So we started the competition straight after we registered for the games, without any preparation.

My son was young and could run very fast, so he performed very well that time. If we'd known about the competition earlier, we would definitely have done some preparation exercises. It was the same for the Unified Run; we received very late notice again and only had time to practice twice in this main hall.

At Special Olympics, he went to his game with the team's teacher and the parents were told not to go with them. He was very excited, shouted out loud and jumped very high when he knew he'd got second place in the running race. He didn't tell me very much when he got home, I think because I'm usually quite strict with him: If he didn't get a gold medal which he should, I wouldn't talk to him for a while.

I wish we could have a space, like a campus sportsground, to prepare for the games. We need more support for their practice so they can get better results. More notice and a practice ground are the things we need. For some exercises, we need the right kind of space. For example, the Unified Run needs a big ground for practice. The floor in this room isn't good, the athletes could be hurt if they fall over.

Q: Does he like playing football very much?

Zhang's mother: For sure, he likes to ride his electric scooter to the campuses—Shanghai Institute of Foreign Languages, Tongji University, Shanghai University—to play football with college students. When he's at the sports ground, he won't hesitate for a second to join a game if other players ask him to. Sometimes I don't like him

³The Unified Run is a popular game with mixed teams of disabled and ordinary people. It is an extended event of Special Olympics and encourages two groups of people to cooperate and understand each other.



Fig. 1 Guojun Zhang and Yaping Deng, a former table tennis Olympic Champion

playing with other people because I worry that he might hurt others with the ball. I keep asking him: “Do other people know about your condition?” Anyway, if he was hurt by somebody else I can’t complain to them, but if it was the other way around I worry that the injured person might come and complain.

It’s why I don’t like him to play football there, but he never listens to me; he keeps going to play football secretly. He used to play quite frequently, several times a week, driving his electric scooter around the Shanghai Institute of Foreign Languages, Train

Head Stadium, and Tongji University. He's been going less in the last 4 or 5 years, I guess because he isn't as fit as before now he's getting older, he's 38 now. Another reason is that he knows that football players usually quit when they get older, so my son thinks he needs to do the same thing. He knows all of those players, the ones in the magazine.

Q: When did you realize your son had become a football fan?

Zhang's mother: It was in 1995, he went to Hongkou Football Stadium to watch a game of Shanghai Shenhua Football Team and he was chosen to be interviewed by a journalist from Shanghai Television. They thought my son looked like a big fan; he was so excited with the game and good at shouting team chants. The journalist asked him: "Where are you from, why do you support the Shenhua Team?" My son said: "I come here to support Shenhua because I'm their fan!" I didn't know anything about this until my sisters and her friends told me they'd see him on the TV. They said to me: "Wow! Jun is on TV!" (She looks very excited.) I never got a chance to watch this program.

My son watches the football program every day, and he likes to buy football magazines. Have a look at these magazines (takes out some football magazines from her bag). He spends a fortune on these things, some of the books are several hundred yuan each, like this set of World Cup books, which is published every 4 years. He doesn't care about the price, but he is obsessive about collecting these magazines, hardbacks, and limited editions. He can tell you the story of everybody that's featured in the books.

This book is around 80 yuan (points at the football book on the table), this one he bought recently and without me knowing, because he likes to take these books to work after he's bought them. But he buys fewer hardbacks than before. I won't stop him buying books that he really likes. At the same time, I'm sure he isn't a wasteful person, if he spends money on books, he definitely saves some money from elsewhere. So I never worry about him for this reason.

Some children in our group have quite loose hands with their money, but my son isn't one of them. He understands how difficult it is to earn money, so he's always very careful with his expenses and plans them carefully. For something expensive, for example, if he wants to buy a laptop, iPad, or iPhone, he will always discuss it with me first and only buy it if I agree with him. For some small things, like buying this magazine, he can make his own decision.

We also have quite a few footballs at home; some of them are gifts from other people. Once my niece went to Spain with her family and they visited the Real Madrid Club and bought a football for my son. It was so expensive, it cost several thousand yuan! I told them not to buy it or choose a smaller and cheaper one, but they didn't listen to me. They said the price didn't matter, because my son loves football!

In Pursuit of a High-Quality Life

Q: Does your son have a problem with recognizing the denomination of bank notes?

Zhang's mother: No, he doesn't have that problem, but he has a problem with big notes. For example, if he pays 10 or 20 yuan for something with a 100-yuan note, he can't work out how much change he should get.

Q: Do you worry about Internet fraud when your son is using his mobile phone and on social media?

Zhang's mother: No, I'm not worried. He doesn't use the Internet very often, but he plays some games online. He used to watch TV at home, so he won't be cheated too easily. On the one hand, he never missed an episode of *The Oriental 110*, he also likes to watch programs like *Law and Morals* every day. On the other hand, I usually tell him don't talk to those strangers who tell him suspicious stuff and walk away from them as soon as possible. My son listens to me and he doesn't talk to strangers if he can help it. He was much more relaxed when he went to the campus and played football with college students, because he knows these people won't hurt him. If some people who are not students invite him to go somewhere to play a game, my son won't go with them.

We have another rule: we don't check each other's phones, because we have to trust each other; but he needs me to teach him how to use the phone sometimes. For example, I taught him how to send a message to his teachers if something has happened. He usually learns this kind of thing very quickly and he doesn't need my help next time. He knows how to download pictures if me or some of his friends send them to him and he can share the pictures with us. With social media, he likes to tag a "like" to his sisters', brothers' and friends' Moments that they post.

He likes to play games and collect gaming equipment. He has lots of model guns, probably more than 100 already. Sometimes when we go out together, if he sees a model gun, he usually has to buy it. He also likes to collect pretty poker sets even though he doesn't play the game. Last time when we went to the Town God's Temple, he bought a poker set and put it in a drawer. Anyway, he likes to buy new poker sets.

My son is very different from the other children in our group. He likes brand clothes, but other intellectually disabled children don't even understand the meaning of brands. My son has to have them. The top he's wearing (holds up her son's clothes) is Adidas. How expensive is an Adidas top! Last time when we came back from a holiday in Tibet, he asked me to go to the Adidas store with him and choose this suit, which was over 1,000 yuan.

Actually, he has his own ideas about lots of things, like branded clothes and quality food. If my good friends go overseas and want to buy some gifts for me, I always say: "Please don't buy anything for me, but have a look if you can find something for my son." So all of my friends know my son likes big name brands and they try to choose something he might like. He just got a pair of New Balance sports shoes. I got a phone call yesterday from a friend who is in Japan at the moment, to ask what my son wants. My son is happy with me, because I have so many good friends (she has a satisfied smile) and all of them like him very much and buy all kinds of gifts he likes.

In fact, my son's mind is very different from the other children in the group, because he grew up with ordinary people from the time he was very young. He attended a regular nursery and school and since he was 18 months old, for 18 years, I took him to my workplace. He also stayed at the other bookstore when I changed jobs. Anyway, he lives with ordinary people and society in a regular lifestyle. When he first went to the district DPF center, he felt very awkward and was reluctant to go;

he only liked to talk with ordinary people. At that time, my sisters said the same thing to him: “You don’t need to go there because you’re much better than those children. Why do you need go?” My son said: “I don’t like to go, but I don’t have a choice because my mom insists!” For me, if you have a disability certificate, then you have to be a part of this group’s way of life. Let’s be honest, it’s not easy to communicate with another group of people after you are used to ordinary people. Anyway, eventually he agreed and started to go to the DPF center events regularly. There are three or four children with a light condition in our group; my son gets on with them quite well, they usually have a day out together during festivals and holidays. They like to chat about games or other interesting things, sometimes they go on a day trip to some places nearby like the Western Suburb Park or Qibao Traditional Town. They enjoy the old town very much, because there’re so many interesting things and street food.

My son doesn’t contact his cousins from his dad’s side by choice, because sometimes he feels too awkward joining their conversations, so he doesn’t talk with them often, but when his cousins talk to him, they will make it easier for him. In my maternal family, nobody discriminates against my son; his seven cousins are very friendly with him. If they go to a karaoke hall, they never leave my son behind even though he can’t sing, but they want to enrich his social experience and get him used to different public places.

Recently, one of my nephews arranged a day trip and he gave my son a lift. Under this family and group environment, my son has become more and more open and talkative, but the real problem is a poor ability to express himself. Sometimes he can’t explain himself properly. He can’t make complex conversation like you and me. So he prefers to talk to people who are close to him but it’s harder to talk with strangers.

Longing for More Sunshine on My Family

Q: How well do you think our society accepts disabled groups?

Zhang’s mother: Under the district DPF, there are five sub-associations: associations for the physically disabled, the mentally ill, deaf-mutes, blind people, and the intellectually disabled. The intellectually disabled group is the poorest; their members can’t speak for themselves and can be easily bullied by anybody. They always get the smallest budget and least attention in the group. So as parents, we’re urging society to give them more attention and care, because they don’t know how to appeal for better welfare. But the truth is, a “squeaky wheel gets oil” (if you make enough noise someone will pay attention).

Even so, we still receive some financial support from the district DPF office annually, a budget of 20,000 yuan a year.

If we want to take more trips with our children, our small group of seven families has to be self-funded. We usually take them somewhere twice a year; for example, we just went to Nanjing for a 2-day holiday. These children’s tastes are becoming more sophisticated all the time; they are choosing travel destinations by themselves. Last year we went to Hainan and this year they chose Zhangjiajie, but the parents have to pay for everything.

The district DPF office training group has a 2-month summer holiday from July to September and we usually take a long journey during this holiday. At the district DPF center, some parents and volunteers are the only people willing to take these children away.

Some parents still have a problem with embarrassment and don't like to go out with their disabled children. So, if they send children to our place, we'll arrange their trips for them. Right now, we're applying for a day trip to the Chongming District.

The children enjoy their trips so much and get so excited when they can go out. To my knowledge, some places outside Shanghai are more willing to give concessions to disabled people than Shanghai attractions. For example, a lot of attractions elsewhere are free, but few Shanghai places give them a half-price concession.

Q: What are your family's expectations for the future?

Zhang's mother: I hope our family life will get better over time, and the government will provide more social care for families like us with more than one disabled member. For the time being, the social benefit policy is weighted towards children with more severe and serious conditions; children like my son, who has a less severe condition receives a reduced subsistence allowance; few social care policies cover them and I don't expect too much. The good thing is since last year, the DPF office introduced a new policy, which has been very helpful for us: if a family has more than one disabled member, they will receive more money, so two people will receive 500 yuan, three people 600 yuan, and if there are four or more than four disabled people in a family, they will receive 700 yuan a month. I really appreciate our Chairman's work for this new policy. I told them: "It's the first time I feel sunshine on my shoulders."

I also want to ask the Bureau of Civil Affairs and other departments to treat all the different kinds of disabled people more fairly; those severely disabled people need allowances, but people with a milder condition need some attention, too! We do have a disabled certificate as well. For example, there are two disabled people in my family, but both of them can't receive a subsistence allowance because according to the welfare rules, the government will only help them find a job at an affiliated company. It's a social support policy made between the DPF office and companies; if the company accepts a social responsibility to give a job and minimum allowance to a disabled person, the company will receive some tax or policy benefit.

Q: What do you think about marriage?

Zhang's mother: It would be his decision to marry or not and it depends on him. If he told me that he likes somebody, I would definitely support his decision. Anyway, I've bought a property for him already. My son isn't very interested in finding a girlfriend even though some of the teachers in our group have introduced girls to him.

Q: What are your plans for your son when you get older?

Zhang's mother: This is what I'm thinking: he's an adult already, I'll look after him and take him for as many trips as I can, but one day, when I can't do it any longer, my plan is to give the property to the old people's home and both of us will move into that place. I can't leave my son a homeless man, so in this way, after I die, the old people's home can keep the property and look after him. I know a disabled man who was a good child before his parents passed away. He spent some time with

his paternal grandma but became homeless after she died in her eighties. I was very upset when I saw this child, his situation was so poor. His story was a lesson that I need to find a better way of looking after my son in the future. I definitely won't leave him to wander around the world.

Q: Have you thought about letting your family or relatives look after him?

Zhang's mother: I can't let a second cousin look after my son, even though they seem like caring persons and they ask about me so often, but the truth is they are just the same as anybody else—they have their own family to look after—how could they pay attention to my son? One of my nieces once said to me: "Don't worry auntie, I'll take care of my brother in the future." But I can't depend on a promise, I have to sort out this problem by myself.

Q: Do your family agree with your plans for your son?

Zhang's mother: Yes, all of them agree with this plan, even my son. I pointed out those poor homeless beggars who never have a proper meal to my son and said to him: "If you can't look after yourself after I die, you might end up like that." My words made him take this thing very seriously. Anyway, I'll join the house-for-pension scheme, and let the old people's home look after him in the future.

Q: Thank you very much for your strong support of our oral history project of Special Olympics. I'm very pleased you could share your story with us. Your life is hard but full of happiness, and I wish you and your family a happy and healthy life.

Interview with Colleague of Guojun Zhang (I)

Interviewee: Mr. Liu (Guojun Zhang's colleague)

Interviewer and writer: Xiaolong Lu

Interview date: November 11, 2016

Interview place: Office of Guojun Zhang's company

He's a Good Colleague and Works Hard

Q: How do you get on with Guojun Zhang, Mr. Liu?

L: We've worked in the same team for years, but I became his driving partner about a year ago. Actually, we've known each other for over 10 years. I moved from the Northeast 12 years ago. When I came to the Xinhua Bookstore, he was the first person I met. We've worked together in the warehouse since then. Last year, I got a driving job and became his partner.

Q: Did you recognize he was disabled the first time you met him?

L: To be honest, I didn't realize it at all. The first time I met Junjun was outside the bookstore, before opening time. That morning was my first working day; I had just arrived in Shanghai and didn't know the city. I was starving after cycling a long way from Huangpu District. Junjun was the first to meet me and asked: "Are you the new worker?" I asked him where I could find something to eat and he took me to a breakfast store downstairs.

That's how we met the first time; I really didn't think there was anything different about him. He was the first person talk to me, I was a total stranger and had been told by HR to wait for somebody by the door and report to them.

Q: How did you find out he was different?

L: If I remember rightly, I got to know this from his mother. We were busy with our own stuff and only met at lunch time; he seemed fine to me, we chatted occasionally, usually at lunch time. So, it never occurred to me he was disabled as he was really good at his work, did things properly and quickly. In fact, I didn't know any disabled people before I met him. For me, Junjun is a very clever guy, his shelves of exercise books and paper are always tidy and organized.

Q: Do you treat intellectually disabled people differently?

L: To be honest, I don't. His mother was our colleague, and everybody is friendly to Junjun. He's a smart guy, very practical. When colleagues and I take a break for a smoke after we've finished some dispatching work, he prefers to clean up the place. In the warehouse, sometimes we have to move boxes that are over 20 kilos; it's not a job for one person and people always have to help each other. Junjun is always very generous, he'll come and give you a hand even before you ask for help.

Q: Does he like to talk with you about his work or personal life?

L: We talk about work all the time; for example, he has to tell me about delivery details before we leave. As his driver partner, I know how to get somewhere, but I can't work out the details of the delivery. If the factory we're going to has more than one gate he usually knows where to park. After we arrive at a customer's place, he's the person who will carry the stuff inside and hand over the documents to their salesman. If there's an electric whiteboard, he has to install the system for the customer as well. He has to deal with all of the delivery details himself, because as a driver I mustn't leave the car or lend him a hand.

Q: Do you ever do something together in your free time or when you are off duty?

L: Of course, we chat a lot when we're free. Sometimes we talk about football, or I'll ask him about a recent game. There are several football fans in our workplace, so we like to talk about this together.

Q: Do you enjoy working with Junjun?

L: It's pretty good; we cooperate well, because he's a reasonable guy. For example, before we load up the van, he usually checks the numbers and size of that delivery's boxes, and then sorts out the van in the best way; he won't leave any boxes behind or make mistakes like this. He likes to do some research about how to load the van and learns from the other workers when he's free.

Q: Have you ever had any arguments or problems with him?

L: No, I don't think so. There's never any kind of conflict between us, but sometimes if I can't park as close as he wants, Junjun might feel a little bit annoyed, that's all. It's nothing personal.

Q: I know Guojun uses WeChat—are you WeChat friends?

L: Of course, we follow each other on WeChat. Sometimes he likes to share some articles about healthy living or football or post his score if he won an online football game. He likes to send greeting messages to me during festivals and holidays.

Q: What do you think of him after you've worked together for such a long time?

L: He's a very good person, reliable, friendly, and hard-working. We're more like brothers than friends after working together for so many years, and we've gotten to know each other better since we've become partners.

Interview with Colleague of Guojun Zhang (II)

Interviewee: Ms. Hu (Guojun Zhang's manager)

Interviewer and writer: Xiaolong Lu

Interview date: November 11, 2016

Interview places: Office of Guojun Zhang's company in Hongkou District

A Nice Person and Good Stuff Member

Q: Do you remember when Guojun Zhang joined your company?

Hu: He's worked here almost 10 years, since 2008. He was a part-time worker at the Heart to Heart Stationery warehouse, which belongs to Xinhua Media Group, but the company closed when Xinhua Media planned to join the stock market. At that time, the stationery company was divided into four parts and they were sold by auction. My company and another three qualified companies won the bidding, which is why Junjun, his mother, and the rest of Heart to Heart Stationery workers joined us.

Q: Did you have any other disabled workers before him?

H: Do you mean "special" workers? No, he was the first.

Q: Were you concerned when he joined your company?

H: Not at all, as a company and part of society, we have a social responsibility. After the Wenchuan Earthquake in 2008, my company donated a lot of schoolbags, stationery, and other goods to people in the disaster area through the Shanghai Federation of Trade Unions. I thought this was the right thing for us to do. We help others if we can, depending on our ability and situation.

Q: Do you remember the first time you met Guojun Zhang?

H: Of course. In fact, I knew him briefly before he worked for me, because his former company had business with us. But I didn't know anything about his personal life or working ability as I do now. I knew his mother for years, and she worked at the warehouse for a while too. I can never remember that his real age is 38, almost 40, because in my mind he still a child, but he's a sensible boy, even though he has an intellectual disability. He never misunderstands anything that you tell him. His only problem is he can't explain himself well enough, but his mind is much more mature than many other intellectually disabled people.

When he came to our company the first day, he was a cheerful fat boy wearing a T-shirt. He never called me boss or manager, he called me auntie from that day and until now (smiles). His main duty at the warehouse is to deliver orders with the driver.

As the Internet business boomed, our business was seriously affected by this trend as were other brick and mortar stores. So I started to sell some of our branches

to the Chenguang company. They were looking to float on the stock market and bought the stores. Now, after the downsizing strategy, we have no stores and fewer workers, but our distribution center still serves the Shanghai market for Hero, the famous stationery company. Junjun still works at the warehouse and deals with the deliveries.

Since last May, in addition to his main duty, I gave him another very important but difficult role and he does very well. I'm very fond of pets and I took in eight stray cats; Junjun looks after them. He insists on feeding and cleaning them twice a day and never forgets. I don't call him Junjun anymore, but "General Cat." He's never looked after cats before, but now he's learned how to communicate with them. The cats know he's coming before he's opened the lift, and know he's going to clean up the place and feed them. Except for some personal business or going outside Shanghai on a trip, he comes to the company to look after them every day, including weekends and public holidays. Junjun is a loving and caring child, I have to say.

Q: Did he ask you for this special job?

H: No, he didn't. In our company, everybody has more than one role, so his second job is to look after cats. By the way he does this, you can tell he has a very warm heart. Actually, he isn't a child anymore, he's almost 40 years old, but to other colleagues, he's still just a child. Sometimes he might think things are too simple but that's his condition, we can always see his loving and caring heart. He enjoys working here and his mother feels at ease with that, because everybody likes him and nobody discriminates against him or treats him differently.

Q: Did he have any training before starting work?

H: He didn't have any formal training in the beginning, but before he went out to deliver orders, he worked with two of the senior employees for 2 weeks. He's worked here for quite a long time now; two of the drivers have retired. He is highly regarded by our drivers and customers. When he was on holiday, some of the costumers called in and asked: "Why didn't the big fellow come this last couple of days?" The costumers treat him very well—he gets a cold drink in the summer and steamed-bread and a meat bun at lunch time. Other people, who covered the job for him while he was off didn't get the same treatment. So, there are a lot of nice and caring people with a positive attitude in our society.

Q: Has he got better at the job?

H: Yes, he has, he knows the job better than before. In the beginning, we had to teach him one step at a time, how to talk to the costumers, deal with the paperwork, and so on. But now, especially from this year, he knows this aspect of the business much better than anybody else. If he has to take a day off, the worker who covers his job has to ask him about the details of any deliveries. He really knows which department and which person he needs to contact, even though some companies are quite big. If you look at his ability at work, it's very hard to tell he's intellectually disabled, and he's different from other disabled people. There's a very big difference.

Q: Would you hire more disabled workers if they came for a job interview?

H: That would depend on their personal condition; if they are as clever as Junjun and don't mind taking a part-time job, they would be welcome to join us.

Q: Do you expect a high standard for his work?

H: I would say that I have a required standard for his job. His work looks simple and easy—he just needs the person in charge to sign the documents after the delivery is completed; in fact, his work is much more complex and difficult than we thought. Because there's a financial aspect with all goods deliveries, he has to be very careful with the documentation, signatures, and invoices. As a sensible worker, he knows when he needs to ask for help if he encounters some problems in his work. Generally speaking, he's improved a lot.

Q: Do you treat him and the other ordinary workers the same, as equals?

H: No, that's not possible. In the company, everybody has to clock in, but he doesn't need to, even though Junjun insists on doing this and reminding anyone who forgets to punch their card. We treat him equally most of the time, but because of his condition, we wouldn't let him do a computing job, that's his weakness, so it's best to let him work with deliveries.

Q: Did he ever make any mistakes at work?

H: He did, but only once; our accountant asked him to take a payment back with him after he delivered an order, but he forgot to take the money back. When I discovered the accident, I just told him not to make the same mistake again. He's a smart boy; he won't forget anything once you've reminded him.

Sometimes we've made mistakes together, it isn't his fault. For example, a while after I've taught him how to clean the cat house and feed them, he might start to miss things here and there. So I keep an eye on him and if I see that something isn't right, I just say to him: "Junjun, I think there's something wrong here, could you show me what you've been doing?" After that, I'll point out any mistakes and what he needs to do by showing him the process again. He'll remember the next time.

I must admit I'm impressed that he's never ever lost his invoice book. A lost invoice book could cause the company some serious problems, but it's never happened to him.

Q: Has he ever won an award from the company for his work?

H: Of course! He received awards for his hard work. In the company, everybody is busy with their own jobs, this includes cleaning up his own working area. Sometimes if somebody forgets to clean their area, Junjun will take the initiative and clean up the floor or sort out the shelves for him, even if nobody asks him to. Actually, I only ever asked him once: "Junjun, please help us clean the floor if we're too busy," and he's never forgotten that. Basically, he usually finishes the cleaning before we arrive, he works voluntarily and never complains. I guess it's his special way of paying back people's favors.

Q: Does he ever arrive late or leave early?

H: Never. He always arrives very early, we start at 9 a.m., but he's usually here before 8 a.m. If he has to take a day off, he usually lets me know in advance. Sometimes he forgets to ask me for a day off, but if I ask where he was, he'll explain why. I don't mind giving him some time off if he gives me enough notice and I can find a person to cover his work.

Occasionally if he forgets to clean up the cat house, I usually try to reason with him about the issue: "Cats are the same as us, they need to eat regularly and live in a tidy place. Think about how you'd feel if you didn't eat for a day and a night? Since

we decided to adopt them, we have to take responsibility.” After my explanation, he definitely remembers what I said and never makes the same mistake again. That’s why I feel quite at ease with him.

Q: What do you think about the way he interacts with you and the other colleagues?

H: About interaction... I always think the environment is the reason for the way things or people can change; this applies to Junjun as well. When he first joined us, he didn’t know us very well, especially me, so he usually avoided talking to us; but after working together for a long time, almost 10 years now, he will chat with us sometimes, chatting and joking. Now, he gets on with the group much better and sometimes he actively joins in our lunch time conversation and enjoys it.

Q: Do you change your way of speaking or subject when Junjun is with you?

H: Junjun has been a part of our community for so many years and we must care for him all the time and under all kinds of conditions. For example, we don’t use terms like “idiot” or “fool” in our company. Everyone who works here knows this. At least they don’t use these kinds of words when Junjun is with us. We do this for Junjun because he’s very different, like a smart child, and we really don’t want to damage his self-esteem.

Q: Are you WeChat friends?

H: Of course. If I post some moments, my colleagues usually tag it with a “like.” We also have a working WeChat group; sometimes I post the company’s notices there. For example, I usually update the pickup place and time and other details before we go on our annual group trip.

Q: What’s your opinion and evaluation of Guojun Zhang?

H: Generally speaking, nobody is perfect. With Junjun’s condition, in other words, his weakness, we don’t have a right to push him or challenge him to do something he isn’t good at—innovative or creative work, for example. He can’t do this kind of thing, but he’s fine with practical work. If he can stay at the top of his own job, that will be good enough for us. He’s a really nice and kind child.

We want to make sure we’re fair to everybody, so we manage his work in a different way. After many years at work, he’s never compromised company policy. If I have to say there is something different, it’s probably that as a part-time contractor, he doesn’t get any annual paid leave. When he needs to take a break for a district DPF event or group trip, I never disagree. We’ve had a conversation about his social life and I support him when he needs to do important events and activities, but for anything else, he has to choose carefully, because he has his duties here. Every time he takes time off, somebody has to take over his job, and he completely understands the meaning of the job. I try my best to keep a balance and support him. Once he took 9 days off for a long holiday with his mother; other colleagues and even myself covered his job, and everybody worked for him voluntarily.

Q: Thank you for your time and your support. I wish you the very best luck of with your business and a successful career.

Interview with Guojun Zhang

Interviewee: Guojun Zhang

Interviewer and writer: Xiaolong Lu

Interview date: December 12, 2016

Interview place: Disabled Persons Federation office of Hongkou District

Work Hard to Be the Best You Can Be

Q: Do you remember anything impressive from your time at school?

Z: When I studied at the Special Education School, it was a long commute and my mom had to take me there and back every day.

Q: Do you have any school friends left who you still keep in touch with?

Z: No, I don't.

Q: Why is that, do you think, is it because of the kind of person you are or you didn't want to get know people?

Z: Neither of these problems, I lost touch with some of my friends after they moved away.

Q: So you did have some friends at school, did you take the initiative to chat with them?

Z: Yes, I liked to talk to them.

Q: Did they like to tell you about their personal issues or something close to their hearts?

Z: No, they didn't. We usually talked about school life or study.

Q: Have you ever invited your friends to visit you?

Z: No, I haven't.

Q: Why?

Z: Because our place is very small.

Q: Did you have some events at school?

Z: Of course, we had a spring picnic trip.

Q: Did your mother go with you?

Z: No, she didn't go with me, because we have to go by ourselves and we weren't allowed to go with our parents.

Q: What were your favorite courses at school?

Z: The cooking class.

Q: Do you cook these days?

Z: Yes, I cook sometimes, but it doesn't taste great.

Q: What other courses did you have?

Z: We had a PE class, too.

Q: Did you have a favorite teacher at school?

Z: Sure, I liked the maths teacher and the domestic science teacher.

Q: Why did you like them?

Z: They cared about me. One of them lived close to my place and usually gave me a lift on the way home.

Q: Now you have a job. Compared with school, which lifestyle do you like best?

Z: I like work.

Q: Why?

Z: Because I enjoy chatting with my colleagues in the workplace.

Q: Why didn't you like to go to school?

Z: Because I couldn't keep up with the pace of my studies.

Q: Who went to the company with you the first time, your father or mother?

Z: It was my mom, she walked me to the workplace.

Q: What did you feel that day?

Z: I'd worked before then, because I did some part-time jobs before joining this company.

Q: What was your first duty when you joined the company? Do you remember?

Z: I worked in the warehouse, helping people sort out stuff.

Q: Did anybody teach you how to do things in those first days?

Z: No, because I'd done similar work before.

Q: Do you ever feel tired of working here?

Z: No, it's not too bad.

Q: Have you ever made a mistake at work since you joined the company?

Z: No, I haven't.

Q: Manager Hu said you once forgot to take back a payment for a customer, and she talked to you about this when you returned to the company? Were you angry that time?

Z: No, I wasn't angry, because it was me who forgot.

Q: Is there anything very difficult about your work?

Z: My duty is to deliver orders, there's nothing too difficult about it, and I'm used to it by now.

Q: I heard manager Hu let you to look after some cats. Do you like cats?

Z: I don't like them, because cats have fleas.

Q: If you don't like cats, why didn't you refuse when the manager asked you to do this job?

Z: I didn't say no; I just thought I should give it a go.

Q: You've looked after those cats for almost 2 years, but you still don't like them?

Z (he has a broken smile): I've gotten used to them.

Q: You mean used to looking after them or now you like them?

Z: Just got used to them, I think.

Q: You mentioned you are very close to your driver partner; apart from him, do you have any other close colleagues?

Z: I get on well with everyone, but my partner is my closest friend.

Q: Apart from work and your job, do you talk about life or personal things with your partner?

Z: We talk about football games, because I like football.

Q: What time do you get up on your working day?

Z: Six a.m. in the morning.

Q: Where do you usually have breakfast, at home or out?

Z: I usually buy something to eat.

Q: When do you leave home and head to the company?

Z: I leave home around 6:30.

Q: How do you get to work?

Z: On my electric scooter.

Q: What time do you start work?

Z: Eight a.m.

Q: Do you need to clock in with the punch card?

Z: We do have a punch card machine.

Q: Have you ever been late for work?

Z: No, I've never been late.

Q: What time do you finish?

Z: Five p.m.

Q: Do you go home straight away?

Z: Of course, I go home directly.

Q: What do you usually do at home?

Z: I just eat, wash the dishes, then I'll take a shower. If there's a good program, I might watch a little bit of TV afterwards.

Q: What time do you go to bed?

Z: I might stay up late if I there's an interesting program to watch, or have an early night. My bedtime is usually around 10 p.m.

Q: So you work from Monday to Friday, and go to the district DPF training program on Saturday and Sunday?

Z: I stay here all the time.

Q: You're a big football fan, where do you usually play football?

Z: Just at the Foreign Languages University.

Q: Why do you go there?

Z: I just found that place.

Q: When did you get to like football?

Z: 1995.

Q: Why did you start to like football?

Z: Since I watched a football game on TV.

Q: Apart from football, do you like any other kinds of sport?

Z: I like basketball, but I can't play.

Q: Do you see anyone frequently apart from your parents and colleagues?

Z: It takes me time to get to know people.

Q: For example, did you get to know somebody from football or at the Foreign Languages University?

Z: It's something I'd like to try.

Q: Between staying at home or going out, which one do you prefer?

Z: I guess, I like go out, because it's boring staying at home. I like to go out and have a look around and play.

Q: I know you spent a while at home after you graduated and before you found a job. Which do you prefer between staying at home and working?

Z: Staying at home alone is quite boring. I prefer to have a job and it's also a way get to involved in society.

Q: What kind of housework do you usually do at home?

Z: Washing or fixing.

Q: Fixing? What do you fix?
 Z: Tighten a screw, or change a bulb, I can't fix more complicated things.
 Q: I saw the lunch box that your father made, last time, but you live with your mother. Does your father bring your lunch to work?
 Z: He comes over to cook in the evening and leaves afterwards.
 Q: When did he start making breakfast for you?
 Z: I used to eat at the company canteen before I came to this company, but we don't have a canteen here, so my dad started preparing lunch for me.
 Q: Do you think the difficult relationship between your parents has had an impact on you?
 Z: I don't think so.
 Q: Do you wish their relationship was better or are you not concerned?
 Z: I think it's better that they are living apart.
 Q: How do you get on with your father? Was there a time when you hated him?
 Z: Yes.
 Q: What do you think of yourself?
 Z: I really don't know, just so-so I guess.
 Q: Do you think you have a happy life?
 Z: No, I'm not happy (he's a bit choked).
 Q: But why?
 Z: Because my family, my parents are separated.
 Q: Even though you say you're unhappy, as an outsider, I think your life is very happy because you can live with your mother, go on trips from time to time and at the same time your father makes you lunch every day. That's the end of our interview. It's been good to meet you and thank you for sharing your happiness and sadness with me. I'd like to wish you a healthy life and successful career.

Observation of Guojun Zhang at Work

Observation time: 6:00–15:10, November 11, 2016

Observation place: A company in Hongkou District, Shanghai

Observer and writer: Xiaolong Lu

Time	Content	Observed activities
6:00	Arrives and clocks on	He doesn't have a fixed clock-in time
6:05	Takes cat food out of a bag and feeds cats	The manager keeps some stray cats and has found a room for them. Since last year, Guojun Zhang has the job to look after them, feeding the cats and cleaning the place

(continued)

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Time	Content	Observed activities
7:00	Goes downstairs and has breakfast at a breakfast store on the street	He has two meat buns and one bowl of congee
8:00	Chats with colleagues and prepares for work	He is listening most of the time but rarely initiates a conversation
8:30	He introduces his collection of model guns, poker sets, football magazines, and his photos from childhood	He takes his collection and arranges them on a small shelf because he knows the interviewer will come today
9:00	Cleans the cat house	He cleans the place twice a day on a work day, and once during the holidays
9:15	Takes a roll of bubble paper from the storage area	It's part of his preparation for work, wrapping packages
9:20	Wandering around the office area and joking with the delivery man	
9:40	Goes to deliver stuff with the van	It's his daily job; usually branch stores or factories
11:26	Helps his colleague to pack stationary	It's not his job, but he comes to help voluntarily
11:30	Chats with colleagues, smoking	
11:40	Lunch time	His lunch has been made by his father; he needs to heat it up in a microwave before he eats
12:00	Plays with his iPad	
12:10	Smokes, sits there for rest	
12:15	Watches a movie on the iPad	
12:30	Plays with his phone	
12:40	Loads up the van and prepares for another delivery	
12:50	On the way to deliver stuff	Sits in the back seat to check the orders
13:40	Carries orders to the customer and checks the list with the customer representative on duty	Sends stuff to the branch store and opens the package with the director, then checks the category
14:50	Goes back to the company	
15:00	Smokes, rests and chats with colleagues	
15:10	Loads the van and goes out with the orders	
15:30	Unloads orders and opens the box for the customer to check	The delivery place is the office of a big company
15:46	Takes back some stuff the customer wants to return and goes back to the company	As a branch retail store, orders can be returned anytime if the customer wants to
16:00	Puts returned order back in the warehouse	
16:05	Helps colleagues to clean up the area and sorts out stuff in the rest area	

(continued)

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Time	Content	Observed activities
16:27	Hammers a nail into the wall to mount a plug board	
16:30	Takes out some cat food from a bag and takes it to the cat house. Strokes the cat	
16:36	Sits at the desk and chats with his mother	
16:40	Packs up his collections on the shelf	
16:45	He switches on the office light when a colleague asks	
16:48	Chats with a delivery man who comes for a package	
16:50	Sits down and takes his iPad out to play	
16:55	At the request of the manager, he cleans up the two cat rooms, and throws litter out	It's part of his daily job, but he forgets to do it this time
17:05	Takes a roll of clothes out	
17:10	Off duty	It's a fixed time, people aren't allowed to leave before 17:10. He needs do some overtime duty sometime

*Translated by Huili Meng.
Edited by Russell Murray.*

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Personal Experience of Social Progress



Yameng Xia

Interview with Mr. L's Parents

L, male, born in 1982. The only child in his family. Level III intellectual disability. Studied in a regular elementary school and a regular middle school.¹ Enrolled in a subdistrict Sunshine Home in Shanghai in 2005, among the first batch of students there.

Interviewees: L's parents

Interviewer and writer: Yameng Xia

Interview dates: October 28, 2016 and December 17, 2016

Interview place: L's home

A Bad Omen

Q: When did you get married?

L's father: In 1978. I was 35 when I married her.

L's mother: We got married late.

Q: Why? Because you were the sent-down youth?

L's mother: No. He did not marry me until he was allocated housing by the Housing Management Bureau. Nor was I pregnant during the first few years after marriage due to infertility. Later, we went to the doctor and gave birth to L.

¹L's parents reviewed and revised the first printed draft. Mr. Xiaodong Yu, another interviewee in this volume, offered help in creating a Word document and input the revised version. The writer thanks him for his help.

Y. Xia (✉)

Fudan University, 220 Handan Ro, Shanghai 200433, China

L's father: Miss Xia, our parents used to live in a 16 m² flat and had four kids, of whom I am the eldest. There was no extra place for me to get married. At that time, no housing was available to be bought or rented in the Chinese market.

L's mother: Both of us are intellectuals and a little bit stubborn. We were advised to ask my husband's family to make room for us as a married couple. I turned down the offer. My husband has three siblings. We could not kick his family out for our benefit. I didn't want to be gossiped about and judged.

L's father: It is easier said than done. We could have asked my family to make room for us. What shall I do after I have a child? We agreed to get married after being allocated housing, otherwise we would not do it at all.

L's mother: We got married instantly after my husband was allocated housing.

Q: You gave birth to L at 38, right?

L's mother: That is correct. Some sufferings are predestined. On January 1, 1982, I woke up because of a stomachache at four or five o'clock in the morning. I got up and saw blood on the bed sheet. I knew that I had to go to hospital immediately. It was too early to take a taxi. As a result, my husband and I went to the hospital on foot. China witnessed a baby boom at that time. I was asked (by the doctor) when the due date was. I said that it wasn't time yet. The doctor wondered why I was at the hospital. I told him it was because of the blood. I was then hospitalized for further examinations. The hospital was crowded. January 1 is a public holiday in China.

As a result, only a small number of doctors and nurses were on duty on that day. I had to wait for my turn on January 2. I was arranged to rest on the tenth bed in the ward. A visitor came in and wanted to visit the patient on the tenth bed. However, I did not know him. Neither did he know me. He explained that he intended to visit another patient. Next, he added that the patient's baby died in the womb. I was told later that the previous patient hospitalized on the tenth bed was the one whose baby died in the womb. On hearing that, I had a bad premonition and rushed to the doctor. I claimed that I, at an advanced maternal age, was too exhausted to give a natural birth and demanded a cesarean section as soon as possible. Medical staff immediately called surgeons in the operating room to prep for my operation after the on-going one was completed. I was then sent there by nurses. In fact, L was already suffering from a lack of oxygen at that time.

Later on, we learned that the attending doctor might have already known that L would be intellectually disabled at his birth. We did not know the truth. The previous patient hospitalized on the tenth bed was the one whose baby died in the womb. Fearing that the same thing would happen to me, I stayed awake during the cesarean section and only relaxed after hearing the baby crying. It never would have occurred to me that he would be intellectually disabled.

Two nurses attending the ward were my husband's and my students respectively. They visited me after the cesarean section. When I was about to be discharged, they came again with the attending doctor. I noticed that something was wrong. He said that it took longer to recover from the cesarean section than from natural delivery. I, after the cesarean section, should take care of myself and hold up. I thought I felt well. Later on, everything started to make sense. The doctor must have already known the truth. That was the reason why one of our students from the hospital was

sent to pay us a visit after I left the hospital. I had thought that the doctor was just thoughtful. In fact, the baby would be diagnosed and evaluated after birth. There was no prenatal testing in China in the past. Currently, technologies such as B-mode ultrasound are applied for pregnancy diagnosis and measurement.

L's father: I took care of her during her postpartum confinement. She stayed in bed with the baby by her side. I had to give classes during the day. I went out in the morning, returned home at noon, left for work again in the afternoon and was home in the evening. If anything occurred when I was absent, she had to put up with it and wait for me to solve it. Fortunately, the winter vacation was coming up.

Busy Testing L's IQ in Different Hospitals

Q: Did anyone babysit L when he was little?

L's mother: He had a babysitter before he went to kindergarten.

L's father: L had a babysitter after my wife's maternity leave ended and was sent to the nursery when he was 20 months old.

L's mother: We had to work. Our parents were too old to take care of L. Consequently, we hired a babysitter to look after L.

Q: The babysitter would babysit L at her home, right?

L's father: Exactly. For example, we would take L to the babysitter's when we were about to leave for work in the morning. She would look after him for the whole day. We were off duty around four o'clock. I had no desire to spend an extra minute in the school. I hoped to bring L home as early as possible. It was best when I could both work and look after him at the same time, otherwise I just took care of him and waited for his mother to return home and make dinner. We should take care of L as much as we can and let the babysitter rest. We weren't too demanding even if we did pay for the service.

Q: Was L looked after at home at night?

L's father: Sure. He was brought home at around four or five o'clock in the evening.

Q: When was L taken to the babysitter's in the morning?

L's father: Before half past seven.

Q: Did you supervise students at the morning self-study session?

L's mother: Yes. I had been the class director before I retired.

Q: When did you find out that L had an intellectual disability?

L's father: L could not speak when he was three. The doctor said that his tongue functioned well and L would be able to speak in due time. We taught him to speak during the summer vacation when he was about three and half or four years old. For example, when looking at a picture of the sun, we would teach him to say "sun." Kids at his age are taught to read the characters of the sun while pronouncing the word.

After he enrolled in kindergarten, the teacher commented that L always reacted slower than other kids did. Or at least, he could not learn how to use scissors or tie

his shoes. We thought that it took time for L to learn these things. He would be able to accomplish them in the future, right? He trims his nails independently now.

Q: Kids are little in kindergarten. It is normal if they cannot learn these things. Is that correct?

L's father: That is right. However, all of his peers had learned to do these things. In comparison, L indeed reacted slower.

Q: Did it come to you to take him to be examined to confirm the case?

L's mother: Sure. We took him to the hospital the first time when we learned that he reacted slower in kindergarten. The doctor asked how old we were. I understood what he meant. First, I was at an advanced maternal age. Second, he wondered whether we considered having another child. If we wanted to, he could certify for us. However, I didn't dare have another child. I could not die in peace if I gave birth to another kid with ID again.

L's father: We have been asked repeatedly why we won't have another kid. We worry about many things. First, what if the second kid remained intellectually disabled? Second, our flat was only 12 m². It was too small to accommodate another kid. Moreover, who would take care of the second baby? We have looked after L from the day he was born till now. Our parents were too old to give us a hand. Therefore, we did not opt to have another child. Everybody would be happy if we gave birth to a normal child who treated L well. However, it might be annoying if the second one did not like L and treated him badly.

L's mother: I did not consider having another child when taking L to be examined. I just wanted to find out what was wrong with L. The doctor might have misunderstood me.

I read an article in a journal but forgot the title. The father graduated from Fudan University, Shanghai, China. He married the Chief Representative for KLM in China. Both of them are part of the elite. However, both of their kids have autism. From then on, the Dutch mother never returned to the Netherlands to visit her parents by herself or with her kids. Instead, she has set up an autism association in Hong Kong. After the association became famous, her parents knew the truth. When reading the article, I wondered what I would do if my second kid was also intellectually disabled. Someone may regard it as a genetic disease. However, the couple in the article are from different countries and talented. Still, their kids have autism. Everything is fated. As a result, I dared not have another kid at that time.

Q: Is it possible that L has suffered a congenital disease?

L's mother: It might also be because of a lack of oxygen at birth. I read that it also led to the intellectual disability of Kennedy's daughter. His other eight kids are normal. None of our relatives is intellectually disabled.

(L's father brought out medical reports.)

L's father: We took L to numerous hospitals when he was in kindergarten and elementary school.

Here is the first medical report, which says "L, an elementary school student; issue: whether he can study properly at the school." Symptoms: "Currently in Grade One; stays down; hyperactive and has difficulties concentrating in class; slow of understanding; gives irrelevant answers frequently; likes playing with a bike and

seeing sceneries along the road; no history of major diseases.” Diagnosis: “conscious and hyperactive; fails to give direct responses; able to add and subtract numbers less than 10; poor answers for commonsense questions.” Conclusion: “Intellectual disability.”

I wanted to tear it up. It was a medical report from Ruijin Hospital. We told the doctor that L was a poor student. Here is the record: “The mother gave birth to the patient via cesarean section at 38; the patient could not speak until three.” L started speaking late. “IQ test score: 39; currently in Grade Three in elementary school; repeating 2 years in each grade.” This part is hard to read. “Able to complete simple calculations but cannot answer easy commonsense questions.” Here is the doctor’s conclusion: “Dementia.”

This is the medical report from Shanghai General Hospital on September 8, 1996: “Lack of oxygen; born via cesarean section; the intellectual level below the normal level.” The doctor’s conclusion: “Self-conscious with well-developed limbs.”

Q: Did L receive any medical treatment?

L’s father: Negative.

L’s mother: It was too late. There was nothing that could cure him.

Q: How did you feel being told by teachers from the kindergarten that L might be intellectually disabled?

L’s father: We were in pain. My wife gave birth to L at 38. We had been thrilled to have him at that age. However, nothing has gone well along the way. How did we feel? Well, we had to accept the fact.

L’s mother: L has been born. We can only accept fate.

Q: It never occurred to you to abandon him, right?

L’s father: Absolutely not. We give L all our love.

L’s mother: L is the top priority in the family. For example, we are invited to eat Chinese mitten crabs. If both of us go, we may have to leave before L goes to school and wouldn’t be able to return home after school is over. In that case, my husband will attend the banquet alone and I will stay at home.

L’s father: We will not go out if we cannot make appropriate arrangements for L.

Q: You will not participate in the activity?

L’s father: We may not participate in the activity at all or only partly.

L’s mother: An acquaintance told me that the kid is lucky to be born in our family. We treat him as a normal child. He is our dear boy even if he is with ID. We are the ones to blame.

L’s father: We will never ever abandon him. He is innocent. We are the ones to blame. He is always carefree and happy.

Conquering All Obstacles for Education in Regular School

Q: Where did L receive elementary school education?

L’s father: Back then, public elementary schools interviewed and enrolled eligible children. L was rejected before being interviewed by the nearby elementary school in the district, which had already learned about the truth from L’s kindergarten.

Q: L was rejected before any interview?

L's father: That's right.

L's mother: His teacher in the kindergarten said that it might be difficult for L to be admitted into the elementary school. The public elementary school had not planned to enroll him at the very beginning. They hoped that we might send L to a school that has been especially established for children with ID.

Q: You mean a special school?

L's mother: Yes. I had no plan to send L there. I visited the special school and noticed that kids there seemed to demonstrate problems in movement coordination. L has outperformed them with respect to that at least. He would be slower in all aspects if he was sent there. I pleaded with leaders in the education system in every way I could. At last, L was admitted into the public elementary school.

L's father: We sought help from the education bureau, which consisted of the middle school and the elementary school education sections, of which the head had been my colleague. He knew about the situation in my family and approved my request. As a result, with the greatest reluctance, the elementary school enrolled my son.

L's mother: L performed poorly at school. He needed 2 years to finish Grade One and two more to finish Grade Two. During that time, the school always tried to persuade us to transfer L to the special school. I insisted on having him educated in the regular school. I would rather have him educated and looked down upon there. He would be surrounded by normal people at least.

Q: What were the reasons for L repeating a year in Grade One? Did his teacher require it?

L's father: No, it was because L could not pass the exam.

Q: L went up to Grade Two after passing the exam in the second year. Is that what you meant?

L's father: In fact, L performed better in the second year. However, he failed to pass the exam again. Nonetheless, the teacher did not want to press him further and let him move up to the next grade.

L's mother: Later on, we communicated with leaders in the school to leave out L's performance from assessing the teachers in order to minimize the impact on his teachers.

L's father: You may be able to understand it. On one hand, the teachers' burden will be relieved slightly if the student's performance is not calculated into their assessment. On the other hand, teachers must consider the impact on the majority. They may also feel stressed when parents of other students doubt why a child with ID is assigned in their class. We are teachers and know clearly that teachers want students to perform well.

L's mother: I want my kid to be assigned to a class with a friendly atmosphere in which he can keep observing and listening.

Q: None of the teachers in the elementary school was inclined to have L educated in his/her class. Is that what you meant?

L's father: That is correct.

L's mother: It is understandable. All teachers hope to teach normal kids.

Q: How did L get along with his classmates?

L's father: No one was willing to be his desk mate for sure. All students wished to sit next to well-performing students.

L's mother: L might be slightly naughty in class. What was more serious was he could not pass the exam. We are also parents. We could not blame his classmates. It was utterly normal and understandable that he was looked down upon in his class. It was already good enough that no one called him names. The situation was worse among the disabled in rural areas in China. Nowadays, the society is more inclusive to the disabled along with social progress.

Q: Would you teach him when he had trouble with lessons in Grade One?

L's father: Definitely. We taught him repeatedly.

L's mother: L would be criticized by his teacher if he could not complete his homework. After all, he was different from his classmates intellectually.

Q: Both of you teach math. How did you tutor him after school?

L's mother: L's performance seemed to be barely satisfactory on math. He could do basic arithmetic calculations.

L's father: He performed poorly on word problems, which should be analyzed first.

Q: He could solve mathematical problems in mathematical notations such as dividing 6 by 12, couldn't he?

L's father: Exactly. However, he was at a loss with respect to word problems such as dividing ten chickens into three groups.

Q: Did you mean that he could not solve these problems even after being tutored at home?

L's mother: People with ID understand things only to a limited extent. They may be able to have a smattering of knowledge even if they can be taught.

Q: L attended classes such as Chinese and math as other students did in elementary school, didn't he?

L's mother: He just sat in the classroom even if he could not understand what the teachers said. After all, he was enrolled into a regular school instead of a special one.

L's father: We merely looked for a place that admitted him so that we could work properly.

Four Years of Learning in Mother's Friendly School

L's mother: We moved later on. On hearing that, the teacher from L's original elementary school urged us to transfer L to the new school nearby. The teacher in the new school could tell at once L's condition and was unaware which grade he should enter at that age. As a result, L could not be enrolled into the new school.

To solve the issue, I turned to my boss, who I thought handled it properly. He admitted L to a class in my school without registration. Nor was his performance considered in the teacher's assessment. Now that L entered a class and behaved himself, I could focus on being the class director.

Things got much better in comparison with those days when L had been all by himself in the original elementary school. His new classmates, knowing that he was a teacher's kid, treated him reservedly anyhow. They would not bully him at least. Rarely did they look down upon him. Kids had called him names in the original school.

His teachers also knew that he was my son and took particular care of him. It was nice that my colleagues would talk to him. He might be in a daze all day long if no one spoke to him. He stayed in my office at lunch time, during which my colleagues there would talk to him. He could at least get more information and keep a more open mind than students do on average, students in special schools at least.

Moreover, various activities such as outings have been held in my school. Being the class director, I might take him to join our class activities from time to time. I wanted my students to know about L's condition to prevent them from bullying him. Many years later, my students, whenever running into me, would ask with concern, "How does your son do, Miss Feng?" I think L is luckier than other kids with ID. He has been less looked down upon. Instead, he has often been encouraged and taken care of.

Q: It is good for him, isn't it?

L's mother: Certainly. Thanks to these efforts, he is relatively outgoing. Some children with ID tend to be introverted under the impact of the environment. They may be looked down upon, have no companions or be laughed at whenever they open their mouth. Consequently, they dare not speak anymore and cannot speak at all eventually. My son has benefited from a friendly environment at least.

What's more, students would visit us frequently and talk with him, contributing to an increase in his capabilities. Things changed after my retirement. L had stayed alone at home in the year before I retired. His class was a preparatory one, in which students would graduate after 4 years of study. A year later, I was also retired. In fact, being the class director, I postponed my retirement for half a year to ensure that my students could graduate and continue to high school smoothly.

L's father: Here is how he finished school in the past 9 years. He spent 2 years in Grade One and two more in the next grade. We moved when he was in Grade Three. On hearing that, his teacher urged us to transfer L to the new school nearby. However, it was useless for his teacher to push us. After all, no other school would accept him. Just at the time when we kept looking for a new elementary school for L, my wife's boss offered to admit L into the middle school in which she worked. Consequently, L skipped Grade Four and Grade Five and entered directly a preparatory class in the middle school. His teachers accepted him and gave him full support. That was how L spent his 4 years there. He would only participate in activities not affecting overall performance of the class. For example, he would not take the demonstration lesson. Regarding PE, his mother just mentioned that he would join in suitable sports activities and sit out other ones. Before retirement, his mother worked as the class director for four continuous years. In exchange, L could attend school.

Q: Was L in his mother's class?

L's father: No. L was assigned to a different class at the price that my wife should be the class director.

Q: It was demanding, right?

L's father: There was no other way out. L might be assigned to the preparatory class. However, he did not participate in multiple activities together with his classmates.

L's mother: At least he was able to see and expand his horizons.

Q: Was L happy at school? Did he like to go to school?

L's mother: Let me put it this way. Later, L participated in an activity held on Guangzhong Road. He would greet his PE teacher and other teachers in my school whenever he ran into them on the road and talk about that after returning home. It was obvious that he used to get along well with these teachers at school.

L's father: L has been polite whenever encountering teachers he knows. He has been attached to them after spending a long time in his mother's school.

Q: How did he get along with his classmates in middle school?

L's father: His classmates would not play with him.

L's mother: They were afraid of him.

L's father: He could not communicate with normal kids. To put it frankly, he just had a place to go in his mother's school.

Q: Would they play ball games together?

L's mother: He merely watched others playing during PE courses in most cases. It is all right for him to run or do radio calisthenics jointly with others. His teacher would not involve him in certain activities such as ball games in order to protect him.

Q: What did L learn at school? For example, how many Chinese characters can he read and write?

L's mother: First, he could not understand courses taught in middle school at all. Regarding Chinese characters, he can only read common ones on newspapers. He can also do basic arithmetic calculations up to ten.

Q: Have you tutored him to read Chinese characters at home?

L's mother: He has learned from several sources. First, he was taught at school. Second, we would draw his attention to the road signs and take him to exhibitions and teach him Chinese characters he could not read. He would also ask about Chinese characters he could not read when watching TV.

L's father: In the year prior to his mother's retirement, his classmates had graduated. As a result, he left school and stayed at home for a year. We left to work and gave him paper and a book to practice writing at home. We were unaware whether he read out the content during writing.

Q: Has he learned and mastered *pinyin*?

L's father: He spent 1 year learning *pinyin*.

L's mother: But he failed to master it.

Q: He has learned to read Chinese characters directly, hasn't he?

L's mother: Or he would read a newspaper.

Q: Did he learn other subjects such as natural sciences at elementary school?

L's mother: The answer to that would be no. We would tell him short stories and basic principles in general.

(L's father wrote several *pinyin* characters on a name card and asked L to read them out loud.)

L's father: Come on, try to read out this one.

(L's father wrote "cat" on the paper.)

L: The first one is cat.

(L's father fetched a newspaper and asked L to try to read out characters there.)

L's father: Let's read out another one.

L: "Country."

L's mother: Good. Come and read out the headline on this newspaper. It came this morning and he did not read it beforehand.

L (read out the headline by dropping the words one by one): "Ensuring sufficient counselors offering personalized services to senior citizens."

L's father: He can read common Chinese characters. He has learned them in Grade One and Grade Two.

L's mother: He can also read those he saw on newspapers, TV, and outside or learn to read them.

L's father: He often confuses Chinese characters. For example, I once took him to take the subway at Zhenping Road Station. He took a glance at the road sign and mispronounced it as Tianping Road Station.

L's mother: The Chinese character "suspicion" consists of two radicals; that is, "water" and "step." L mispronounced it as "step."

He plays word games at the Sunshine Home. The teacher may specify a word such as "country" or "spring." Students take turns to list songs of which the lyrics contain the word. L can give correct answers. Moreover, he can also tell at once the singer of a song. Therefore, L, after being influenced by what he constantly sees and hears, tends to be more agile than other people with ID.

Q: He has learned these things on his own in daily life, but studied *pinyin* in Grade One and Grade Two. Is that correct?

L's mother: L plays the 24 Game well.

Q: Do you mean that he was good at math?

L's mother: No, just the 24 Game.

L's father: I will prepare the 24 Game the next time you meet L. To tell you the truth, you may be no match for him. He is indeed a good player in the 24 Game. Middle school students and most volunteers from the Benevolent Society cannot beat him. Why is he so skilled at the 24 Game? We would travel by bus sometimes on his way to school. Sitting in the front row on the bus, I might ask him to calculate the four numbers on the license plate of the car ahead. Consequently, he is familiar with the rules.

Q: I should practice the game first.

L's mother: Someone joked that L might inherit that from us since both of us have taught math.

(L's father took out L's Certificate of Study in Middle School.)

L's father: My wife used to work in that school. The school was very nice and granted a Certificate of Study for L after L was admitted there for several years. It also gave us a Certificate of Graduation of Elementary School, which is useless because it is not stamped. We cannot have it stamped since L did not finish elementary school.

Q: You did not require him to acquire any knowledge during 4 years in middle school, did you?

L's mother: We just wanted to find the right place for him, otherwise we could not concentrate on work. Now, either of us can stay at home and look after him.

Q: Didn't you work in the same middle school?

L's father: No, my wife's middle school is better than mine.

Considerate Mother Leading the Class to Win Honorary Title of Advanced Collective

L's mother: I did an excellent job indeed. My class was the only one in my school that won the honorary title of the advanced collective at the district level. I took over a class in 1993. These students graduated 4 years later, that is, in 1997. I was supposed to retire in February 1999. I told my boss that I didn't want to be the class director since I would retire in a year and a half. However, he insisted on that.

The new class had performed poorly in math. I cooperated with my former partners teaching Chinese and English to improve the situation. Thanks to our efforts, the class ranked first in math and won the honorary title of the advanced collective at the district level. Consequently, I was thought of highly in the school (smiling).

Q: The school wanted to make you class director, didn't it?

L's father: After all, L was admitted by the school. After school, L would stay in her office while she taught students in her class. The school was over at five o'clock, but she remained working.

Q: Because she was the class director?

L's father: She monitored the class while studying. Some parents would come to school at half past five and wonder why the school wasn't over yet. They admired her on seeing that she remained teaching students at that time. She was full of energy while I did housework in the evening. Accordingly, her class was rated as the advanced collective at the district level and she was awarded the third prize of "the most caring" teacher in Shanghai. She further received the honorary title of the advanced teacher from her school.

L's mother: My class performed the best in the final math test in comparison with the other six classes in the school. One of my students obtained the only quota in my school to be sent to the science class in the High School Affiliated to Fudan University.

L's father: She also did all these things for the sake of L.

L's mother: I was grateful. My boss was kind to admit L. I could not settle down in my job if L had no place to go. I could concentrate on my work so long as I knew that my son was admitted in the school. Moreover, I think it was better for L to stay in my middle school than in the elementary school.

L is slower in learning things. He has to be taught repeatedly to acquire certain knowledge. When teaching students, I would also think of that and treat all my students equally and patiently.

L's father: We prefer to put more energy into teaching students who are slower in learning, instead of despising them.

L's mother: Exactly. Some parents commented that their kids were lucky to stay down in my class. I was also inspired by gaining their recognition. My own kid is slower. Therefore, I would care more about such students in my class. They may not be born clever. However, I think things would be worse if they became self-abased and gave up on themselves after being criticized frequently by the teacher.

L's father: Students repeating the year's study in her class made great progress. She was also popular among temporary students.

L's mother: Later on, my class became the largest in the grade. Temporary students and students staying down were initially required to study in my class. These students staying down shocked everyone by performing well in the final test.

L's father: First and foremost, a teacher should not look down upon any student. Teachers with kids have a deeper understanding with respect to that.

L's mother: I cared about my students and they respected me in turn. My husband can vouch for this. I retired at 55. When I was 70, my students organized a class reunion to celebrate the anniversary of their graduation. Thirty students made it. Students staying down in my class who had been naughty took photos with me. They are aware that they could not perform so well now without my devotion at that time.

(Looked at photos.) This is the class I am talking about. This is the photo of me winning the third prize of "the most caring" teacher in Shanghai. Here is my unit, my name, subject, and age. I won the prize at the end of 1998 and retired in 1999. The class, which had been disordered at first, was rated as the "advanced collective at the district level" in the end. The class performed the best in the final math test among seven classes in the school. Its average math scores were 6.69 points higher than the average for the district.

L's father: Parents are relieved so long as their kids are placed properly.

L's mother: Parents of my students were clear about my condition. They knew that I would care about and encourage their kids who might not perform well and learn slower.

Staying at Home Alone for a Year and Receiving Strangers' Care When Strolling Around

Q: Did L graduate in 1998? How did he spend time from then on till 2005 when he went to the Sunshine Home?

L's father: He stayed at home alone for a year. It was quite hard.

Q: When did that happen?

L's father: He finished compulsory education and graduated in 1998. He stayed at home alone in the coming year since both of us had to work. He was not taken care of for the whole year.

Q: How did he go through that time?

L's father: L would be locked at home to practice writing Chinese characters when we went to work in the morning. We were anxious about him wandering around.

Q: Practice writing Chinese characters?

L's father: Whatever he would like to do. He might also watch TV. When either of us did not have a fourth class in the morning, we would return home to cook for him and return to work after he finished lunch. He would also go out and stretch his limbs in the afternoon if the weather permitted.

Q: Could he go out alone to exercise?

L's father: Sure. We would tell him to come back around four o'clock or half past four. We also managed to return home at that time. He would stay at home on rainy days.

After all, he merely strolled outside. I used to receive a call from a woman. She used to go outside to enjoy the sunshine and often saw L wandering around. Kids at his age ought to be at school. She was afraid that L might skip school and his parents were unaware of that. They talked, and L told her my phone number. I thanked her for her concern and explained that L was with ID and had no school to attend.

Q: Didn't you worry that he might get lost?

L's father: Never. He knows the way home.

Q: What else did L do in 1998–1999 except writing Chinese characters, watching TV, and strolling?

L's father: Nothing else. He was alone at home. We were quite satisfied as long as he could practice writing Chinese characters and not get into any trouble.

L's mother: I started accompanying him after retiring in 1999. Things had been hard for him indeed during the previous year.

Witnessing the Establishment of the Sunshine Home and Enjoying Himself

L's mother: I retired in 1999. At that time, no activity was held for children with ID. I sought help from authorities concerned, hoping that those children can be organized to be trained or tutored instead of merely idling at home. Parents would cover the costs.

L's father: My wife really cares about L. Disabled persons were reassessed in China in 1999. We took the opportunity and got a Disability Certificate for him. After retirement, we have started to think about how my son and other people with ID can make a living after the parents are too old to take care of them. My wife took L to seek help from the district-level DPF and the street civil affairs section.

L's mother: I tried to explain L's situation, hoping that the district-level DPF could recommend a job for L. I could go with him and teach him if the job was beyond him. Officials there said that the federation did not do that. Moreover, China has achieved social and economic transformation, making it hard to find a proper job for people with ID.

L's father: My wife also turned to the street civil affairs section. She asked whether the authority could organize any activity for L to participate in if it could not offer a job opportunity. Back then, no organization was set up for people with ID exclusively. Officials offered to contact the association of people with physical disabilities to see whether it would admit L in its activities. After all, it has organized formal activities. Of course, L was rejected since he was not physically disabled. Around 2003 or 2004, L participated in activities held by community disability service assistants² for people with ID.

The "4050 Program"³ was launched in Shanghai in 2004. Some females at the age of 40 and males at the age of 50 retired or were laid off in industries such as the textile industry and the instrument industry. So did eligible employees with physical disabilities engaged in simple productive labor. The policy was released to find some other means of livelihood for them. Those unemployed physically disabled people were recruited by the DPF to manage people with ID and organize and hold activities for them. They are referred to as community disability service assistants. On one hand, they can make a living. On the other hand, outdoor activities can be held for people with ID.

Q: The post of community disability service assistants is set for people with physical disabilities, right?

L's father: Yes, the government helps reemployment of people with physical disabilities.

From then on, people with physical disabilities have started to manage people with ID and organize activities. Kids like my son participated in these activities. They did not have a fixed venue at first. A community disability service assistant might lead

²The post of community disability service assistants has been a part of the "Employment for Ten Thousand People" project launched by the Shanghai Municipal People's Government in 2004. The post has been offered primarily to males at the age of 50 at most and females under 45 with mild physical disabilities and those certified disabled people that are unemployed, in service but not in duty and preserve employment relationship based on agreement due to low vision. If the post is vacant due to a high employment rate of the disabled, it can be offered to immediate family members living with the disabled that are unemployed and preserve employment relationship based on agreement and surplus labor in poor rural households.

³The "4050 Program" has been implemented by the Shanghai Municipal People's Government to facilitate reemployment of females above 40 and males over 50. A majority of females above 40 and males over 50 have been unemployed from the end of the last century to the beginning of this century due to reasons such as industrial restructuring in China. It is hard for them to be reemployed due to age and the low education level. In 2001, the Shanghai Municipal People's Government released a series of policies for reemployment of those above 40 or 50 desiring to work again via effective market and social mechanisms. One of these policies was to develop public service posts in communities.

them to do exercises such as radio calisthenics for 1 or 2 h in public places near the community. Then would they return home.

L's mother: At first, they did not have a special venue for activities but merely did radio calisthenics in green areas. Nonetheless, it was better than nothing.

L's father: The first step of the Special Olympics movement was to encourage people with ID to go out. They could then participate in activities. Radio calisthenics was taught first since it is easy to learn, does not involve any equipment, and doesn't cost much. I saw how community disability service assistants taught people with ID. It was hard indeed. Normal people might have mastered the movements long ago after repeated instruction by these assistants. However, people with ID such as my son have limited ability to understand and are slow to learn. The assistants were patient and kept teaching them until they learned these movements.

L's mother: We also stood there and encouraged them. They could learn these movements with more practice.

L's father: The officials in charge have gradually paid more attention to this sector and allocated a special venue for them to do exercises.

L's mother: Then came the Sunshine Home. Finally, people with ID had a fixed indoor space for activities organized by dedicated teachers. Next, a waist drum team was set up for people with ID in Hongkou District. People with ID could participate in an increasing number of activities such as table tennis, badminton, and basketball shooting in a school's playground during the weekends. I accompanied L to these activities at first. He refused to join them alone. Now, he won't miss them for anything.

Q: When did the Sunshine Home come into being?

L's father: Around 2006–2007 when the 2007 Special Olympics World Summer Games were held in Shanghai. The Sunshine Home was created by Former General Secretary Hu Jintao, meaning the home was shone over by the glorious Communist Party of China.⁴ Hu also visited the Sunshine Home in Quyang Subdistrict in Shanghai. At that time, teachers in the Sunshine Home were physically disabled.

L's mother: The project was shaped from 2004 to 2007. From then on, it has been completed and managed by dedicated personnel.

Q: Did L start to participate in these activities in 2004?

L's mother: That is true. My son has been among the first batch of students to learn radio calisthenics initially and register in the Sunshine Home established in 2005. However, he had to be accompanied to join any activity at first, otherwise he would not go. He thought the activity would be boring if he could not learn how to play it. I also took him to join the waist drum team at the beginning. I learned to play the waist drum first and taught him myself until he could play it.

⁴Shanghai won the bid to host the 2007 Special Olympics World Summer Games in 2002. In 2005, the Shanghai Municipal People's Government set the "Sunshine Action for People with ID" as a practical project to "organize 10,000 people with ID to be treated and trained for simple and easy work tasks to enhance their capabilities to take care of themselves and fit into the society". In 2007, the practical project was to complete construction of 240 "Sunshine Homes." On October 1, 2007, Jintao Hu, former President and General Secretary of the Central Committee of the Communist Party of China, visited the Sunshine Home in Quyang Subdistrict in Shanghai.

L's father: An increasing number of activities have been held such as badminton, table tennis, and tug-of-war.

L's mother: Community disability service assistants organized a variety of activities at first. We saw them starting from nothing to performing well in these activities. We feel from the bottom of our hearts that the government has spent a lot of effort for more than a decade to reach today's achievements. I can tell that from the change that occurred with my own child. He could not play basketball or the waist drum in school. He has learned them from activities held by the assistants.

Q: What does L usually do at the Sunshine Home?

L's mother: There are so many activities held here. L told us that volunteers from organizations such as the Benevolent Society would teach them to make cookies, do handwork, draw, dance, do radio calisthenics, or play games.

Q: What about cultural activities held at the Sunshine Home?

L's mother: There is also a wide range of physical activities. For example, table tennis tables are also available at the Sunshine Home.

L's father: A doctor was also recruited to teach them the basics of healthcare.

Q: Is the Benevolent Society a voluntary group?

L's father: Yes. Volunteers from the Benevolent Society often hold activities at the Sunshine Home. They bring materials themselves and teach students handwork. They will take a photo for the student and his work after the job is done. Here is the handwork L completed jointly with volunteers from the Benevolent Society (fetched out an A8-paper-sized wooden handmade photo frame with small stars pasted all over the frame). L brought it back as a souvenir after completing it.

Q: Do volunteers from the Benevolent Society visit the Sunshine Home regularly? How often?

L's father: No, the times are not fixed. The Sunshine Home organizes activities regularly. A volunteer teacher gives a dance class every week or every other week at the Sunshine Home. She also taught these students to take part in a municipal dance competition.

L's mother: The dance music is *Beautiful China*. The teacher, being mother to a student at the Sunshine Home, is a great dancer and teaches students there once per week. Thanks to her great efforts, these students can make such great progress today. They also draw on Wednesday and dance on Monday and Tuesday.

L's mother: We can contact the Sunshine Home to see when it holds activities if you plan to observe L's performance during these activities, otherwise there's no point in going. It is a time-consuming task.

L's father: Numerous activities are held over the weekends.

L's mother: L is happy no matter how much he can learn. I think students there should be taught to widen their horizons. Volunteers would also teach them to make moon cakes and other sweets. L often tells us what volunteers from the Benevolent Society plan to teach them the next day. He is happy whenever he talks about that. I asked him: "Are you willing to learn that?" He said that he was. I just hope that L can be happy every day. I have to do everything to make it happen. Don't you agree?

Q: I agree.

L's mother: Students are happy at the Sunshine Home. As a result, even if they are criticized when not performing well, they accept criticism and change accordingly. If they were unhappy there in the first place, they would no longer go there once they were criticized. I could not recall any student enrolling into the Sunshine Home and dropping out. When meeting new students whose parents may worry about the new environment at the Sunshine Home, I take the initiative to assure them that teachers there are nice, and it is a friendly place. My kid is happy there. Hearing that, these parents believe me and are relieved.

Q: Great.

L's mother: Once, we were invited to a parent-teacher conference. I was astonished. My son was dancing there. I never even considered him dancing. He performed quite well as a whole. I think it is challenging for the teacher to teach students with ID. They may not move to the beat strictly. Nonetheless, they have made dramatic progress, right?

Q: Yes. They are well taken care of at the Sunshine Home.

L's mother: That is true. I think the Sunshine Home has been developed for a long time together with retired or former teachers. Development of people with ID has attracted concerns both from the local governments and nationwide. Authorities have implemented practicable measures to make satisfactory achievements.

L's father: L is glad to go to the Sunshine Home. For example, it rained heavily yesterday and the day before yesterday. He went there all the same.

L's mother: His father tried to persuade him not to go.

L's father: I told him that it rained heavily. His clothes and shoes would get wet in the rain. It would be uncomfortable to wear them. When he heard me, he sat down on a chair. After a while, he jumped to his feet and said that the rain let up and he could go to the Sunshine Home. He loves to be there.

Q: Does L go to the Sunshine Home alone?

L's father: Yes.

Q: He returns home all by himself in the afternoon, doesn't he?

L's mother: That's correct.

L's father: Many parents frequently buy watermelons in summer and pastries on other occasions at their own expense and send these things to the Sunshine Home.

L's mother: These kids greet me when they run into me ongoing upstairs. I also treat them as if they were my own. They can only play with each other or with their siblings. It is unrealistic for them to get along with other normal kids.

L's father: The Sunshine Home organized an autumn outing to the Great Garden the day before yesterday. Students brought snacks and shared with each other. They brought back leftovers.

L's mother: We bought a cake on L's birthday and L shared it with other students. They may be in their twenties or thirties but they act like teenagers. Normal people in their thirties are not at all like them. In summer, parents living near the Sunshine Home may take watermelons there. Living far away, we cannot do that. We may send pastries instead. It is no longer necessary for us to do that. L takes pastries to the Sunshine Home himself and shares them with other students.

Q: Have you taken him out recently?

L's father: The three of us went to a scenic area in Ningbo at the end of September. L wanted to buy local specialties for his classmates immediately, who would also do the same thing for him. One of his classmates went on a trip to South Korea and gave them key rings as a souvenir. Another one went to Shandong Province and brought them nori.

L's mother: These students share things with each other.

L's father: L has no idea what the local specialties are. Nonetheless, he asked us to buy these things.

L's mother: We bought Ningbo crisp bean candies. There were 32 students in L's class. L gave each of them a pack of candies.

L's father: Last time, parents of kids with ID from subdistricts such as Jiaxing Subdistrict, Tilanqiao Subdistrict, and Guangzhong Subdistrict attended a meeting organized by Special Olympics East Asia and talked about the operation of Sunshine Homes. I listened and noticed that Sunshine Homes have been operated differently by the subdistricts. The Sunshine Home in our subdistrict has performed well and held numerous activities. Some Sunshine Homes serve as nurseries and barely hold any activities. The best one is the Sunshine Home in Quyang Subdistrict in Hongkou District. It was visited by former General Secretary Jintao Hu. L goes to the Sunshine Home in Jiaxing Subdistrict. L's mother knows that the Sunshine Home in Quyang Subdistrict is better and wants to transfer L there. L refused because he is familiar with all his classmates in the current one. Moreover, it is stipulated that students who register their permanent residence in one subdistrict cannot be transferred to a Sunshine Home in other subdistricts. L, with his permanent residence registered in Jiaxing Subdistrict, cannot go to the Sunshine Home in Quyang Subdistrict.

L's father: One flaw lies in the operation of the Sunshine Home in Jiaxing Subdistrict. It should not share a place with the Sunshine Psychiatric Garden,⁵ which is applied to managing people suffering from mental illnesses. The disabled are categorized into five groups: the physically disabled, the deaf-mute, the blind, the mentally disabled, and people with ID. It would be a threat to personal safety if the mentally disabled had a seizure. Parents of students at the Sunshine Home worry about their kids' safety. Beyond that, we approve of how the Sunshine Home is operated.

Encouraged by Parents to Join the Waist Drum Team Early

L's mother: L is a member of the waist drum team established by the Hongkou District DPF and participates in activities held on weekends.

Q: Where are these activities held?

⁵Sunshine Psychiatric Garden is the community rehabilitation institute established for the mentally disabled by subdistricts or villages and towns in Shanghai since 2009. It primarily provides services such as daycare, psychological counseling, therapeutic recreation, and training in basic skills and social adaptation abilities, aiming to bring the mentally disabled back to society and participate in social activities as others do.

L's father: At No. 22, Guangzhong Road. It is called the Hongkou District Disabled Persons' Federation and Hongkou District Cultural and Sports Training Center for Persons with Intellectual Disabilities.

Q: When was the waist drum team established?

L's father: Around 2004 or 2005 when the Sunshine Home was set up. Community disability service assistants organized activities for students in the Sunshine Home and taught them to play the waist drum. At first, they organized these students to do radio calisthenics in the lane near their office, which was located on Wuhua Road in Hongkou District. Meanwhile, the subdistrict office purchased some waist drums. As a result, these students began to play the waist drum and do radio calisthenics alternatively. However, playing the waist drum in the lane would disturb residents there. After receiving complaints, assistants found a new place to do that. Nearly all students doing radio calisthenics have learned to play the waist drum. Well-performed ones have been selected for the waist drum team.

Q: Assistants would mobilize students good at radio calisthenics to play the waist drum. Is that correct?

L's mother: Right. These students have to do radio calisthenics first. Then they will play the waist drum. An original member of the waist drum team quit. The organizer thought highly of my son and persuaded him to join the team.

L's father: My son did radio calisthenics but was unwilling to play the waist drum. At first, students were making noises rather than following beats to play. My son, being annoyed by the noises, would rather cover up his ears. The waist drum team was just established. Assistants also hoped to build a sound team. Seeing that L performed well when doing radio calisthenics, they went all out to persuade him to join.

Q: Why did L select to play the waist drum instead of participating in other activities such as square dancing?

L's mother: Square dancing has emerged in China in recent years. At first, assistants organized students to do radio calisthenics. It is the simplest activity and can be done anywhere. Parents would bring their children to the designated place to do radio calisthenics. They might also teach their children if these children could not do it. Then the waist drum team was set up. It is also easy to hold the activity. All you need is the waist drum. The team can play in Miyun School⁶ on weekends, during which students there have a rest.

Q: Does Miyun School also supply waist drums?

L's father: Definitely not. Waist drums are supplied by the Hongkou District DPF. The subdistrict office might also buy seven or eight drums at its own expense at the request of the district government, which could not afford these waist drums itself. The waist drum L uses is one purchased by the subdistrict office.

L's mother: The waist drum team would practice in the playground of Miyun School. However, residents nearby complained about the noise. In fact, it is also noisy for students there to do radio calisthenics in the morning during weekdays.

⁶Miyun School is a special school established for students with ID to receive 9-year compulsory education in Hongkou District, Shanghai.

Nonetheless, it is done in 10 min. However, the team would play the waist drum for a longer time. Consequently, the team has been organized to practice in the current venue.

L's father: For example, the lane is empty now. Residents nearby may complain if they hear discordant drumming for a whole morning. In fact, that is the reason why the waist drum team has changed venues twice.

L's mother: Back then, people playing the waist drum might have come from several subdistricts.

L's father: The waist drum team practices at No. 22, Guangzhong Road. In fact, residents nearby have also complained about that. However, the team has no other place to go. As a result, sound-proof equipment has been installed. You saw it on that day. You also saw three community disability service assistants, of whom two are physically disabled. Community disability service assistants tend to organize activities near the Hongkou District DPF. For example, their office is located near our community. They will hold activities near the office.

L's mother: Other members have already played the waist drum for a while and made great progress when L joined them. Being a substitute, my son was unwilling to play at first because he could not catch up with them. I accompanied him and learned to play the waist drum myself. Then I taught him at home until he mastered it. It took about 2 months for L to catch up. I think all things are difficult before they are easy. The waist drum team also started from scratch and performs well now. Moreover, these members could not play the waist drum in the first place. They may take the waist drum home and not play it. They claimed that they could not play it. It takes time to master a skill.

L's father: We encourage L to participate in activities. However, L may be afraid that he cannot perform well and is sometimes unwilling to go outside. In comparison, some parents might be embarrassed about their kids' performance and reluctant to allow them to join activities. Some other parents would even worry that their kids could get lost. Consequently, these kids would rather stay at home. It was painstaking for assistants to visit these families repeatedly to mobilize these kids to participate in activities. They put forward the slogan of "Going Outside and Joining Community Activities." These kids had been reluctant to go outside at all.

L's mother: My husband and I are teachers and open-minded. If I were afraid of my son embarrassing me, I would not let L stay in my workplace for such a long time or rack my brains to encourage him to go outside. In my opinion, he is born to be a person with ID. I have to make him to see the world and communicate with people to fit into the society.

People will not laugh at him even if they know that he has an ID. Someone may mock him if they know nothing about him when meeting him for the first time. If they know about him, they will feel pity for him. Therefore, L was encouraged to participate in a variety of activities when he was little.

People with ID from the whole Hongkou District may join these activities. The waist drum team has been promoted as the organization affiliated to the Hongkou District DPF. It must reach people with ID from a large area to be promoted on

TV. The team, which has been operated attentively for years, is a highlight among activities held for people with ID.

L's father: My kid goes out every day. He goes to the Sunshine Home on weekdays and joins activities held by volunteers on Guangzhong Road on weekends.

L's mother: L is happy. It is demanding for people with ID to learn to play the waist drum. The waist drum team has selected those who perform well. L is smarter in comparison with his classmates in the Sunshine Home. That is why he was selected for the waist drum team. Moreover, he is tall and was selected as the flag bearer.

L's father: He is both the flag bearer and a member of the waist drum team.

Q: Can he also perform the dragon dance and the lion dance?

L's mother: Sure. He learned that on Guangzhong Road.

L's father: He can also play the flat drum now.

L's mother (gesticulating with hands): It is barrel-shaped.

L's father: He performs well in dancing and playing the drum.

Q: Does he like to join activities organized by the waist drum team?

L's mother: He will go there unless the activity is cancelled.

L's father: He may not go there if the teacher in charge tells him not to.

Q: L would never miss any practice, would he?

L's father: Absolutely not.

L's mother: He likes to do that.

Q: What if he feels under the weather? For example, what if he catches a cold or has a fever?

L's father: L is physically healthy all the time.

(L's father took out L's waist drum.)

L's father: Tomorrow is Saturday. L will go to Guangzhong Road with this waist drum.

L's mother: At first, I accompanied him and urged him to go there, otherwise he would not go.

L's father: Exactly.

Q: You spent about 2 months accompanying him and then teaching him at home, right?

L's mother: Yes. He has been interested in playing the waist drum after he learned how to play it. No one can stop him from going there.

Q: Does he join the waist drum team on weekends all by himself?

L's father: That's correct. We didn't live in Quyang Subdistrict until last September. He knew the way to Guangzhong Road from our original home. After moving here, we accompanied him to the Sunshine Home and Guangzhong Road several times. He knows the way now and can go and return all by himself.

Q: Does he also need to take a bus?

L's mother: Yes, he does that alone.

L's father: My wife is careful and patient and has accompanied him several times. I only accompanied him once. After a while, he knows the area better than we do.

Q: Is he good at remembering bus routes?

L's father: He is. For example, he knows that one can go to Lu Xun Park via bus route 959.

L's mother: After moving here, on weekends, L went to Guangzhong Road in the morning and strolled around in the district in the afternoon. He knew the area well after a while.

Q: Are activities of the waist drum team held in the morning on weekends?

L's mother: Yes.

Q: L will return home for lunch and go out again in the afternoon. Is that what you meant?

L's father: He likes wandering around if he is free in the afternoon.

L's mother: That is how he gets to know the area.

L's father: It may also be one of his habits. He was alone at home from 1998 to 1999 because we had to work. He would go outside in the afternoon. He has developed a habit of strolling around in the afternoon if he is free.

A Sports Fan Participating Frequently in Local Special Olympics Activities

Q: Has L participated in the Special Olympics Games? Which programs?

L's father: Badminton, table tennis, and basketball (see Fig. 1).

Q: Is it because L is as tall as 183 cm?

L's mother: It is not a regular basketball game. They play horse.

L's father: He cannot participate in all programs. Everyone is encouraged to play a part.

L's mother: First of all, I want to clarify that L is not a professional Special Olympics athlete.⁷ He participates in sports activities held by the Sunshine Home.

L's father: Shanghai hosted the Special Olympics World Games.⁸ Outstanding athletes were selected from all districts in Shanghai to compete in contests. Winners would represent Shanghai to participate in the 2007 Special Olympics World Summer Games. L failed because he did not perform well in bowling. Consequently, he has never joined major Special Olympics Games.

Q: Hasn't L participated in any Special Olympics World Games?

L's father: No, he has participated in neither Special Olympics World Games nor the municipal Special Olympics Games. He has joined in Special Olympics activities held at the district level or below.

Q: Has he played a part in the Hongkou District Special Olympics activities?

L's father: Sure. He has participated in most Special Olympics activities at the subdistrict level. Sports activities are held constantly at the grassroots level.

Q: Are these activities held at least once a year?

L's mother: That is correct.

Q: L is a sports fan, right?

⁷L's mother means that L is not an athlete participating in the Special Olympics World Games. Special Olympics athletes are not categorized as professional and amateur athletes.

⁸Refers to the 2007 Special Olympics World Summer Games.

Fig. 1 L (left) received an award after he won a table tennis match organized by the Hongkou District Disabled Persons' Federation



L's father: Yes, he really likes sports. He could ride my 28-inch bike when he was in elementary school.

Q: Has he developed a good balancing capability?

L's father: When he was little, he would ride a bike by stretching one of his legs across the triangle frame of the bike. However, for safety, we didn't let him ride the bike after he grew up. He knew nothing about traffic rules. We used to live in a newly established community, in which yards were interconnected. L could ride a bike there. My wife cooked while I kept an eye on him. I take credit for his interest in sports.

Q: Did you take him to do sports?

L's father: My wife basically did all the housework and I took care of L. I like sports. I used to be the sports secretary in my class in high school and college. Consequently, I would take L to do some sports. For example, I might put two chairs together and play table tennis with L at home. Or we would play badminton in the yard. Sometimes we might do exercises in spare room in the lane.

Q: How old was L?

L's father: About 6 or 7 years old. It was easy for me to borrow sports apparatus from the school's gymnasium and play table tennis, badminton, football, or basketball with L to cultivate his interest in sports. We would play sports he was capable of.

Mother's Concern Over Proper Manual Labor

Q: In my last interview at the Sunshine Home, I heard that L got his clothes dirty when helping clean the bathroom. Is that correct?

L's father: Yes, Ms. Ni brought it up. It was handled by my wife.

L's mother: That is correct. Well (giggling with embarrassment), I can explain. L wears a cotton-padded jacket when he goes to the Sunshine Home in winter. He helps deliver food there. As a result, it is common to see grease stains on his clothes. Once, I saw that he got his jacket dirty again. He had poop stains on his clothes. It had never happened before. I asked him and learned that L was told to clean up the bathroom after a student had defecated.

L's father: The student was mentally disabled.

Q: Did the student ask L to do that?

L's father: One of the three teachers at the Sunshine Home takes care of the mentally disabled. It was him that told L to do that.

L's mother: The student might have pooped outside the toilet. L was told to clean that up and got his clothes dirty. L could not tell me exactly what happened. I had to investigate first. The Sunshine Home opens at nine o'clock. On the next day, I waited at the gate at half past eight and asked students there about the truth on the previous day. I was told that L cleaned up the bathroom after a student had defecated. Some students were nervous and afraid that teachers passing by might overhear our conversation. I have got the same story from several students and had my answer.

My son didn't show up at the Sunshine Home on that day. I told the teacher that L needed a day off. His cotton-padded jacket was washed because it was covered in poop stains. He had no extra jacket. A teacher responded that L could not have only one jacket. I told him that I would not let L wear the other one to clean up others' poop and get dirty even if he had two (indignantly). I told these teachers that it was all right for L to participate in manual labor. However, never would I consent to let him clean the bathroom. In my school, professional cleaners were paid to do that. Hearing my words, teachers at the Sunshine Home told me that they have also recruited professional cleaners to do that. I claimed that I conducted a survey and knew the student that had pooped. I also told them that the student was named Jun. Hearing my words, students there stared in one direction instantly. A teacher asked

loudly who told L to do that. In fact, she was the one that told L to do that. I told her that students there were either with ID or mentally disabled. She would frighten them if she kept yelling. That was not my intention. I went there to ask a day off for my son. The students, teachers, and I knew the truth. I didn't mean to find out who was to blame. L could not go to the Sunshine Home until his cotton-padded jacket was dry. I would not allow the same thing to happen again.

L's father: In your last interview at the Sunshine Home, you could see a cleaner in blue cleaning up the bathroom. She also cleans the table after students have lunch. Previously, students took turns to be on duty and took care of these matters.

Q: Was it a routine for students to clean up?

L's father: Sure.

L's mother: The teacher asking L to clean up other's poop is still working at the Sunshine Home. On the next parent-teacher conference, a parent, who learned from his daughter that I had been upset, asked me why. I shared L's experience with other parents.

L's father: We reached a conclusion at a parent-teacher conference. If the same thing ever happened again, teachers at the Sunshine Home will call the student's parents to handle that. After all, teachers are unwilling to clear up the mess themselves. Nor should they ask other students to do that. Parents can handle that properly. Later on, Jun's parents apologized to us. We get along well now. Kids are innocent. It is the teacher that should be held responsible. A student also added that L was playing cards when the incident occurred. The teacher taking care of the mentally disabled asked him to stop playing cards and clean up. I believe that is the truth.

L's mother: A similar thing occurred before. The Sunshine Home used to be located below our building. The lane is cleaned up on Thursday. I was home when L and his classmates were cleaning up the lane once. There was some green space between every two buildings in our community. It has been dirty. I saw mouse droppings and human feces when I went there to get my bike. No one would clean them up. However, subdistrict officials asked my son and his classmates to do that. I went to talk to them immediately. I was told that the subdistrict office and the Sunshine Home entered into an agreement to have these students participate in manual labor. I asked them whether there was anybody to instruct these students. I was told to ask teachers at the Sunshine Home.

On seeing these teachers, I told them that it was all right to involve these students in manual labor. However, being with ID, they would be unaware and incapable of protecting themselves when cleaning up mouse droppings. A teacher listed the example of a person with ID being employed and working as a cleaner. I replied that cleaners would wear special gloves and use tools. These students with ID do cleaning with bare hands in the outdoors. Who should be held responsible if any of them gets sick? Professional cleaners are unwilling to clean up the area. How could these teachers ask students with ID to do that? I asked them whether any teacher or subdistrict officials would instruct these students.

After my interference, these students were no longer asked to do that. I probably offended somebody. However, I had no other choice. Could the subdistrict office and the Sunshine Home be held responsible if my kid gets sick in the process? My

neighbors remarked that L would be in trouble in the Sunshine Home. In my opinion, the subdistrict officials and the teacher from the Sunshine Home have already burned their bridges the moment they asked students with ID to do that. I was not afraid of them.

Q: How old was L at that time?

L's father: It was around 2006 or 2007. L was 25 years old. The Sunshine Home used to cover two rooms on the first floor opposite our building. It often held activities in the community. Being supported by the community in daily operation, teachers from the Sunshine Home in turn organized students to help clean up the community as a sign of appreciation. However, first of all, these teachers or subdistrict officials should show students how to do that. Second, they should not arrange students to do jobs that others are unwilling to do. For example, rubbish would be thrown from upper floors. Street vendors nearby would poop in green spaces in the community if they had to. As a result, the green space is dirty and full of buzzing flies. Mice have also been seen there.

Q: It is understandable that you would worry about that.

L's mother: I didn't do that for L's sake alone. I also speak on behalf of other students with ID. They cannot be taken advantage of. I saw on TV that a student was forced to wear a bathroom wastebasket on his head in a school in Beijing. Teachers from the school explained that it was a joke among students. I disagree. It is school bullying, just like students with ID being arranged to clean up the green space. The Sunshine Home has been moved to its current location. The incident of L cleaning up another student's poop happened after that.

Kind-Hearted and Polite

Q: How does L get along with others?

L's mother: L greets his teachers whenever he runs into them on the road and talks about that after returning home. He also used to get along well with our neighbors when we lived in Dalian Community or Jiaying Road. He is not familiar with our new neighbors. We teach him to be polite and considerate. We used to live in a building of which the entrance was a big iron gate. We told him to hold the door for senior citizens who had their hands full. He listened and did well.

However, I saw him pulling a person's hair once. We live on the seventh floor. One day, I came back with him from outside. He walked in front of me. He suddenly pulled a woman's hair when reaching the third floor. I was stunned. It had never occurred before. I have learned later that the woman was teaching her daughter a lesson. Her daughter was a pupil and might have done something wrong. L did that in an attempt to help the pupil. I followed up in a hurry and asked L to apologize. Later on, I was informed that the woman told others that L pulled her hair on seeing that she was punishing her daughter. Such a thing only occurred once. After that, the woman would greet me when we met.

Q: Did L play with other children in the yard when he was little?

L's mother: No, we lived in Gongfang, an independent apartment.⁹ Children there did not play with each other.

L's father: Nowadays, normal people rarely contact with each other, let alone normal children and disabled children or people indifferent age groups. Basically, L amuses himself or plays with us.

Q: Miss Feng, do you have siblings?

L's mother: Of course.

L's father: I am the eldest son in the family and have three siblings. My wife is the youngest sister in her family and has two siblings.

Q: L has cousins, hasn't he?

L's father: Sure.

Q: Do they keep in touch?

L's mother: Rarely. For example, the whole family would get together at his cousin's wedding. These kids do not meet separately. His cousins start to work and play with normal people. We are the only people that play with him.

L's father: These kids would play with each other when they were little during family get-togethers. They have grown up now and got married. As a result, we don't meet as frequently as we did. For example, my younger brother may spend the spring festival with his family. As do we.

Adequate Self Care for Shopping and Orientation

Q: When did L learn to dress and wash himself?

L's mother: L could brush his teeth when he was little. He was taught to brush teeth up and down in Grade One. Consequently, bristles of his toothbrush curl upward and downward. I have already told you that L could not put on shoes or tie his shoelaces in kindergarten. He learned to do these things gradually later.

Q: When?

L's father: Probably in senior grades in elementary school or in middle school. We would also buy no-laces shoes for him.

Q: Did you teach him to tie his shoelaces?

L's mother: Yes. He was taught to button and zip in succession.

L's father: No one is born capable of doing these things. It takes time to learn them. For example, L still ties his laces this way (forming a loop on top of the two ends and tying a knot).

L's mother: L ties his shoes in the exact way he was taught.

L's father: One can also tie shoes in different ways. However, L can only tie them that way (gesticulating).

⁹Gongfang originally refers to housing built for factories' workers and their families. Multi-layered residential buildings with public kitchens and bathrooms were constructed on a massive scale for workers in Shanghai since the 1950s. Housing with independent gas and sanitary fittings have also been built widely after the 1970s. Currently, "Gongfang" is still refers to apartments that are different from shikumen-style buildings but have independent gas and sanitary fittings in Shanghai.

Q: Have you taught him to tie shoes using different methods?

L's father: No, we would rather let him be. After all, he has already learned to tie shoes via the first way. He is instructed to do that at home. I will show you.

Q: How long did it take for L to learn that?

L's father: I tied his shoes for him and taught him before he went out. It took about 1 or 2 months for him to learn the skill.

Q: You have mentioned that you would go for a bike ride with L before or after dinner. Did you do it to let L get acquainted with the surroundings?

L's father: When dinner was not ready or after dinner, I would take L for a bike ride. I installed a small chair with a piece of board to rest his feet on at the front of the bike when L was three. We lived in Dalian Community at that time. The flat was only 12 m², which was as big as the living room of our current one. Facing north, it was hot in summer and cold in winter. Quyang Community was located behind us. Construction had just started. The place was unoccupied with light traffic. I would ride there to kill time on one hand and point out ways for L on the other hand. L knew the way well. Sometimes I would try to ride along a different way. He might grasp the handlebar and insist on me following the original way.

L's mother: L knows the way well. He goes to Guangzhong Road to participate in activities held by the waist drum team alone. After we moved here, we showed him the way twice and he could go there all by himself.

L's father: L knew the area quickly. We moved here over a year ago. He has already got acquainted with the surroundings and told us where there is a lane nearby.

L's mother: We have showed him the way repeatedly.

L's father: My wife is anxious about letting him go outside alone. I do not agree.

Q: How well can L take care of himself? You have mentioned that he could not cook, right?

L's father: He can only dress and wash himself.

Q: Is that all?

L's father: He can also take a bath, make his bed, and wash socks and shorts independently.

Q: L can wash small clothing items?

L's father: He cannot wash larger items such as T-shirt.

Q: What about the washing machine?

L's father: We don't use it at all. In fact, L outperforms his mother when using home appliances such as the TV. He would even teach his mother how to use a home appliance in some cases.

Q: Can he use a mobile phone?

L's mother: We are willing to buy him one, but he does not want it.

Q: Can he go shopping all by himself?

L's mother: Of course, he can buy refreshments. He would tell us that he spent 2 yuan to buy a steamed stuffed bun on his way home.

L's father: He can buy food to feed himself. My wife had an operation last year and I had to take care of her in the hospital. I gave him 15 yuan for lunch. He preferred wonton at the Qianlixiang Wonton Restaurant. At first, he would order a bowl of

wonton which was priced at 8 yuan. Later on, he had to eat one and half bowls, which cost 13 yuan.

Q: Does he know how much change he ought to get?

L's father: Of course, he can perform basic mathematical calculations.

Q: Does he know that he will get 1.5 yuan if he pays 5 yuan for a commodity priced at 3.5 yuan?

L's father: It is interesting that he will give 5.5 yuan to get change of 2 yuan.

Q: What if he gives 100 yuan for something worth 41 yuan?

L's father: He knows the amount of change. We have gradually given him pocket money. We would hardly do that in the past. L could keep the change if it is a 1-yuan coin. It is a tradition in our family. That used to be the source of his pocket money. Nowadays, we have gradually given him as much as 5 or 10 yuan. I told my wife that we should teach him to spend money since he has already grown up. Last time, he paid 100 for a meal worth 60 yuan and got change of 40 yuan. I let him keep it. My wife would not do that. In summer, he also buys a cold drink which may cost 3.5 yuan. He does not care about the price but buys it if he wants it.

L's mother: Once, he returned home from Guangzhong Road at half past 12. We asked him why he was late. He explained that the waist drum team was dismissed late. He was hungry and bought two steamed stuffed buns, one being stuffed with vegetables and the other one with meat, on his way home. I told him that he could directly return home and have lunch.

L's father: Once, when I returned home, my wife asked me to guess how much L spent on a meal. It was 27 yuan. He ate one and a half bowls of shrimp wonton for a change of taste. We never ordered shrimp wonton in the restaurant. We would rather have vegetable and meat wonton which is cheaper. L is not sensitive to the price. He will buy food if he wants it and can afford it. He can also recharge the transportation card independently.

Q: Can L cook?

L's father: No. We used to soak cooked rice in boiled water and eat it. He never eats that.

Q: Can L cook instant noodles?

L's father: No.

Q: He knows the way and can buy food for himself. Is that correct?

L's father: You can say that.

Q: Did he ever spend a whole day at home alone?

L's mother: No, but he would stay at home alone for half a day. For example, we have bought some financial products. As a result, we may be invited for dinner. My husband would go and I would stay at home to look after L. We would both go if it is a lunch. L can have lunch at the Sunshine Home.

L's father: We may worry about two things. First is the door. Being alone at home, L will rush to open the door if the doorbell rings. Second is gas. We told him to never touch that.

L's mother: Safety issues are crucial after we moved here. There were a wooden door and an iron door in our former housing. Others could not enter even if the inner door was open. Moreover, we would tell L to bolt the door after we left. We further

locked the iron door from the outside. L didn't have the key to the iron door. In that case, he would be protected by the iron door even if he opened the wooden door. However, our new housing has one door only. Others can enter directly if the door is open. As a result, we never leave him alone at home. Nowadays, thieves may cheat L if they know that L, a person with ID, is home alone. After all, it is common to see normal people such as college students get fooled.

L's father: Once, my wife was hospitalized for a week. I asked my younger sister to look after L at her house. My wife has been hospitalized again for a week this time. I managed to take care of L and her all by myself. I left the hospital after nine o'clock at night and returned home to accompany L. I returned to the hospital again after L went to the Sunshine Home.

L's mother: None of the families we know that have family members with ID would let these people stay at home alone. Previously, neighbors might have given a hand by keeping an eye and looking after the person with ID. Nowadays, neighbors are strangers, leaving readily exploitable loopholes for criminals. I do miss those peaceful old days.

Worrying About an Uncertain Future

Q: L is 35. Have you considered him getting married?

L's mother: It is tough. Our acquaintances mentioned introducing someone to L. However, L refused.

L's father: He does not know anything about romantic relationships.

L's mother: It is also hard for us to discuss it with him. After all, it is impossible to tell whether a couple can get along with each other.

Q: Does L know the concepts of love and marriage?

L's father: Absolutely not. Seeing a pregnant woman, L would misunderstand her as a conjoined twin.

L's mother: He saw conjoined twins on TV.

Q: You have not considered the issue for now because L knows nothing about marriage. Is that correct?

L's father: We are in a dilemma. Our friends care about him and ask about that repeatedly. However, it is complicated. L could get married and have a baby. But who would take care of the baby? We have been exhausted in looking after L.

L's mother: Someone suggested that we find some girl who comes from outside of Shanghai or is physically disabled. They can be complementary. In my opinion, they should get along with each other first. Their motivation also matters.

L's father: We were told to find some poor or less-educated girl.

L's mother: I think it is a question of fate. You can lead a horse to water, but you can't make it drink.

Q: Have you ever tried to introduce anyone to L?

L's father: He knows nothing about love and affection.

Q: How do you plan his future?

L's father: First of all, we hope that the age limit can be raised so that L can continue going to the Sunshine Home after reaching 35.

L's mother: It is crucial. It is stipulated that students at the Sunshine Home must be 35 or younger. L was born in January 1982. He will be 35 in January 2017 and will be too old to enroll in the Sunshine Home. Teachers there told us that L could spend an extra year at the Sunshine Home because both of us are over 70. Well, the age limit was set when the Sunshine Home was just established. Nowadays, activity centers have been established for senior citizens exclusively to play the waist drum or play chess after retirement. These 35-year-old people are more energetic. If there is a chance, could you please help pass our request on? Can the age limit be relaxed in the Sunshine Home and allow those who are willing to go to continue going there? L behaves himself and has won numerous awards. He can also give assistance to teachers at the Sunshine Home. He is active and participates in a variety of activities. He likes going to the Sunshine Home. It is understandable that an age limit was set when the Sunshine Home was established at the very beginning. After exploring the business for over 10 years, a stable operating model has been developed on the basis of rich experience, and breakthroughs have also been made there. Consequently, the age limit could be raised.

Q: What do you worry about when you think of L's future?

L's mother: We worry that no one will take care of him in the end. Being afraid of having another kid with ID, I did not give birth to a second child. I tried to solve the issue. L is the top priority in our lives. I asked about a senior apartment program several years ago. After buying an apartment at a price of 600,000 yuan, my husband and I could move in and pay monthly property management fees to be taken care of. If both of us passed away, the apartment would belong to the property developer. We inquired whether we could involve our son in the program. We even offered to buy a larger apartment or two apartments. The answer was negative. Consequently, we did not select the program. The same goes for nursing homes. No one would take care of L if both of us went to a nursing home.

Regarding relatives and friends, they can only give a hand in cases of emergency. It is impossible for them to take care of L indefinitely. I was fertile 50 years ago. If I gave birth to another child at that time, I would leave all property to him at the premise of him looking after L. The truth is that L only has cousins. Nowadays, some children are unwilling to take care of their parents even if they inherit everything, let alone cousins. I also heard that a nanny murdered a host and took away the property. People do not trust each other as much as they did. It is really hard for us to handle the issue.

L is happy at the Sunshine Home. We hope he can always be happy. Regarding the senior apartment worth 600,000 yuan, we would not move in directly even if we bought it. We would go all out to keep L included in the society. We would move in the apartment if L is no longer admitted to any institution. We are willing to give away our housing if a formal and reliable institution can take care of L and us. However, we do not trust any charitable organization only by name.

Of course, some people are grateful. I watched a video several days ago. A Chinese fellow, who used to stay at an old lady's place when pursuing postgraduate studies in Norway, has taken care of her in China. The old lady, who was childless, treated

him as her own child and helped him a lot in Norway. They kept in touch after the young man completed his studies and returned to China. The old lady was in poor health. As a result, the young fellow took her to China. She liked staying in China and wished to be buried there. The young man has taken care of her for over a decade until she passed away. Then he buried her in a cemetery in China. The young man, together with his parents and his wife, treated the old lady well. However, it is rare to see people like this Chinese guy in today's society.

Special Olympics entered China over a decade ago, leading to a great improvement in living conditions for the disabled. So long as related actions are taken, changes will occur at the grassroots level. We are fully aware of that.

Q: Do you mean that relevant policies have been made for the disabled in China?

L's mother: Sure. The government has to work out solutions. It has implemented the family planning policy. As a result, many families have raised only one child, but the child is with ID. No one would take care of the child after the parents passed away. Moreover, families who have lost their only child suffer more than we do. It is an unimaginable tragedy for them. We however have been already preparing for over 30 years.

Q: What is the preferential policy made for people with ID like L? Do they receive an allowance to ease the burden on the family?

L's father: L receives an allowance of 1,150 yuan.

Q: Is it a monthly allowance?

L's father: That is correct. L also receives two extra subsidies of 330 and 150 yuan, respectively. In addition, L obtains an annual medical subsidy of hundreds of yuan.

Q: Has L received sufficient subsidies to meet his basic needs?

L's father: We certainly hope that L can obtain as many subsidies as possible. In fact, the subsidies are sufficient for L. Both of us are well paid but spend less.

L's mother: We are careful in our day-to-day spending for L's sake. Economically, L is in an easy situation based on the monthly subsidy of 2,000 yuan and our help. Yesterday, one of my co-workers told me that I was too old to spend a lot of money and suggested that I save money for L in the future. The amount would be sufficient for L to spend for the rest of his life.

While that is true, we cannot leave behind our care and concern for L. I have always been worried about the issue that no one will take care of L after both of us pass away. Because of this constant worry, I look older than my peers. We are older than parents of other students in the Sunshine Home.

L's father: We are 73 now. Everything works smoothly at the moment. However, we will be 75 in 2 years and then 77 in another 2 years. By then, we will bear more burdens and suffer more problems. It is a universal issue in families likes ours.

Interview with Mr. L's Teacher

Interviewee: L's teacher

Interviewer and writer: Yameng Xia

Interview date: December 8, 2016

Interview place: A subdistrict Sunshine Home in Shanghai

L Should Improve His Ability to Take Care of Himself

Q: How do you feel about L's performance at the Sunshine Home?

Teacher: He is active and helps us do things he is capable of. With a father teaching math, L outperforms others in math.

Q: What kind of things may L offer to do?

Teacher: For example, he helps to serve breakfast and lunch and does some manual work because he is tall and energetic. He has a sense of group loyalty and takes the initiative to work.

He is also a main player in singing and dancing performances. People with ID are also categorized according to levels of comprehension. L understands a new thing faster than other students do. As a result, he is selected to complete difficult and complicated tasks. For example, he represented the Sunshine Home to join in the Shanghai Sunshine Home Talent Show and performed outstandingly in the 24 Game. However, the 24 Game is merely calculation and less attractive or amusing. Consequently, he was able to pass the preliminary contest but failed to enter the final. He is tall and good at both cultural and sports activities. He has often participated in sports events such as playing table tennis and shooting basketball and won awards.

Q: What about L's shortcomings? Is it hard to manage him?

Teacher: No, L is obedient and well behaved. His parents are teachers and teach him well.

I cannot see major weaknesses in him. He develops good habits and is polite.

Q: Which aspects do you think should L improve as a whole?

Teacher: He should improve the ability to take care of himself. After all, his parents are old and cannot look after him forever. It is also the point I have made constantly. Many families have raised only one child that is with ID. Parents are unwilling to have a second child, resulting in the situation in which two old people take care of a disabled younger one. The child can live comfortably if both parents are healthy. However, parents will get old and have deteriorating health. These children need to be able to take care of themselves.

Q: What do you think are the solutions?

Teacher: I think the government should implement policies in place to help solve these issues. The Sunshine Home is not omnipotent, training students with ID to be capable of everything. It can only help these students to be more capable of taking care of themselves. None of the teachers can train these students to achieve certain quantitative standards.

These students have gone to a sea of special schools in Shanghai but failed to become well rounded. After all, they are with ID and have limited understanding capability. Hence, I think they should be helped in developing the ability to take care of themselves both in the school and at home.

For example, charity institutions can offer opportunities to train these people to complete simple tasks such as tallying commodities in the supermarket or serving coffee in Starbucks. That way, they can make a living. I saw a US film about a person with ID that works in a coffee house. Various challenges have been set to see customers' and his reaction. For example, he serves an unreasonable customer that mocks him. I think the program reveals problems we may neglect in daily life. People with ID should be helped by the whole society instead of institutions such as the Sunshine Home only. The Sunshine Home covers a small area. We have done everything we can. The government authorities have also done their job. The key lies in the family.

People with ID should be trained as much as possible to take care of themselves so as to have less of a rough time in the future. Their parents will pass away. These people will also be admitted to a nursing home in the end. They need to be taken care of if they lack the ability to take care of themselves. It is known that a nurse has to look after several persons simultaneously in a nursing home. As a result, people with ID will certainly suffer inconveniences in their daily lives. We should not merely teach students knowledge. We aim to teach them to be polite, handle things properly, and get along with others. That way, they will be able to protect themselves when living alone in society. They are protected by their parents now. They will be self-supporting after their parents pass away.

We know that the disabled are vulnerable and should be looked after in society. However, few would put that into practice. For example, the disabled are free to take a bus in Shanghai. In comparison, in cities without such a preferential policy, some children with ID don't even know how to spend money. It is impossible for them to pay for a bus pass. For example, a person with ID may have a 10-yuan note but need 2 yuan to take a bus. It is hard for a normal person to ask for change, let alone the person with ID. He is not capable of changing the note for ten coins and inserting two coins to get on a bus. These things are trivial. Nonetheless, the truth behind these things is worth thinking about. It is impossible for them to develop these capabilities in the Sunshine Home alone. Nor can a government authority make decisions on a whim and address all of these issues.

I think the key is that people with ID must learn to take care of themselves. After all, they live in the society. The narrower their scope of activities, the worse their living conditions will be. They are born with ID. It makes things worse if they stay at home and watch TV all day.

L has developed the basic abilities to take care of himself. Living far away, he knows the way and can take a bus independently to go to the Sunshine Home. It is clear that people with ID must be trained to master these abilities. I think L needs to develop more common sense. Issues that can be solved by money are not major issues.

Q: Has he ever been absent from school?

Teacher: He has hardly been absent except for family affairs.

Q: How long have you worked in the Sunshine Home?

Teacher: For less than 3 or 4 years. I used to be a community disability service assistant. A teacher here was sick and retired early. I was transferred as a replacement.

This is how I see it. People with ID should not be over-protected. I think it does no good for them if they merely sit around and don't master the ability to take care of themselves. They should experience setbacks to learn lessons. I do not approve of over-protecting them. They will be completely useless in society. Many of these people cannot wash clothes or use home appliances such as the washing machine and the microwave oven. How will they be able to live independently? In fact, we might teach things they will never apply in daily life. I may be exaggerating a little bit.

Q: What policies have been put in place to help people with ID?

Teacher: Well, in Shanghai, unemployed severely disabled people receive a monthly allowance of 1,150 yuan and an extra subsidy of 330 or 600 yuan according to the level of intellectual disability. In addition, their medical expenses can be fully reimbursed. You can compare it with the statutory minimum wage in Shanghai, which is 2,190 yuan.¹⁰

Q: What is the relation between the Sunshine Home and Special Olympics?

Teacher: Special Olympics accelerated the establishment of the Sunshine Home. The first International Special Olympics Summer Games were held in the United States in 1968. Shanghai hosted the 12th Special Olympics World Summer Games in 2007. It is also the first Special Olympics Games organized by Special Olympics East Asia. The Sunshine Home admits students in the age range of 16–35. A majority of young people with ID in the community go to the Sunshine Home, making it a reservoir of athletes for the Special Olympics Games. The Special Olympics World Games are held every 2 years. China hosts the National Special Olympics Games annually. So are the Shanghai Special Olympics Games and the subdistrict Special Olympics Games. Athletes are selected at the subdistrict level, the district level, and the city level to participate in the Shanghai Special Olympics Games.

Q: Can you tell us about the operation of this Sunshine Home?

Teacher: Six non-profit organizations such as the Benevolent Society organize volunteers to hold activities at the Sunshine Home from time to time. The Sunshine Psychiatric Garden, which was established for the mentally disabled, shares the same location with the Sunshine Home, which was set up for people with ID, in our subdistrict.

Interview with Mr. L and His Parents

Interviewees: L and his Parents

Interviewer and writer: Yameng Xia

Interview date: December 17, 2016

Interview place: L's home

¹⁰Shanghai has increased the allowance to unemployed severely disabled people to 1,270 yuan and its statutory minimum wage to 2,300 yuan per month from April 1, 2017.

An Outgoing Man of Many Interests

Q: We have talked a lot. Can I have a chat with L?

L's mother: Sure. Come here, L.

L: Yes, Mom?

L's mother: Just answer a few questions.

L: All right.

Q: What were you doing just now?

L: Watching TV.

Q: Which TV programs do you like?

L: *Boonie Bears*.

Q: Is it the program featuring two bears, Briar and Bramble? My younger sister also likes it. Do you like watching cartoons?

L: Of course.

Q: Can you list other TV programs you like? What about *Animal World* and other programs on the Discovery Channel?

L: I do not watch them.

L's mother: Well, which TV program do you watch at night? Music program?

L: Listening to music.

L's mother: You like watching music shows, right? Something about *Outstanding*?

L: *Outstanding Song Collection*.

L's father: It is a program playing Chinese folk songs at half past seven in the evening on CCTV-15.

L's mother: Can you introduce the TV program, L?

L: It starts at 5:50 in the evening, not half past seven.

L's father: It starts at five o'clock on Saturday.

L: Friday to Sunday.

L's father: It is on at half past 7 from Monday to Thursday.

L's mother: Who are your favorite singers, L?

Q: Who are your favorite singers?

L: Singers performing in the *Chinese Superstar Concert*.

L's mother: Well, can you list some?

L: Andy Lau and Emil Chau.

L's mother: And? Do you remember the singer you read about in the newspaper yesterday?

L: Dawei Jiang.

L's mother: Can you list some of his songs?

L: *Where is the Road*, the ending theme song to *Journey to the West*.

L's mother: And?

L: And what?

L's mother: What are other songs sung by Jiang?

L: *Riding a Horse to Protect the Frontier*.

L's mother: And?

L: *Where the Peach Blossoms are in Full Bloom*.

L's mother: And?

L: *Spring in the North*.

L's mother: What else? What's the most famous one that starts with "Ah"? Do you remember?

L: *Song of Peony*.

L's mother (smiling with satisfaction): That is correct.

Q: Did you read these names for the first time yesterday?

L's mother: He has listened to these songs frequently. What did Yunfei sing yesterday?

L: *Father's Prairie and Mother's River*.

L's mother: Who is the original singer?

L: Jiangyang Zhuoma.

L's mother: Who else has sung this song? A singer with Teng in his name. Do you remember?

L: Liyuan Peng.

L's mother: No, someone named Teng?

L: Tengri.

L's father (asking the interviewer): Shall we ask another question?

Q: All right.

L's father: Which songs have moon in the name?

L: *Above the Moon*.

L's father: That is correct. And? How many can you list?

L: *The Full Moon*.

L's father: Yes, and?

L: *The Moon Turns Perfect Round on the Day after the Mid-autumn Day*.

L's father: And?

L: *Go with the Moon*.

L's father: You have named three. Can you list more?

L: *Purple Moon*.

L's father: Anymore?

(L thought hard but failed to name any more.)

L's father: That is a game the waist drum team frequently play at No. 22, Guangzhong Road. You have missed *The Moon Represents My Heart*.

L: Bingbing Li¹¹ sings that one.

L's father: L likes listening to these songs. He used to be a basketball fan and watched NBA Games on TV. He could even name all the players in NBA teams in a season. He may have forgotten them now.

L: I watch the game and remember them.

L's mother: Can you list any of these basketball players?

L: Tracy McGrady and Ming Yao.

L's father: That was before Yao's retirement. Can you list players from the Los Angeles Lakers?

L: Kobe Bryant.

¹¹Bingbing Li is a Chinese actress.

L's father: L used to watch NBA Games. He started watching much less after Yao's retirement. Instead, he listens to music. Speaking of cartoons, he watches one featuring two bears, Briar and Bramble.

L: I watched it several times during the Songjiang Summer Camp.

Q: Pardon?

L: Songjiang Summer Camp.

L's father: L also watches drama series. Which is the one you have watched most often?

L: *Happiness...*

L's father: *Happiness Knocks the Door*. Wenli Jiang, a Chinese actress, plays the heroine.

Q: I have not watched it.

L's father: You haven't. Well, L has watched it six or seven times. He will watch it if it is on. The hero is called Zheng Song.

L: Jun Song. (Correcting his father's mistake regarding the hero's name.)

L's father: Yes, Jun Song.

Q: Do you still remember the story? What happened?

L: She is gone.

L's father: Who is gone?

L: The old lady is rescued at the Emergency Center.

L's father: Which old lady?

L: Zheng Song's grandma.

L's father: Yep, Zheng Song is naughty at home. Her grandma falls into a rage and passes away.

L: No, two men go for her.

L's father: Right, two rascal high school students seduce her. If the drama is on TV, L can sit down and watch several episodes one after the other.

L: I am watching *Left Hand*.

L's father: Which *Left Hand*?

L: *Left Hand Family*, *Right Hand Love*.

L's father: It is a new drama series that recently came on the air.

L: Its Lili Liu again.

Q: Who is Lili Liu?

L's father: An actress playing a part in the drama.

L: She is with Lu Jiang.

L's father: Liu plays the role of the sister of Wenli Jiang in *Happiness Knocks the Door*.

Q: Do you watch the drama because you like the actress?

L's father: That is correct. He has also watched a drama series telling the story between a daughter-in-law and a mother-in-law. Who plays the role of the mother-in-law?

L: Xiulin Xu. Yuan Lu and Tong Lu also play a part in the drama.

L's father: Yes. The mother-in-law has three sons. The eldest son and the second son are called Daqiang and Erqiang respectively.

L: Well, Guoqiang Tang, an actor, plays a part in it.

L's father: Yes. L can understand the story but cannot tell it clearly.

L: I watch other TV programs.

L's mother: Which one do you watch now?

L: *Boonie Bears*.

L's father: L also likes to watch Snooker games and billiards matches.

Q: Can he play billiards?

L's father: No, but he knows the rules.

(L talked about his understanding of billiards rules in Shanghai dialect.)

L's father: The player pockets a red to get six points and a black for seven points.

And?

(L failed to say anything else about it.)

Q: You and your parents went on a trip to Ningbo last time. Do you remember?

L: I have been to Ningbo.

L's father: We also went to Changxing.

L: And Xianshanhu Wetland Park. I took a photo there.

L's mother: My husband will go get it.

Q: Did you enjoy yourself in Ningbo?

L: We ordered too much food.

(L kept saying these words while his father fetched the photo.)

L's father: These families were in the *Special Olympics Oral History* program.

Q: I have met this person.

L's father: This one. This boy also joined us on that day. These three (pointing at the photo) were observed at the Sunshine Home on Wednesday and you went there on Thursday. This boy is from the nearby subdistrict. Six families in our subdistrict and four from other subdistricts have participated in the program of the *Special Olympics Oral History*. Ms. Zhou organized kids participating in the program for a 3-day vacation in Changxing County, Zhejiang Province. I took L and went there. This is the father in another family participating in the program.

L: I was happy.

L's mother: He enjoyed himself. He will go on another trip soon.

L: I will travel again in the middle of this month.

L's mother: They have birthday parties. A girl from the trip celebrated her birthday and invited the other three students. We went there together.

Q: Do you remember your school time?

L's mother: Which elementary school did you attend?

L: Dalian Community Elementary School.

L's father: What about junior high school?

L: Junior High School Affiliated Hongkou Educational Institute. I still remember a classmate.

Q: Was he your classmate at elementary school or junior high school?

L: We were not classmates in Dalian Community Elementary School.

L's father: What is his name?

L: Liu.

Q: Why do you remember him?

L: Eh?

Q: What did he do to impress you?

L: He ran into me.

L's father: L ran into him once on the way.

L's mother: Do you remember any of your classmates in the junior high school?

L: Well, He.

L's mother: That is his teacher.

L: Yes, Mr. He.

L's father: What was your class director's name?

L: Mr. He.

L's father: Your class director.

L: Mr. Xu. I ran into him on Shuidian Road.

L's father: L also ran into his PE teacher on Guangzhong Road.

Q: Did you like going to school?

L: Sunshine Home.

Q: Do you like to go to the Sunshine Home?

L's mother (repeated the interviewer's question): Do you like to go to Junior High School Affiliated Hongkou Educational Institute?

L: My name will be on the screen next week (kept talking about things that happened in the Sunshine Home and not answering the question).

L's mother: What screen?

L: An activity is held at the Sunshine Home next Friday. My name will be on the screen when Mr. Hong plays it.

L's mother: What screen?

L: The activity organized by the Benevolent Society.

(No one understood L's words.)

L's father: He might be talking about an activity which was recorded yesterday. The video would be played next week.

L: I was there.

L's mother: You and other students at the Sunshine Home.

L's father: He tells us about these things. We don't know whether it is true. Let it be.

L: You can ask my parents. I was on *Thirty Minutes in Hongkou*, a program on Dragon TV.

L's mother: You were on camera.

L: I was on camera. *Thirty Minutes in Hongkou*. Bowling.

L's father: Sure. This year, Special Olympics organized some activities, attracting the world's focus on disabled people. These people have been on camera in some TV programs. The person in charge is called Zhen Ni. You have met him at No. 22, Guangzhong Road.

L: We will start off on Saturday. Zhen, as in Dizhen [meaning "earthquake"].

L's father: Mr. Ni may be 82 or 83 this year. He has indeed devoted himself to this career.

L: He took me to dinner once.

L's father: He is active and a role model in the system.

L's mother: He is old. We might have had a brush with him on that day. Nonetheless, he is nice and has committed himself to his career.

L: He takes us to participate in activities and invites us to dinner after these activities.

L's mother: The waist drum team may have dinner in a restaurant on occasions such as the spring festival.

L's father: Back then, we spent all our savings on L.

L: Several teachers took Zou to go shopping at E-mart¹² in 2017.

L's mother: L said that teachers would go shopping for an activity held at the Sunshine Home. Some students will help push the shopping cart.

L's father: For example, refreshments would be prepared for a party. As a result, teachers may take a student to give a hand. L used to be such a student. He no longer does that now. Can you tell me why?

L: It is far way.

L's father: Exactly. We live far away from the Sunshine Home. It is inconvenient.

L: I was replaced.

L's father: A student living near the teachers in charge has replaced L.

L: Mr. Kong and Ms. Lin.

L's father: You cannot understand L if you don't spend a lot of time with him.

L: I don't go. They do. They are strong and ask me to help carry stuff.

L's father: Strong students have to give a hand and help unload stuff. L is tall. Ms. Zhou often asks L for help if an activity is to be held at the Sunshine Home.

(L talked about an experience of carrying stuff.)

L's mother: They prepared the scene.

L: We pasted "0" and "2".

L's father: Mr. Lei, the parent of a student there, asked L to do that.

Q: Did you like your junior high school?

L (irrelevant answer): I prefer playing with another classmate.

(L's father repeated the question.)

L: I knew the teacher. I like him.

L's mother: L joined the class in the middle of the course. He had nothing in common with his classmates. As a result, he didn't have a friend in the class. I was also aware of that. He is my son. Consequently, he was not bullied. However, he was not close to others. The teacher teaching PE would involve him in class activities. Therefore, he got along well with the teacher. He could not follow other teachers. That is why he does not talk about other teachers. That is our understanding.

L: A teacher got angry at the playground. A student called Zhang hit a girl on the head with a basketball. I was scared to death.

L's mother: L said that a student accidentally hit a girl on the head with a basketball. He only mentioned the teacher teaching PE because they were close. Of course, the teacher told the boy off.

L: The teacher did not criticize a girl student.

L's mother: L meant that the teacher would let it go if a boy was hit by a basketball.

¹²E-mart: a supermarket.

Q: L explained the accident clearly.

L's mother: Sometimes others don't understand him. We do because we live together.

Q: Are you happy at the Sunshine Home? Do you have any friends there?

(L pointed at the group photo taken at Changxing and was proud.)

L: Look, we have been there.

L's mother: She asked you whether you have any friends at the Sunshine Home.

L: Of course.

L's mother: Who?

L: Zhou and Han.

L's father: Anymore?

L: Sun. They were there.

L's mother: You need to string together a sentence. You can express it this way. Regarding my companions that went to Changxing together, these are my friends. What's more, these are also my friends.

Q: Do you like joining the waist drum team?

L: I go there.

Q: Do you like playing the waist drum?

L: I can.

L's mother: Did you like playing it at first?

L: No, but I like playing it now.

L's mother: I accompanied you to join the team at first.

Q: Why didn't you like it at the beginning?

L: There were so many people.

L's mother: L said that he could not play it at first. Later on, he learned to play it and became interested in it. From then on, he has been willing to participate in the activity.

L: It is crowded. More people will join us tomorrow. We will also make cookies tomorrow.

L's mother: They are organized to learn to make cookies. Will you play the waist drum tomorrow?

L: Yes, we will. We will do cookies after playing the waist drum.

L's mother: Make cookies.

L: Make cookies.

Q: Do you play the waist drum first and then make cookies?

L's mother: Who will teach you?

L: Those volunteers.

Q: Do you like going to the Sunshine Home?

L: I go there. Take 528.

L's mother: You were asked whether you liked going to the Sunshine Home. You should give a positive answer. Which bus do you take?

L: 528.

L's mother: Or?

L: 751, 134.

L's mother: You should add "or" in between. Don't speak nonsense.

Q: I have noticed that a variety of courses are provided at the Sunshine Home. Which one is your favorite?

L: The Benevolent Society organizes activities.

Q: You like activities held by the Benevolent Society the best, don't you?

L: It was yesterday. I did not eat up the snacks and candies. I brought them home.

Q: Do you like handwork and making gifts for others?

L (irrelevant answer): I have not eaten them up yet.

L's mother: Students are usually supervised by teachers. Volunteers from the Benevolent Society and other organizations come from time to time and organize novel activities.

L (pointed at his handcraft): Look, I made this at the activity organized by the Benevolent Society too. There are more.

L's father (pointed at L's handmade photo frame): L participated in some activities yesterday and brought back some snacks. These are also L's work. He pasted them one by one.

Q: L likes playing with volunteers, right?

L's mother: These children with ID like getting together. It has already become a routine. If it is a student's birthday, the student's parents will bring refreshments to all the students at the Sunshine Home. Students like sending and receiving gifts. If it is a hot summer day, fathers will send cold drinks and watermelons to the Sunshine Home. Mothers cannot carry watermelons. They are too heavy. These students will share happily. They also go on trips together. All of these efforts are made to make sure that they enjoy themselves.

Q: Do you prefer going to the Sunshine Home or staying at home?

L: I like playing with people. Yesterday, we played Dafanguai.¹³

L's father: Do you remember your game yesterday?

(L thought for about 10 s.)

L: I did this. The traffic lights, red and green.

L's mother: L might mean that it is go if the traffic light is green.

L: I gestured to go (confused narration and failed to state clearly yesterday's activity).

L's father: He cannot make himself understood clearly. He might try to tell you about yesterday's activity, in which another kid played the role of a thief. Did you go bowling?

L: The red was against the white. Ms. Zhou was there.

L's mother: Which ball games can you play?

L: I took second place when playing badminton and table tennis. I didn't get it. Four of us ranked second when playing table tennis.

L's mother: Who won?

L: Shen from Jiaying Subdistrict.

L's mother: I never knew a Shen from Jiaying Subdistrict. Is he also a student at the Sunshine Home? No, he entered the activity via another channel.

L: There was no first place. Everyone was ranked second.

¹³Dafanguai is a word game.

L's mother: Rankings are significant for students when participating in activities such as sports activities at the Sunshine Home. L and other players ranked second.

L: Once, I returned home at a quarter past 11 at night after an activity.

L's mother: The activity ended at a quarter past 11. You ate steamed stuffed buns in a restaurant and returned home at 12 o'clock.

L: I did not mean that one. It was 2 weeks before that week. I returned home late one night. 597 and 875 [stopped].

L's mother: Well, that was during the Shanghai World Expo.

L's father: Not that one. L meant the opening ceremony of the 2007 Special Olympics World Summer Games. He returned home late that evening.

L: 597 and 875 stopped.

L's father: L returned home after 12.

L: A quarter past 11.

Q: How did you return home if the bus stopped?

L: I took 97 to the terminal station and transferred to 47.

L's father: I didn't go with him. It was too late. The bus stopped. Ms. Zhou saw to it that these four kids returned home by taxi. I couldn't sleep and waited up at home. I called Ms. Zhou on the telephone and was informed that these four kids took a taxi to return home.

Q: When did that happen?

L's father: I forget. It was during the Shanghai Special Olympics World Summer Games.

L's mother: Their events were on TV. Either of us would stay awake and wait for L if he didn't return home.

L: I waited for a long time but both bus routes stopped. It was too late.

L's father: Which bus stopped? Can you express yourself clearly?

L: Both of them stopped after half past 11.

L's father: L could take bus routes 597 and 875 to return to our original housing. They stopped early at night. If so, L would take bus route 97 and transfer to route 47. Ms. Zhou told them to take a taxi directly. We taught him to take a bus while the teacher teaches them to take a taxi.

L: Well, we were separated and returned home individually.

L's mother: Who were separated? After arriving at the destination?

L: No, the four of us were separated. One took 597 and another took 875.

Q: Let's conclude here today. Thank you.

(L stood up and bid farewell to the interviewer when the interviewer ended the interview and left.)

Observation of Mr. L in the Drum Team

Observation time: 09:00–11:00, November 19, 2016

Observation place: Hongkou District Disabled Persons' Federation, Shanghai

Observer and writer: Yameng Xia

The waist drum team consists of 16 members who are from eight subdistricts. They are divided into two groups. Most members have mild intellectual disability. They cooperate with those having moderate intellectual disability. Instructors include Ms. Zhou, the teacher teaching musical instrument, and Ms. Lin, a student's mother.

Time	Team activities	L's activities
09:00	The waist drum team started to play	L took out the waist drum and drumsticks brought from home to get prepared. The teacher instructed them to form a line according to height. L stood at the back because he was the tallest in the team. The team started to play. The teacher praised L
09:10	The team took a break	It was boisterous in the training room. L chatted with his friends. He took the initiative to come over and told the observer that he had played at Mr. Feng's the day before. Mr. Feng is a teacher at the Sunshine Home. He then looked for his father instantly
09:20	Dancing	L danced with ease to the song sung by Phoenix Legend, a Chinese popular music duo
09:27	Boxing with the music	After a song ended, L started to dance to another song. He moved like a boxer and shouted out "ha" with the rhythm
09:31	The team took a break	L continued chatting with students he knew
09:42	Preparing to play the flat drum	L offered to carry the flat drum from the office to the training room
09:51	Students worked in pairs to play the flat drum	
09:54	The teacher called for a pause to correct them	
09:56	The team continued playing the flat drum	
09:59	The teacher rearranged participants.	L was asked to stand by and watch
10:06	Other students played the flat drum to the song of <i>Without the Communist Party, There Would Be No New China</i>	L stood by and watched
10:08	The team took a break	
10:09	The team continued playing	L joined them and played the flat drum to the song of <i>Without the Communist Party, There Would Be No New China</i>
10:12		L played the flat drum to the same song again

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Time	Team activities	L's activities
10:17	The team took a break	A student told L's father that L had asked another student to hit the student in the head and had not watched his language and cursed the student's mother to die. L's father explained that L didn't mean it
10:34	Practicing	L stood by due to the limited number of flat drums
11:01	The activity was over. The teacher remarked on their performance. The team was dismissed	L packed his belongings and prepared to go home by himself

Observation of Mr. L at the Sunshine Home

Observation time: 09:00–16:00, December 8, 2016

Observation place: A Subdistrict Sunshine Home in Shanghai

Observer and writer: Yameng Xia

Time	Activities	L's performance	
	09:04	Doing radio calisthenics	L moved his limbs coordinately and performed well
09:10–09:50 Psychosocial Rehabilitation Training Course Staff from the Community Health Service Center gives a lesson every Thursday to treat students via psychotherapy	09:10	Students carried chairs and formed a circle while preparing for the course The teacher asked students to close their eyes, relax and follow the teacher's instruction to imagine	L cooperated, looked up, closed his eyes and relaxed. He opened his eyes from time to time and mumbled. The teacher asked them to imagine butterflies flying about amid flowers. Hearing that, L smiled, did not cooperate anymore and fidgeted. He opened his eyes, turned down his lips, scratched his face, and watched the teacher moving around He continued to cooperate. The teacher corrected his posture
	09:16	The class stood up in a circle to stretch their limbs	L talked cheerfully with the student beside him

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Time	Activities	L's performance
09:25	The teacher asked the class to bend down and touch the ground	L cooperated and bent down to touch the ground. He could hold the pose for a long time. L stood up when the teacher corrected others
09:30	The teacher asked the class to swing arms	L was chatting and laughing with the student beside him while swinging his arms. The teacher corrected L alone and remarked that he stood way forward
09:35	The teacher asked the class to wag from side to side	L was chatting joyfully with the student beside him while following instructions L understood clearly to wag from right to left or left to right and helped students that got confused. He shouted left and right during wagging and performed properly The teacher asked students next to L to follow L and wag
09:40	The teacher asked the class to kick out feet alternatively	L shouted "left foot" and "right foot," and did exactly as he was instructed
09:43		L made a mistake in wagging from side to side and was corrected timely. L kicked out right and left feet correctly
09:46	The teacher asked the class to hold hands and form a circle and rush towards the center on hearing the teacher's order	L cooperated with the teacher, held hands with students on both sides, shouted words such as catching fish, ocean, and catching starfish and rushed towards the center and scattered L focused on the game and was happy

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Time	Activities	L's performance
	09:50	L was criticized by name because he kept chatting with the student beside him
09:57–10:39 Extracurricular activities	09:57	The class started to draw on masks
	10:03	L played table tennis with a teacher
	10:06	L returned to the classroom to fetch a brush. He left the classroom and chatted with his classmates. L played darts for three series, which included five darts each. He didn't miss the target and two of his darts hit the bull's-eye
	10:10	L's father asked L to play the 24 Game
	10:39	Lunch
12:40–14:00	Lunch break	L went to the lounge upstairs. There were sling chairs. L's chair had the comforter his mother prepared for him
14:00	The teacher explained rules to go bowling and set an example	L responded actively and clapped after the teacher set a successful example
14:07	Six students were asked to go bowling	L was player No. 3 in the boy's team. He raised his hands to show that player No. 3 was to throw the bowling ball. He understood the rules well
14:11		Obedying the captain's order, L tried to hit the head pin but missed

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Time	Activities	L's performance
14:28		L knocked down pins in the third row
14:31	The game was over. A new game started. The two teams saluted to each other	L saluted to the other team
14:35		L sat at a corner, watching the game and chatting with his classmates. His friend was in the game. L applauded for his friend
14:45	A set ended	L stood up to help set bowling balls and returned to the corner to continue chatting with his classmates
15:01	A set ended	L stood up again to help set bowling balls
15:04	The teacher gathered the students and the activity was over	L was the tallest and stood at the back

Translated by Weizhen Yang

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Out-of-School Child Entering Sports Field



Di Zhang

Interview with Dan Cao's Mother

Dan Cao, male, born on January 1, 1983. The only child in his family. Grade IV intellectual disability. Admitted into the Sunshine Home in Shanghai's Hongkou District, 2005.

Interviewee: Ms. Zengdi Wang (Dan Cao's mother)

Interviewer and writer: Di Zhang

Interview dates: November 4 and December 23, 2016

Interview place: Cao's home

Weak and Sick Ever Since Childhood

Cao's mother: With a head of long and curly hair, my son was born a pretty baby, very good looking by Shanghainese standards. The doctor scored him 10 and there was no trace of Down syndrome... at all. Yeah, he was indeed the apple of everyone's eye in the family.

By the time he was 2 years old, I found that he wasn't able to control his bladder. While he was telling me "Mom, I want to pee," he'd already peed. We visited almost every hospital in Shanghai about it, only to be told everything was okay because doctors saw nothing wrong with it.

This lasted until he went to kindergarten (sobbing). He still wasn't able to control his bladder. While he was telling the teacher "I want to pee," his pants were already wet. The teachers demanded to see me every day and they would rebuke me," What's wrong? He's no longer a baby, but he always leaks as soon as he wants to. He is rotting our floor... No way! We cannot accept him if he continues like this!" I had no choice but to take him home.

This problem persisted until he went to school, starting at the age of seven. As soon as he shouted, "I want to pee," he'd peed. He was beaten numerous times for

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this. Sometimes I thought he was just too occupied with playing, so he forgot to go to the toilet. However, later I found out that he really had trouble with it.

Why do I say so? Well, he had a lot of urine even while sleeping at night. We took him to the doctors and were told not to let him drink water after ten at night. I questioned, "How can we not allow such a little kid to drink water?" According to the doctors, there should be no water for him after ten at night, even in summer. Well, this was impossible for us to follow as parents. While sleeping at night, he would become restless if he needed to pee. The doctors' opinions were that we let him pee too frequently, so he had very short intervals between urination. They advised us not to interfere with his time to pee. I tried but then he just peed involuntarily. If you told him, "Son, get up and pee," he would empty his tank immediately. If you let things take their natural course, however, he always ended up wetting the bed. After all, he was so young and therefore a heavy sleeper!

We have visited all of the hospitals in Shanghai, big and small, countless times about this. Both my husband and I have spent as much as we can earn. They say dried lychees are effective for this problem, so we made him eat probably dozens of pounds of dried lychees each year, even up until today. I have tried everything that is said to be effective, be it food, nutritional supplements, popular folk prescriptions, and even acupuncture, but all in vain. My son has indeed had enough of them.

Later, we turned to my husband's cousin, a medical graduate, for help. "I am sorry I don't know how to treat this," she said. "However, I do know a director at Shanghai Children's Hospital. He generally would only see a limited number of patients, but I can call him to see, if that would help?" So, she managed to make an appointment for us with that doctor. My husband and I took our son to him. Oh, the doctor was already very old. It was really not easy for him to continue seeing patients of special needs. After diagnosis, the doctor said, "Take it easy. I will prescribe to you some TCM for a period of 3 months. I assure you he will be fine after taking the medicine."

Well, that was 20 years ago, and it cost us over 8 yuan per week for the prescribed TCM. It was really very expensive for us. You see, my husband and I literally spent all the money we had on him. Sometimes, we didn't even have any money left for meals, and I had to ask my parents to help me out (giggles). I would tell them that we were starving for the sake of this kid. My parents were really helpful. They would say, "Then send the boy to us instead of hiring babysitters. Let us take care of him." I was reluctant to do so due to concerns of their age and health. How could I ask for more when they already supported me financially? Anyway, when I visited them, I always received money from them, sometimes 50 yuan, and sometimes 100 yuan, which was almost a fortune in those days.

So, we fed him on TCM for 3 months, but it had no effect at all. Then we asked the aunt's daughter to contact that senior doctor again. "How was it," he asked, "Is the boy okay now after taking the medicine for 3 months?" I replied, "To be honest, I'm sorry to say that there has been no change at all." Hearing this, this old professor was very surprised. His immediate thought after that was: "Alright, you don't need to tell me more. Let me make a call to arrange an X-ray for your son. He most definitely has a problem with his spine." How could it be, I wondered. Although my son had never taken an X-ray for his spine, we had him take a bone X-ray for the lower part

of his body when he was young. The doctor, however, was very certain, because he had seen another kid with the same problem. So he helped us get in touch with the director in charge of radiology at the department of pediatrics.

The director told me that he would first prescribe some laxatives for my son to take after 10 the night before taking the X-ray, so as to empty his bowels. I asked, "Will he get the runs during the night? I need to get myself prepared for that." According to the director, it wouldn't be as bad as that; generally speaking, the bowels would be emptied after going to the toilet once or twice, and that's why he recommended taking the laxative after 10 p.m. I didn't listen to him. I still waited until my son woke up from his sleep after midnight to let him take the pill. Then he had loose bowels (giggles) throughout the rest of the night... Since the doctor said it wouldn't be that bad, I simply wrapped him up with a few large towels. However, this turned out to be a bad idea, because his bowels were running all the time and it even got our quilt dirty (giggles). Being very sensitive to all kinds of medicine, his bowels kept running till twilight. I said to my husband, "It's already 3 a.m. now, we should get up. We have no quilt to use anyway (giggles)." We left our last quilt on our son and then got up. My husband asked me what I was going to do. I said laundry. There were so many things to wash and there was no way of getting around it.

I told my husband to boil some water, the more the better, because all the stuff, being so smelly, had to first be soaked in boiled water. My husband thought I was being funny. According to him, why bother, simply washing them would suffice. I said if that was the case, I would rather throw them away (giggles), so no way.

In the morning, we took him for the X-ray. The doctor told us that the result would be ready in 2 h and an appointment was made with that old professor. The professor assured us that he would wait for us because he knew we had such a difficult time. Indeed, at that time we had tears in our eyes all day long (giggles).

Two hours later, we fetched the X-ray film to give to the professor. Just as he expected, there was a crack on my son's spine, which was a congenital problem and the reason behind his inability to control his bladder. Whenever he felt like peeing, he would leak instantly. The professor told us not to beat our son for this, because the kid himself also suffered. Just think of the countless Western medicines and TCM he had taken. I asked the professor what to do. According to him, there was no treatment. We could only let things take their natural course and wait for him to gradually develop. If the spine is sealed up once he becomes fully developed, the problem will be gone; otherwise, it will remain throughout his life. The professor recommended us to give our son more nutrition, so that he could start his physical development earlier and have the spine crack sealed up. Well, things really turned better later. When he turned nine, the problem suddenly disappeared.

Another problem with him was that he dared not walk by himself even when he was 2 years old. He only dared to walk when there was something for him to lean on, but not independently. I was at a loss, so we took him to Xinhua Hospital and he also took an X-ray. When he was taking the X-ray, we were very afraid, because we had seen many kids unable to walk owing to bone problems in their legs. My husband and I were really anxious to know what his problem was. If he was like those kids, his entire lower body would need casts. A week later, the X-ray result

came out. The doctor told us that our son did not have any bone problems. “Then how come he could not walk?” we asked. According to the doctor, this was because our son was timid, so we had to make him braver. I wondered why he would be so timid. The doctor recommended that we let him walk along the edge of supportive objects. “Well, he does walk beside the bed or the sofa,” I said. “He just refuses to walk independently.” At that time, he was two and a half years old.

My employer told me that I had to go back to work because never ever had anyone enjoyed such a long maternity leave. My husband was a section chief in our workplace. I found it too embarrassing to tell others that my son wasn't able to walk yet. I dared not mention it.

I worked on and off, going to work one day and taking sick leave the next day, because I had no one to help me take care of my son. At that time, my husband's grandfather was already very old and very ill. He had no one to take care of him but my mother-in-law. Then I was left without anyone at home to help take care of my son. The only choice for me was to hire a woman living across the street to be the babysitter. I asked her to help whenever I was not allowed to take sick leave and I told her not to worry about being underpaid. If I remember correctly, the cost of babysitting at that time was already 300 yuan. Literally I was paying my entire salary to her. Even so, it was like begging her to babysit my son, because no one was interested.

When my son was in someone else's hands, he would not get as much care as from his mom (giggles). The babysitter would simply put him beside the wall. I was told after I took my son back home that the babysitter left him alone standing beside the wall, and she told him to either walk over by himself or whatever. Somehow, this forced my son to walk independently (giggles). Not bad. That babysitter said to me, “He would never be able to walk independently if he was in your hands. See, now I have taught your son to walk.” Oh, I was really very grateful to her and I bought her gifts. “Thank you so much! He would never be willing to walk independently if he had me at his side,” I said to her.

When he turned 4 years old, my employer did not allow me to take sick leave anymore, or the sick leave would be counted cumulatively as long-term sick leave. What should I do? What's more, that babysitter quit due to her mother's health issues. According to her, she could not babysit for me any longer no matter how much more I was willing to pay her. Then I turned to an old lady living on the first floor of our apartment building for help.

At the age of 18, Dan Cao underwent surgery. He had been suffering from serious cerebral hypoxia, so my brother managed to find an expert overseas, who worked together with Xinhua Hospital on transplanting omentum into my son's brain. This would do good for his brain development afterwards. If there's a serious lack of oxygen to your brain, you would finally lose consciousness, and as a result, you would totally lose the ability to look after yourself. The surgery was costly. We spent hundreds of thousands of yuan on it.

According to that expert, Dan Cao seemed to have had meningitis when he was 2 or 3 years old. This sounded impossible to me. I brought him up by myself, so I am the person who's most clear about whether he had meningitis before or not. “Why

do we suspect that he had meningitis before?” The expert explained, “His vertex was covered with a layer of scab, just like the scab we would see forming on a cut finger. Such a cover on the vertex leads to insufficient supply of blood to the brain. We have now torn off this cover.” According to the expert, this is typical among people who have had meningitis. I told him, however, that I was personally attending to my son when he was 2 or 3 years old, and never ever did I find him running a high fever. I discussed this matter with the expert and asked him if high fever was a symptom of meningitis. He said yes. Anyway, they were of the opinion that he had meningitis before.

Q: So it could not be determined whether it is congenital or acquired?

Cao’s mother: Exactly. Not even to this day.

After the surgery, he has seemed to be faring well, able to do some simple things on his own. To be frank, it might not have been possible for him to be admitted into the Sunshine Home, but now he is, and he is able to do some simple things.

Out of Touch with Relatives From the Father’s Side

Cao’s mother: My husband is the only son in his family. The rest of the siblings are all sisters, older or younger. Therefore, when our son was born, he was the apple of everyone’s eye in the family. At that time, his great grandfather was still alive, over 90 years old. He particularly travelled over from Ningbo, in high spirits, to see his great grandson. Everyone was so happy.

Q: When he was diagnosed with the illness, was your first reaction to conceal the fact or reveal it directly to your relatives and friends for help?

Cao’s mother: There’s no way to conceal it. We never tried to hide it from our relatives. As for help, however, that was out of the question. His aunts panicked upon finding out. They were afraid to see him. It may not sound nice, but they avoided him like the plague.

Questions: How did the other family members feel?

Cao’s mother: Of course, they felt depressed.

His grandparents, especially his grandfather, were very fond of him at first. When he was a newborn, he often had his days and nights reversed, sleeping during the day and awake at night craving attention. I should say it was always his grandfather who got up to pick him up and hold him in his arms.

As a matter of fact, before he turned 2 years old, he had always been in his grandfather’s arms. He was really pampered. Whenever his grandfather received any bonus gifts from his workplace, he would give them away to my son. Remember my son could not control his bladder when he was young? Knowing that dried lychees would be effective for this, his grandfather would buy a few pounds every month for him.

However, after learning that his grandson had intellectual disability, his grandfather has been avoiding us for almost a score of years. His grandfather is still alive, but he just refuses to be in touch with us. So do my son’s aunts. We were not even informed of the weddings of their sons or daughters. They keep us out of the loop because they don’t want to see Dan Cao.

At first, I myself also... seemed to be unable to come out of the shadows. How unfortunate it is to have a son like that. Later, however, I came to know more people, and I have always been encouraged to face the reality: "It is destiny that brought this kid to your house. There must be a bond between you and him. You care so much about him after all."

Q: Have you ever thought about having another child?

Cao's mother: In fact, my father and mother wanted me to do so badly. At that time, they kept persuading me: "Have one more kid, not for your own sake, but for the sake of Dan Cao." I told them that I would not be able to handle it, because I was already tied up with this kid... How could I manage to have one more? I could not afford it, whether financially or energy-wise. My parents offered to bring up Dan Cao for me so that I would only need to take care of the second kid. I asked what if the second one still had problems? They doubted we would be so unfortunate. Anyway, I was not willing to have one more kid, neither was my husband. As a result, my father-in-law was not happy with me. My parents-in-law refused to stay in touch with us just because of this matter. They did not talk to us, nor could they understand us.

Q: So you are afraid that the next child would still...

Cao's mother: Have intellectual disability.

Q: That's why you don't want another child?

Cao's mother: Yeah. Besides, here are some more of my husband's considerations: It would be great if the next kid was a healthy one, but then you would spend all your energy on him or her, in addition to expenses on education. Dan Cao would then be neglected. If the next kid still had problems, that would mean lifelong suffering for us. Well, let us resign ourselves to Dan Cao, the one and only kid of ours, and let us treat him well. My husband is really a very good man. He decided that we would not have any more kids and we would just be responsible for Dan Cao, taking good care of him. I asked, "I feel pressure from the way your parents treat us now that we've decided not to have another child, what shall I do?" He answered, "You don't need to care about them. Why should we have another kid just because they want us to? Dan Cao is so sick. Why haven't they helped us for even 1 day, instead holding Dan Cao in such contempt?" My mother-in-law is okay, but my father-in-law really turned his nose up at Dan Cao. He seemed to be utterly disgusted at Dan Cao's presence...

Q: They don't understand you, do they?

Cao's mother: Right, they do not understand. They questioned why we would treat such a kid so well.

None of Dan Cao's aunts could understand us. At that time, we wanted to improve our housing condition. After all, Dan Cao's father had worked in Xiamen for more than 10 years, so we had saved some money. My brother told us, "There is a unit in European Garden¹ at a very good price. I know their boss. Are you interested?" Dan Cao's aunts suggested that after we bought the new house, Dan Cao's grandfather could live with us. "How about his own house then?" I asked. One of the aunts answered, "It is to be divided among us, and he is to live with you." "Why am I

¹Name of a residential community in Shanghai.

supposed to do that?" I said. "I have a disabled child to take care of, and you want me to take care of his old grandpa as well?" We felt it so unfair that we did not buy the new house.

Later, my husband's eldest sister was entitled to my father-in-law's house, and my father-in-law lived with her. I said, "Fine. Since you have done this, I won't ask for anything from you." Now she has sent my father-in-law to a senior care center, but my father-in-law has kept calling my husband to bring him home. My husband said, "You want me to bring you home after you've given away your property? I only have such little space in my house." I told my husband to visit his father (giggles). After all, his father was already over 90 years old. My husband replied, "For what? He didn't even want his grandson. More than 10 years have passed and never ever has there been a phone call to us."

Dan Cao has an aunt whose work is within 5 min' walk from our house, but (she has never visited us). On very hot days when the temperature was as high as 40 degrees, if I went to work, Dan Cao would spend his time alone at home, in the room at the back of the house... (tears) In the past, my husband was sent to work in Xiamen for more than 10 years and I took care of Dan Cao all by myself. Dan Cao's aunts never come to see him.

When I was at work, I couldn't help but worry whether my son would have heat stroke on such hot days... you know the front part of our house has a rather high ceiling and good ventilation, while the room at the back is very small, only 9.8 square meters, and it's very stuffy and hot. Oh, what could we do about it?! I couldn't take care of Dan Cao's lunch, either. Therefore, I told my husband to install a pull switch on the rice cooker. You know every morning after I cooked the rice, I could not unplug the cooker, otherwise the rice would be cold by lunchtime. I told Dan Cao, "I will cook the rice for you every morning and keep it warm. After lunch, just pull the switch. Do not touch any other electrical devices. I'm also going to set an alarm clock for you. After you get up in the morning, wash your face, brush your teeth, and eat breakfast. Then wait until the alarm clock rings to have your lunch." He said yes, but he did not quite understand. Sometimes he got up at eight in the morning and had his breakfast. At nine o'clock, he felt a long time had passed, so he ate his lunch. Then he would not have supper until around half past seven in the evening after I got home (sobbing).

Questions: Do your parents-in-law live far away?

Cao's mother: We used to live together. My father-in-law was affected by the Cultural Revolution. Later, thanks to policy implementation, he was allotted an apartment in Yunguang Community and they moved there.

Q: Has Dan Cao ever been to his grandparents' house?

Cao's mother: Yes. I often took him to visit them when my husband worked in Xiamen. Sometimes they would call us saying that Grandma was not feeling well, and I would take Dan Cao to visit them on such occasions as well.

When my father-in-law needed heart surgery, Dan Cao was about to receive the omentum transplant. Dan Cao is certainly not a smart guy, but it seems sometimes he could firmly remember things that he was not supposed to remember. While at the hospital, he kept the doctor's words in mind. The doctor told me that to perform

four surgeries at the same time would involve fatal risks. He heard everything. Then he said to me, “Mom, I may die. The doctor said I might not get out of the surgeries alive.”

I told him to stop talking nonsense while he said, “I’m serious. I heard the doctor’s words. It is a big operation.” I said, “Take it easy. It is just an operation to make you smart and there will be experts from abroad! Take it easy. Your uncle is even going to send people from the TV station to videotape it, and he’ll be in the operating room, too. Take it easy.” At that time, my brother worked at the TV station, and Dan Cao’s surgery was indeed a big one, to be jointly performed by Xinhua Hospital and foreign experts. The TV station planned to videotape it and broadcast it if it turned out to be successful.

He said: “I can’t... I know there is danger involved in the operation. The doctor has said so. I heard his words. Please call my grandfather to see me, so that I can see him, too. Maybe this will be the last time for me to see him.” Oh, hearing this, I could not hold back my tears. I said, “You will be fine. Stop talking nonsense. You know your mom believes in Buddha. Mama has prayed to the Buddha and the Buddha has given you his blessings.”

He seemed to be missing his grandfather so much, so I said to my husband, “Call your dad, and let us bring him over by taxi or my sister can pick him up.” Dan Cao’s grandfather just refused to come. He refused all the time, saying that he would not go to see Dan Cao.

I could not tell my son bluntly that his grandfather didn’t want to come, so I said, “Your grandpa is old and not very well.” Want to know Dan Cao’s reply? He said, “Grandpa is old, so is Grandma (on mother’s side). How come she comes every day?” I said, “Grandpa is not very well.” We could only explain it to him in this way. We could not tell him that his grandfather refused to see him.

I was actually angered by the fact that Dan Cao’s grandfather refused to see him in spite of Dan Cao’s earnest requests.

Q: So you rarely visited his grandparents afterwards?

Cao’s mother: Very rarely.

Shortly after Dan Cao had his surgery, my mother-in-law fell ill. She was diagnosed with colon cancer in the beginning, and later it spread to the liver. I had been taking care of her since she became sick. My mother-in-law was a nice person, very honest and docile, while my father-in-law was rather tough. Although she had four daughters, none of them would take care of her, because they all regarded her as useless. Seeing that she was sick with no one to attend to her, I decided to take care of her. The doctors in Shanghai General Hospital commented to my mother-in-law, “Your daughter is really good, and those four daughters-in-law seem to be quite mean.” They found it hard to believe when my mother-in-law told them it was just the opposite. I accompanied my mother-in-law for 7 days and nights at the hospital after she had the surgery, and finally I had a swollen face. When my younger sister came to see me, she complained: “You are crazy! She has so many daughters, so why you? She’s not your mother.” I said, “Well, don’t look at things this way. I regard my mother-in-law as my mother, too. My mother and his mother mean the same to me. My husband is such a nice man. I shan’t treat his mother unfairly, shall I?”

Q: Did your mother-in-law ever come to see Dan Cao?

Cao's mother: Rarely. My mother-in-law was a timid person. If she came frequently, she would be told off by my father-in-law. So, she didn't dare come. She did come secretly, though, but she would rush back home after a very brief stay to prepare a meal for my father-in-law, who is now over 90 years old. He received university education, which was quite something back in his time. Indeed, he had a very feudal mindset.

Q: Does your husband stay in touch with them?

Cao's mother: They will inform him if anything occurs.

Q: You rarely visit them, but sometimes they will ask you to come over?

Cao's mother: Right. They would call me to come over. You know my mother-in-law was admitted into Shanghai General Hospital, which is just across the street from our house, so they wanted me to take care of her. I had to do that. I believe the Buddha is watching. Anyway, I make sure that I do what I am supposed to do as a daughter-in-law.

Finally, my mother-in-law passed away. My father-in-law then had heart bypass surgery. He demanded I take Dan Cao along and take care of him. In fact, Dan Cao was so young at time, and he also had surgery only a few months before. I said, "My husband has three sisters, all of whom are homemakers. Why can't they do the job? I work every other day and on days I work, I ask my mother to come over and take care of my son. Now you tell me to take care of you. Two of your daughters are retired. You don't turn to your daughters for help, but to me, the daughter-in-law?" Daughters would be in a better position to do such things than in-laws. It's really awkward for a woman to attend to her father-in-law. If my father-in-law is already very old and oblivious, it's okay for me to help him take a bath or clean his body. Now that he is clear-headed, how could you ask a daughter-in-law to do those things, especially when her husband is away? Don't you agree? However, my father-in-law insisted on me taking care of him because I am a meticulous caregiver. I offered to hire him a nanny at my expense, but he rejected the idea. He just wanted me to take care of him. According to my husband, I had no choice but to obey. I had no choice indeed, so I took Dan Cao along to go and take care of him.

Sometimes, I said jokingly to my husband, "Cao, your family is simply treating me as a nanny (giggles) rather than a family member. They asked me to take leave from work to take care of your father while you were away from Shanghai. Actually, I didn't even have enough time to take care of Dan Cao. Am I right?"

Q: That's really tough. How long did it last?

Cao's mother: Three months, and Dan Cao went there, too. On my workdays, Dan Cao stayed in his grandfather's house. I made a deal with my father-in-law that I had to go to work. I would take care of him on days off work, and his daughters would take care of him on the other days. Those days, no matter who was taking care of him, I would get up at four o'clock in the morning to prepare the meals before going to work, so that they would not need to be cooked. Even so, they were still very mean to Dan Cao.

Q: What did they do?

Cao's mother: At that time, Dan Cao was still taking medicine for brain rehabilitation. I told them that I would have Dan Cao take the medicine in the morning and asked them to remind him to take the medicine again at midday, otherwise he would forget to do so. They simply needed to say, "Dan Cao, take your medicine after you've had your lunch." Dan Cao could take his medicine by himself and he knew how much to take. I've already taught him these things. I would have Dan Cao take the medicine again in the evening after I return from work. My father-in-law then said, "He's already over 20. Can't he take the medicine himself? Why do we have to remind him?" I told him that Dan Cao indeed would not remember, otherwise I wouldn't have asked them to help me remind him. I said a simple reminding would do. Yet he refused, claiming that was not their business.

Anger was burning in my heart at their unfair treatment of Dan Cao. After taking care of my father-in-law for 3 months, I decided to quit. Nevertheless, when my husband returned home during the National Day holiday, I still encouraged him to pay a visit to his father with Dan Cao. I said, "After all, he's your father, who gave birth to you and brought you up. I wouldn't mind if you do that. I am an in-law, an outsider. Go and take Dan Cao along. I'll get the fruit and nutritional supplements ready. It has just been a couple of months since your father had the major heart surgery. Go and see him."

After my son returned from that visit, he told me, "Mom, it was very strange. Obviously, Auntie still has cooking oil at home, but she asked Dad to buy a bucket of oil for her. She has been asking Dad to buy this and that for her. As a matter of fact, I can tell that she has everything in her house." I told him to stay away from us adults' business. I said, "Your dad hasn't been home for several months. It's okay for him to buy things for your old grandpa." My son said, "But Grandpa has a pension to live on. You've been toiling to take care of me, but even so, you don't tell Dad to buy things for you." I answered, "I can buy things myself and I am strong enough to carry them, but your grandpa is too old to carry things himself." "They are taking advantage of us," my son retorted. "Don't say that," I told him, "Who's going to take advantage of us? No one. We are young and we are not afraid of being taken advantage of."

Anyway, my husband was not in a good mood that day after he returned from his visit to his father, but he said nothing to me. Later when he was about to travel back to work, he told me, "You are set free now. They will not trouble us anymore." I asked why and he told me his father's words: "This is your last visit to me. You don't need to come any more. I don't want to see you, and I don't want to see Dan Cao." My husband has never gone to see his father ever since, and neither has Dan Cao.

Well, 11 years have passed. Later, his father sold his house and lived with his eldest daughter. In fact, my husband was making investments on the stock market at that time and he asked his father to buy and sell stocks on his behalf. Since the stocks were under my husband's name, his father could only do transactions but not withdraw money from the account. One day, his father had the documents related with the stock account sent back to us by express delivery, saying that he was not going to do transactions for us anymore. I called my husband. He told me to take

them and said that he would deal with them when he came back. A few days later, a former classmate of my husband's, who was on very good terms with my husband and worked at a notary office, gave me a phone call, informing me that my father-in-law had gone through notarization procedures to put his house under the name of his eldest daughter. I said, "Fine, as long as she treats him well. We can do without his property. We are not greedy and we rely on ourselves."

My husband has a sister who's been out of touch with us for more than 10 years, but now we've started to see each other again. She lives in Pudong. Four years ago, she took the initiative to visit us with gifts, and she apologized, "I am sorry about what I did to you in the past. I should not look down on you when your family is already in a pitiable condition." I replied very politely, "It is okay and we are fine. To us, Dan Cao is no different from any other kids, so you don't need to say that." Later, she invited us to her son's wedding. I did not want to attend, so I gave her 5,000 yuan as gift money instead. I don't mind restoring our relationship with them, but I would not take the initiative to have anything to do with them, either. Actually, it was no big deal that we started to see each other again. We would visit each other once during the Spring Festival and call each other once or twice on a monthly basis. To be frank, she had ulterior motives. Last year, she intended to change her registered residence into our address. You know she's already over 60 years old. Why did she want to do so? For the sake of our house. She had given her house to her son after he got married. If she registers her residence as our address, after we become old, she could take advantage of Dan Cao's ignorance to possess our house. She will definitely not treat my son well. She will send him to a senior care center. I would rather give away my house to the government because the government will take care of Dan Cao. I told her, "I cannot let you register at our address." Currently, my family is living a peaceful life with three of us registered under one household. I told my husband very calmly, "If that needs to be done, let us divorce first, with a notarized arrangement that the rear room of nine square meters at the back would belong to you and the front room of twenty square meters belong to me, so that Dan Cao and I will have a place to live. Then I would not interfere if you want to help her register her residence in our house. I will not put Dan Cao in their hands. I will definitely raise him by myself."

Last year, she called us unexpectedly, informing us that the eldest sister had sent my father-in-law to the senior care center. My husband readily accepted the fact. According to her, the eldest sister's husband had been quarrelling with my father-in-law all the time, and the reason was that they lost their patience taking care of him. I questioned, "But Dad is not confined to bed. Although he's over 90 years old, he is still well and able to take care of himself." She said, "They are tired of him at home anyway, so they sent him away."

My father-in-law has mentioned to her several times that he is missing us. I said, "What he really misses is not us, but the fact that I could take care of him. When I was attending to him, I helped him take a bath every day and I also cleaned his house. Now he has realized that there's no one to take care of him, so he wants me to do it again." Later, I told my husband to visit his father at the senior care center. My husband refused. I said, "Why, he's your father after all. Go and see him." My

husband told me, “If I go to see him, he will definitely want to come back with me, and then you will have to take care of him. Forget about it. There’s no point in doing so. You just make sure that you take good care of Dan Dan.”

Q: You are not in contact with relatives from your husband’s side. How about relatives from your own side?

Cao’s mother: We are on very good terms. My siblings and I are very affectionate towards each other. I have an elder brother, a younger brother, and a younger sister, who all give us a lot of care and treat my son very well. My sister buys clothes and other gifts for Dan Cao every year. This year, she went to Australia, but she got new winter clothes ready for Dan Cao before she left. I asked, “Why did you do that, for fun?” She said, “Well, I am just used to doing it. These are for his New Year clothes.” The nutritional supplements Dan Cao is taking now are also brought back by my sister from Australia. Since my parents have passed away, we have now inherited the new house allotted by the government as a result of the relocation of their previous residence in Huangpu District. I actually told my siblings, “I do not care. Divide the property as you like” My brother said, however, “Take it. You deserve it.” Some families will fight over these kinds of things, but not us.

My sister, being a businesswoman, is very busy. Therefore, her child lived with us, such as during vacations, when she was young. Dan Cao spent a lot of time in his childhood with my sister’s daughter, and he did not seem to be too different from her. We also bought her a lot of toys such as building blocks and toy cars. They had no problem playing together.

When my sister’s child came over, I would tell her, “Fruits are washed and ready for you kids to eat. When it’s time for lunch, please keep an eye on Dan Cao. Make sure that he does not eat too much. Dan Cao is heavily overweight, so his diet has to be controlled.” She did an excellent job. My sister’s child is actually 6 or 7 years younger than Dan Cao, but she was able to take care of him.

Q: Didn’t your employer know Dan Cao’s condition? What was the consideration behind your concealment of the fact?

Cao’s mother: Indeed, I didn’t tell them. Why? My husband was a section chief in the factory, not a high-level position but still an important one. In charge of the production line, he had to make sure that production tasks would be completed on time, otherwise he would be blamed by his boss. It was impossible for him to make everyone happy. That was why we decided to keep our situation a secret to avoid being mocked at work. My husband was advised to join the Communist Party, but we declined. However, they kept persuading my husband, so he finally submitted the application letter. At that time, you know, there would be a family visit for investigation purposes if you applied to join the Party.

Q: So you were afraid of such a visit, weren’t you?

Cao’s mother: They found it out when they visited us. Dan Cao was about 7 or 8 years old at the time. The visitors from the factory asked, “Why didn’t you tell us?” I said, “It’s not worth mentioning. I haven’t even told my best friends. None of my colleagues know.” There was a rather close friend of mine who once dropped into my house without notice. I was sitting with my son talking to him. She could tell after a while that it was not like communication with a normal kid, so she asked if

my son had a problem with his intelligence. I replied, “Why? No.” She complained, “You are trying to hide it, even from me.” I then said, “What’s the point of telling the world?” A few days ago, she called me saying that she wanted to come over to see my son. I said, “For what? He is no different from your daughter, two eyes, one nose, and one mouth. There’s nothing special about him to see.” She said, “Your son is a good boy. We would like to see him and spend time with him.” I replied, “There’s nothing special about him to see. He is fine.” Anyway, now some people know the condition of my son, hmm, but it was after we retired.

Q: So you rather rejected the idea of talking with her about this topic?

Cao’s mother: Right. I didn’t want my colleagues to know. At that time, my husband was working outside Shanghai. I never attended activities such as dinners at my workplace. I even gave away my rewards like free trips when I was elected a model worker.

Q: After your situation was known at your workplace, did you get any help?

Cao’s mother: No. At that time, my workplace was not doing well in business. The opportunity of receiving help was gone. There was a co-worker in my workshop that was said to have a kid in a similar situation. According to our leaders, he received subsidies every year. I said to them, “Would he make a fortune out of such subsidies? Apart from the fact that I don’t want you to subsidize me.”

Barred From School in Spite of Every Possible Effort

Q: What’s the consideration behind your sending your son to the kindergarten for normal kids?

Cao’s mother: It was time to enroll kids and my son didn’t seem that intellectually disabled at the time. He was enrolled through the normal procedure but was rejected by the school half a year later. He was also enrolled in elementary school through the normal procedure. The teacher visited us first and interviewed him. He answered the questions very well.

Q: Did he like going to kindergarten? Did he refuse to go the next day?

Cao’s mother: At first, he liked going, to elementary school as well. Later, however, after he was scolded and beaten by teachers, he refused to go.

In fact, when he was in kindergarten, we found that he might have a problem with his intelligence, but we were not aware that it was so serious. After he studied at the elementary school for normal kids for a month, the teacher told us that he could not write. He could manage to answer (questions), but he could not write at all. His brain just could not control his hands. Elementary schools usually teach Chinese phonetic alphabets in the beginning. The teacher advised us, “Teach him at home. You son is still not able to write the phonetic alphabet.” I said, “We’ve been teaching him all the time at home.” He was even beaten or scolded for that. Of course, we also gave him a lot of instructions on how to write. Every day, we held his hand (teach him to write) for 1 or 2 h, but he just couldn’t do it. Sometimes he also hated himself, and he would complain that his hand felt sore from being held to write for so long. I said, “Then you try to write on your own.” He said, “I simply cannot do it!” He is like this even today. His brain cannot control his hands.

Later, he leaked one day at school and was scolded by the teacher. After that, he was no longer willing to go to school. I said, “You still have to go to school.” He said, “He called me stupid, an idiot, a fool. The classmates also said I was stupid, too stupid. I do not want to go to school.” I frowned at his words, “If the teacher labeled you this way, you have to try harder.” Later, the teacher advised us to drop out of school. He said, “Your son cannot learn, nor can he control his bladder, and he cannot even write. Don’t you think he’s dragging our class behind?” The teacher told us to make him take an IQ test. Well, I remember he got only 57 points, while the minimum passing score is 60.²

According to the teacher, “You should try the schools for low-intelligence students. Such schools recruit students once every 2 years, not on an annual basis. You just missed their recruitment this year, so you won’t get enrolled this year. Next year there won’t be recruitment, so you have to wait until the year after next to register.”

Q: The teacher even scolded and beat him?

Cao’s mother: Right. Beat him and pinched him. He sometimes said to me, “Mom, I got this bruise because the teacher pinched me...” We would go to ask the teacher, but he would not admit it. He would say, “No, we never (beat him). Perhaps he got it by hitting something somewhere. How could it be that we pinched him?”

Once there was a kid nearby, who is still on very good terms with Dan Cao today. He told us that they saw the teacher pinch Dan Cao. You could do nothing about it, except burst into tears. You could do nothing... Sometimes we felt it so heart-wrenching that we let him drop out of the school to avoid being bullied.

Q: How did he get along with that classmate who was on rather good terms with him?

Cao’s mother: Now we do not see him often, but at that time he often came over to see Dan Cao. He did care about Dan Cao. He said that he was a very good and friendly guy. He is still very friendly to Dan Cao today when they meet, but we will not disturb him. After all, he is a normal person and now he is married and has his own kid. Dan Cao is a less intelligent person, isn’t he? As time goes by, we no longer have as much (contact)...

Q: Did he ever invite his classmates over to play?

Cao’s mother: No. At that time how could he (understand)... Now he will invite his buddies at the Sunshine Home to come over to play. He will also treat them with snacks.

Q: Did you refute at that time when your son was scolded by others?

Cao’s mother: Refute to whom? You spoke up only to be dismissed from school. The same thing happened in the kindergarten.

Q: So they kept him out of school?

Cao’s mother: They kept him out of school. At that time, there seemed to be little attention to this aspect. How I wished he could go to an elementary school to learn a few more characters. His brain could not control his hands, but at least he could

²According to the classification criteria adopted by the second national disability sample survey in 2006, people with intelligent quotient (IQ) of 70 and below are intellectually disabled.

recognize the characters. I kept paying visits to the Education Bureau and schools for people with intellectual disabilities, but in vain.

Two years later, we still wanted to find a way for my son to receive an education, so I went to the Education Bureau of Hongkou District on Wujin Road. My son had previously studied at Limou Elementary School. According to the Education Bureau, Limou Elementary School did not return my son's information to them, so I had to go back to Limou Elementary School to ask the teachers to do so first. Then I went to Limou Elementary School, but was told that they had submitted the information a long time ago. I went to the Education Bureau again, but they said they never received it. They were just trying to pass the buck. I suggested they could call each other to see which side or which step had caused the problem, right? Anyway, I went back and forth between the two organizations countless times. In the end, I was told to contact the school for people with ID by myself. The school was located within the community of Xing Fu Cun, near Dalian Road. I was told to find out where the school was by myself.

So I went to find the school, but the school said that they could not accept Dan Cao without the Education Bureau (proof), because "how could we know whether you are residents in Shanghai or from elsewhere?" I said that I could show them our household register to prove that we were local residents from the Hongkou District of Shanghai. "We cannot accept him. We only enroll according to the name list sent by the Education Bureau." Oh, so much buck passing. I took leave from work and paid visits to these organizations for more than a month. I felt really frustrated... Finally, I decided to give up. So he stayed at home.

Q: Without schooling, how did you teach him reading and writing? Using textbooks?

Cao's mother: No. I was very busy all day long, and at that time my mother was not very well. I had a day off from work every other day, so sometimes I would take him to my mother's house to be a helping hand. In the afternoon when we got back home, I would say, "Dan Cao, do some reading and writing, okay?" He would doodle on the books for a while. Tied up with housework, I had no time to supervise him, so...

We bought him so many comic books in the past, all of which ended up being torn apart by him...

Q: Have you ever given him any guidance on learning?

Cao's mother: Yes. Actually, my son has a very good memory. When he was young, we taught him some English words like apple, tiger, bicycle, soccer, etc. To be frank, my memory is failing as I become old. He still remembers those words clearly.

What he remembers, he remembers. He just could never learn how to write. Even today, he still cannot write his own name. I told him, "You have to know how to write your name." He said, "I cannot hold the pen."

Q: Has there been any training on his intelligence?

Cao's mother: Training? There were no such training schools at that time. We just taught him by ourselves. No special training.

Q: Later there was not much teaching at home?

Cao's mother: Not much.

Lonely Growth with the TV for Company

Q: Could you describe a typical day at home?

Cao's mother: A working day would be like this: My work usually started at six in the morning, so I had to leave home at five. I got up very early, sometimes around four o'clock, and then would prepare breakfast for the family. After that I would tell them, "Get up, wash up and then eat." Sometimes I would bring the laundry to my workplace. I worked in the canteen, so once cooking was done, I would do my laundry during the break. There was a washing machine in the canteen. After washing and spin-drying, the clothes would be carried back home and they would only need to be further dried in the sun. This could help save quite some time (giggles).

My work would finish at half past two and sometimes (would be earlier than that). Nobody at my workplace knew Dan Cao's situation, but I had pretty good relationships with my colleagues. Sometimes I would tell them that I had to leave a little early, in which case I would arrive home at two o'clock.

Q: When you left home for work, Dan Cao would not have got up.

Cao's mother: Right. My husband worked on regular shifts that started at eight. Before he left home at seven-thirty, he would see to it that Dan Cao had his breakfast. While we were at work, we would ask an old woman downstairs to take care of Dan Cao.

After Dan Cao dropped out of kindergarten, I first asked an old lady living on the ground floor for help. I said to her, "Auntie, thank you, please help look after my son." Since my husband worked on regular shifts, I would try to work on morning shifts, starting early and finishing early. Every day I would also bring some snacks from my workplace for her. I felt obliged to do so. In order to ask her to look after my son (giggles), I kept buying her gifts. Later she said because we lived in the same building she was too embarrassed to refuse me. I told her, "You could leave him alone. Just let him stay in the back room on the third floor. Go to see how he's doing every hour to make sure that he does not get into trouble or tamper with the electricity or gas. I will not pay one penny less to you. You will be paid the full amount." He was generally very timid, and would not mess around. However, I had to work for 8 h after all, so I still felt rather uncomfortable that nobody was home with him. After all, he was only 4 years old. She then agreed to look after him for me.

Later, however, the old woman on the ground floor refused to look after him anymore, because an accident occurred...

He grew up. When he was in his teens, he refused to take a nap in the afternoon. The old woman, however, needed to take a nap. She then let him sit beside the gate downstairs, telling him not to walk away. My son was very disciplined. He said yes and remained there. There was a boy a couple of years younger than him, who lived in the front section of the building. He ran over towards Dan Cao, called him a fool, threw stones towards him and then immediately ran away. He repeated this several times. Very sensitive to the boy's words, my son was really exasperated. He picked

up the stones thrown at him and waited. Unaware of this, the boy came over again and called my son a fool! Out of sheer anger, my son threw a stone at him.

That boy had thrown stones at my son four or five times but missed the target. Maybe hit his hands or feet, but that would not have hurt. My son, however, was prepared. He threw the stone and it hit right in the corner of the boy's eye. His eye became swollen right on the spot.

I was unaware of this because I was at work. Work finished at six and I got home at seven. After seven o'clock, that boy's father came to look for me. He avoided mentioning how his son bullied my son, nor the entire story. He simply said, "Your son threw a stone at my son today. My son's eye was hit and is now very swollen. We don't know yet if he will be blind or not in that eye." I said, "Oh my god, what shall we do?! You take him to see a doctor right now and I will be responsible for all the expenses, including the medicine prescribed. Now it's already half past seven. Since my son has intellectual disability, please do not hold him liable for that. I would like to quickly prepare some food for him to eat. I'm fine without a meal, but I cannot let my son starve. Please take your son to see the doctor first and we will rush to the hospital after my son eats his supper." Shanghai General Hospital is just across the street, you know, fairly close.

After I appeased that parent, I started to cook for my son. I blamed him, "Damn it! You've caused a lot of trouble today!" I could not blame the old woman on the ground floor, although she was supposed to be responsible for supervising him. She even tried to hide the truth. What she said was that "Your son was not behaving himself. He threw stones at others." I told her that I had brought up my son all by myself and the neighbor living opposite to us looked after him before as well. My son was known to be a very obedient boy. I was not trying to defend my son, but if he was not provoked, he wouldn't have behaved like that.

The next day, the two neighbors living opposite to us told me, "You don't need to pay that guy for his son's eye check-up." I said no, because my son was responsible for his swollen eye. The neighbors said, "Don't pay him a penny. We can be your witnesses. It was his son that called your son names again and again. We actually told him not to do it, but he still ran over to your son, threw stones at him and called him a fool. It just happened that when your son threw the stone, it hit him." I said, "Would that help? The old woman on the ground floor would not tell the truth. Are you going to be my witnesses in front of him?" They said, "We will be witnesses for you. We would speak up for you." Then two or three neighbors who witnessed the incident went to that boy's parents and said, "What a shame that you should ask Ms. Wang to pay for your son's eye check-up. Your son threw stones at her son five or six times. We told your son to stop calling names and throwing stones, but he continued to do so. Dan Cao finally threw the stone back because he was too exasperated to stand it any longer. And the stone he threw was the one that your son had thrown at him." After three or four people pointed this out to the guy, he seemed to be embarrassed, and he said that the old woman on the ground floor didn't tell him these things. She simply said that Dan Cao threw the stone. I said, "It does not matter. Let me know how much you paid for seeing the doctor and I'll compensate you for that." However, he was too embarrassed to let me pay the money. I felt really

bad hearing that someone else's son threw stones at Dan Cao, but I had no way to prevent it.

There was another old woman living on the second floor who was really very nice. She said to me, "There are many kids in my family, so I cannot look after your son, but I can keep an eye on him." Her daughter-in-law was taking sick leave from work during that period of time due to breast cancer. She helped to look after my son a little bit as well. On hot days she would say, "Dan Cao, come to our house and enjoy the air conditioning. Our house is a little cooler; your room at the back is too hot! If you get heat stroke, your mom would be worried sick." He was unwilling to go to their house. I asked, "Why not? Even to cool off for 1 or 2 h would be great." He said, "No, I do not want to go. Mom, my brain is not good. If I go to their house, they would give me the cold shoulder. I'd rather watch TV at home than go to their house. Leave me some cold water and I'll drink. Sometimes Granny would come upstairs and bring me some refrigerated green bean soup." That's why I have always been very grateful to her. She once said to me, "Wang, whatever nice things you've had in your house, you've given them away to me." "Yes," I replied, "because you've been so nice to my son, even nicer to him than to me, a lot nicer." You know we have logical thinking and are able to understand things, but he, being such a kid, doesn't understand much so he needs care. Oh my, I really feel sad when it comes to him (sobbing).

I bought a TV, but I did not buy a color TV for fear that it would be bad for his eyes. I purposefully asked someone to help me get a black-and-white TV for the back room. He watched TV all day long, but when he felt tired, he would take a break.

Q: He watched TV all the time from 7 or 8 years old till 20?

Cao's mother: Right.

Q: He watched whatever programs he liked?

Cao's mother: Generally speaking, I would help him choose the programs, but he would make his own choices as well. He usually would watch *Popular Old Songs*. He liked to watch singing programs.

Q: Has he ever offered to sing for you?

Cao's mother: He really enjoys singing. He knows many songs and singers, the names of which I have no idea (giggles).

There used to be a TV program *Popular Old Songs*. He really enjoyed singing. He would say, "I'll sing!" And then he would sing along with the singers in the program. He would say, "Mom, let me sing for you."

Whenever there were singing programs, he would say, "Mom, let me watch this. I'd like to listen." After that we would find singing programs for him to watch every day.

Q: Have you ever thought about developing his singing ability?

Cao's mother: Oh, this has never occurred to us (giggles).

Q: After you finished work, that is, after two or three in the afternoon, basically it would be you who took care of him?

Cao's mother: Always me. After I got home from work, I would help him a little bit with learning. Reading is fine, but when it comes to writing, his brain simply could not control his hands. He could not write.

His father would finish work at half past four. Since he took management roles in the company, usually there would be meetings for him to attend, so he would be home rather late. I would do the cooking. He wouldn't be home until after six o'clock when dinner was ready. Once he was home, he would help me to take care of the kid as well.

Q: When did he learn to take care of himself?

Cao's mother: Whatever things he was supposed to learn I have taught him, and he is now able to do it all.

He can dress himself, which he was able to do without being taught. After he gets up in the morning, he will fold up his quilt in the back room very well. When he comes home from the Sunshine Home, he will also change his clothes by himself.

Q: Does he help you with your housework?

Cao's mother: Sometimes, when we asked him to do so. When he came back from the Sunshine Home on weekends, I would tell him to help pick the edible parts of vegetables for cooking. He would say, "No problem, leave it to me." He would do things like peel green soy beans, which he can do really well.

Q: When was his father dispatched to work in Xiamen? He was away from home for a dozen years.

Cao's mother: Well, at that time the company was not doing well, so later... when Dan Cao was 4 or 5 years old, he was dispatched elsewhere.

Q: He was dispatched when Dan Cao was 4 or 5 years old, and he came back to work in Shanghai when Dan Cao was almost 20?

Cao's mother: Yes.

Q: A long time.

Cao's mother: Indeed, more than 10 years. After that, they wanted to dispatch him again to work in Baoding. We refused. I told him, "I would rather you be laid off than work there. I really suffered taking care of the family alone. You only visit us several times a year and each time you would stay only about half a month. He always travels by air, every 3 or 4 months, because he could never take his mind off us. After all, I was bringing up the kid alone, right? Let alone working at the same time.

Q: So you were actually always on his mind while he was away.

Cao's mother: Well, he would call us every day, every day, but sometimes we would not be at home. One day, somehow there was no electricity at home except for the kitchen area. What was I supposed to do? I could not get any help. I asked someone to fix the problem, but according to them, our house was too old for them to be able to fix; they had no idea where to reconnect the power. So I called him, but he said he could not help me, either, because "I have just taken leave for a family visit so no way to come back again." What could I do then? I had no choice but to have a very, very long wire connected from the back room to the front through a very long power strip, otherwise I couldn't even use the refrigerator. I told the repairman that I did not require anything else but that the power strip could ensure getting power to the refrigerator. What about the power supply for the rest of the house? For me, the power strip would be enough to support most of the power consumption in the front room. I could manage to do without the others except for a desk lamp. The power

connection was finally fully restored 3 months later after he came back home again for a family visit.

Q: You can't have no man at home to take charge.

Cao's mother: Indeed. Later he said, "I'll call my father to come over and take a look." I said, "No no no. Your father is rather weird and lukewarm to us. I would rather leave it as it is now. No big deal. Let us just wait until you come back." (giggles)

At six o'clock in the morning, I woke up Dan Cao, telling him to go to sleep in the back room because I didn't feel it was safe to leave the front door open. After all, I wouldn't be home for the whole day, right? Even so, our house was still broken into by that little guy who lived behind us.

Q: Oh, when?

Cao's mother: I went to work and I told Dan Cao to stay in the back of the house. It was around six o'clock on a cold morning, so Dan Cao fell asleep again, having no idea what happened. It happened just at that time (the thief broke into the house). In that year, the five-drawer chest happened to be on this side (pointing her finger to the position of the chest). I did not like to take furniture keys with me, so after I locked the first drawer of the chest, I put the key in the second drawer of the chest. There was a small window in Dan Cao's room, and that little guy climbed into our house through that window. Now my husband has blocked the window with boards (giggles). Those days, I did feel that the money I put in the drawer became less from time to time. He did not steal all the money in one go, because otherwise you would know. For example, if I had 5,000 yuan in the drawer, he would take 1,000 yuan. You would find it difficult to tell this to others, because people would say, "You jerk! How come the thief didn't steal all the money, only 1,000 yuan, with the lion's share still there?" You got me? I couldn't bring myself to complain about it, so I just remained a silent victim instead. I kept losing money, sometimes a few hundred and sometimes a thousand. He came in through the window and went out through the door after properly shutting the window and the door, so you had no idea that someone had entered your house.

After losing money for a period of time, about a few months, you know how we discovered it? It was time for the Spring Festival, and we were to celebrate my husband's 50th birthday before the Spring Festival. My mother said she had not bought a gift for my husband, but because my husband treated her really well, she would like to have the gold ring kept in the family melted to make a bigger one for my husband. I said, "No, let him buy it himself. He is able to make money in Xiamen." My mom said, "If you buy it, it's just something you buy. As for us parents, this is a small token of our appreciation." I then agreed. That day, my mother and I took the newly made gold ring back home, and I still put it in the drawer. In the evening, I called my husband to tell him that my mother prepared a big gold ring for his 50th birthday and it was already waiting for him in the drawer of the chest in our house. The next day, after I returned from work, I opened the drawer only to find it was gone. He came to steal again.

Q: So this was finally discovered?

Cao's mother: The theft this time was the most obvious.

So I cried and cried at home. Later, the neighbor on the second floor asked me why I had been in low spirits. "It seems that you have been in a bad mood over the past 1 or 2 months." You know the neighbor on the second floor had always been on very good terms with me. I told her, "I have a lot of things on my mind, but I dare not talk about them with you guys. Please don't get me wrong when I tell you what happened to me. In the past month or two, money has been disappearing from my house, though not in large amounts. For example, if I put 5,000 yuan in the drawer, the next day after I come back from work, I will find there's only 4,000 yuan left. A few days later, several hundred will be gone, and after a few more days, several hundred more will be gone. Can you believe that? If this was done by a thief, how come the thief would only take away 1,000 yuan? However, last night, I put a gold ring in the drawer that my mother bought for my husband, and today after I came back from work, it was gone." She said that I had to report it to the police. I said fortunately the receipt of the gold ring was still there. I was so stupid that I didn't even know how to report it to the police, because I had never had such an experience before. Finally, I called my younger sister, who accompanied me to the police station.

There was a police station administering public security work on Gaoyang Road. The police car sent me there to record my report in writing and I was reprimanded for failing to manage my personal belongings properly... They asked me who I thought was the suspect and I said I suspected it was that young man who lived behind us, Zhao.

Originally the entire third floor belonged to us, and it was acquired by my husband's grandfather with 52 gold bars from the Japanese. During the chaotic Cultural Revolution, one room was confiscated, but that was a very small one, only a little more than 7 square meters. This young man who lived behind us was from the countryside. I have no prejudice against people from the countryside, but he would even steal my son's money. My son had a savings box, and he liked to put it in his room at the back so that he could count the money in it whenever he wanted. I thought it was fine, because the highest value of the coins was 1 yuan, and the rest are 50 cents, 5 cents, 2 cents, or even 1 cent. Anyway, that was a large box of coins. How did we discover the money inside it was gone? Well, one day after I got the breakfast and other things ready for him in the morning and was about to go to work, I noticed that I had no 1-yuan coins in my purse to pay the bus fare. "Dan Cao, please give me 2 yuan from your savings box so that I can take the bus." After we poured out all the coins from his savings box, those 50-cent and 1-yuan coins were all gone. We could not even find any 10-cent ones. There were only 5-cent, 2-cent and 1-cent coins left. I questioned Dan Cao about where the money was. He said he didn't know. According to him, Zhao would count the money for him. "Each time after he counted the money, when I shook the box, I would feel that there was less money, but I have no idea how much less." That guy took all the 1-yuan and 50-cent coins away, as well as the 10-cent ones. At that time, he was studying at a vocational school. He seemed to be older than Dan Cao.

It was already seven o'clock. I couldn't talk with him about this matter any longer because otherwise I would have been late for work. After I returned from work that day, however, Dan Cao was in tears. He told me, "Zhao ate all my food today!" The

lunch I prepared for him that day was Yeung Chow Fried Rice, a combination of rice with sausage, egg, and green beans. I asked, “How did he end up eating it?” Zhao just put some white rice there. Dan Cao had his own tactics, though. He said, “I’m not going to eat that rice. I’m going to leave it for my mom to see! You ate my food.” Oh, I was really mad at this. I reprimanded Zhao, “You bastard! How could you eat Dan Cao’s meal? He starved for the whole day! If you like it so much, you could just let me know and I would cook more for you. You cannot just eat his lunch! He starved for the whole day!”

At the police station, I reported these two incidents. I said that I suspected he was the thief, because we had lived in the building for decades and no thefts had ever occurred. In the past, on hot days, we all slept with our doors open at night and no such thing had ever happened. That’s why I cast my doubt on him. His family were the only newcomers to our building. I didn’t discriminate against new neighbors, but ever since his family moved into our building, a lot of things have happened.

The young guy happened to have winter examinations to take at that time. The police said they would have to wait for a few days to start their investigation. It was probably not until the last day of his exams that he was directly taken away by the police from the school after he finished all his exams. This was the first time (he had got arrested), so he confessed everything. All the thefts were committed by him. Well, the police officers said to me later, however, “You are such a careless woman. He has stolen far more things from your house than you are aware of.” He had also stolen other things such as my husband’s big-brand shirts (giggles).

Q: You didn’t find out, did you?

Cao’s mother: No (giggles). According to the policeman, he also stole a pair of Parker pens from us—which were given to my husband by someone as a gift—and sold them. The receipt for that gold ring was still with me. That ring cost more than 3,000 yuan over 10 years ago, and he sold it for 700.

Q: What’s a typical day in your family like now?

Cao’s mother: Sometimes my husband and I will do some exercises on the balcony after getting up in the morning. After seven o’clock, we’ll wake up Dan Cao. Dan Cao leads quite a regular life. Every morning, he’ll go to the washroom first, and then wash up. After he finishes his breakfast, he goes to the Sunshine Home.

Q: Who takes him there, you or your husband?

Cao’s mother: Me, in most cases. But after I got burnt, my foot was burned by boiling water, although he still wanted me to take him there, I told him that my foot wouldn’t allow me to do it, so his father takes him there these days.

Q: Are there any disagreements between you parents when it comes to taking care of him, receiving treatment, and education?

Cao’s mother: Generally no. My husband always goes along with whatever I decide.

Q: Has Dan Cao ever expressed his appreciation for what you have done for him and his love to you?

Cao’s mother: Yes, he would say such things.

Especially to me, but not very often to his father. After all, his father was not home for more than 10 years. He just visited us several times every year and each

visit would last only a few dozen days. To me, he would (say), “Mom, you’ve done so much.”

Q: Do you feel especially happy upon hearing this?

Cao’s mother: Very, very happy. My son has grown up, after all (giggles).

Beaming with Joy After Returning to School

Cao’s mother: In the 1990s, due to poor business, the company I worked for was to be dissolved. My husband had been dispatched by the company to work as a manager in Xiamen. Then the boss suggested, “How about going to Xiamen together with your husband?” I said, “To leave my hometown as well? I’ve never lived there. Let me go to see the place first. If I can adapt myself to the life there, I’ll stay; otherwise I won’t. I have a requirement as well. I must bring my son along; otherwise it’s not going to happen.” The boss agreed, “Okay, you can go to see the place first.” So I went there and found that I felt comfortable with the air and food there. I asked Dan Cao if he would like to go to where his father worked and he agreed. So we stayed there for one and a half years.

In Xiamen, we met a director of the organization department of the Party committee at the district level. Knowing that our son did not have good intelligence, he asked us if we would like to take him to a local school. People in Xiamen were really different from people in Shanghai. They were very ... really very, very friendly towards my son. I told the director, “But my son has never gone to school, he was even abused by teachers and called a fool at school in Shanghai. My son feels inferior, so we are afraid to send him to school.” He assured me that the local school was very good, so Dan Cao studied at that school for about 7 or 8 months.

Q: Which school?

Cao’s mother: Pei Zhi School, which was a school for people with ID in Xiamen. He studied there for 7 or 8 months. I sent him there in the morning and picked him up in the afternoon. It was really a good school and the teachers were very good. My son got along with them quite well.

Q: I see. Have you been to their school?

Cao’s mother: Yes, I went to their school every day. I took him there and picked him up every day.

Q: What do they teach?

Cao’s mother: Well, Chinese, arithmetic, and also painting and singing. There were many foreigners there, and their school was frequented by the wives of Singaporean and American expatriates.

Q: Oh, did Dan Cao like the school?

Cao’s mother: Yes, he did. The school in Xiamen had one issue, though. There were also students with a propensity for violence.

After Dan Cao studied there for 7 or 8 months, I said that I did not want to send him to the school anymore. Dan Cao was already over 20 years old by that time, which was 10 years ago. Later, my niece got married, and my sister called to invite us to her wedding in Shanghai. So I brought Dan Cao back to Shanghai, but my husband stayed in Xiamen. I told my husband, “I don’t want to stay out of Shanghai for a long time, so I would rather remain in Shanghai with Dan Cao. You have been

working so hard away from home for more than 10 years, so look for opportunities to (come back) as well.” He came back to Shanghai a year later.

Afterwards, the company dispatched my husband to work in Baoding, but he did not adapt himself to the life there very well. According to him, Xiamen was fine, because he originally came from Ningbo, which had one thing in common with Xiamen: a lot of seafood. He was not, however, used to the lifestyle of the north. As a result, he stayed in Baoding for half a year and decided to quit. I encouraged him to come back and retire, so he quit his job.

Q: Dan Cao went to school in Xiamen for 7 or 8 months. Why was it discontinued?

Cao’s mother: Our household was not registered there... We actually lived there for one and a half years. My brother then called me, “If this is the case there (going to school), let me take you (through introduction) to Shanghai Children’s Home, where they also teach reading and writing. So, we went to Shanghai Children’s Home after we returned to Shanghai.

Shanghai Children’s Home was in the community of Xing Fu Cun, near Dalian Road. I asked Dan Cao if he wanted to go there, and he said yes. So I sent him there. In fact, he was already over 20 years old at that time, beyond the age limit for enrollment. My brother actually helped to let him in “by the back door.” After my son was enrolled into the school, the Principal once said to me, “Your son looks so neat and handsome, how come he would end up in here...”

He was at Shanghai Children’s Home for about 5 years. I was on very good terms with Teacher Tang and Teacher Ye at that school (giggles). We are still occasionally in touch with each other even today. They taught the kids singing, painting, and writing. I observed their classes. There were no teaching objectives for them to fulfill. They just taught the kids to do what they could do.”

Twenty years ago, I was already doing volunteer work, and was the Chairman of CAPIDR. Later, after the establishment of the Sunshine Home, community leaders came to talk to me, “Since you are the Chairman of CAPIDR, we would like to have your support, and you should send Dan Cao to the Sunshine Home.”

Q: What is CAPIDR?

Cao’s mother: China Association of Persons with Intellectual Disability and their Relatives.

I had been doing work for this Association before we went to Xiamen. At that time, no one was involved in such work in the community. A leader in community work contacted me. I had a full-time job back then and Dan Cao was only 16 or 17 years old. He did not go to school and stayed at home instead. The community leader told me, “You can obtain a Certificate of Disability for Dan Cao, but prior to that he has to take an IQ test.” I said okay, and took him to have an IQ test. After that, we obtained the Certificate of Disability.

Shortly after we obtained the Certificate of Disability, the leader contacted me again, asking me if I would be interested in working for the disabled. I said, “I know nothing about it because this field is totally new to me. Dan Cao has just obtained the Certificate of Disability, and I don’t even know what it is.” He said, “No worries. We can work together. Unlike others, you seem to be very caring about the disabled. You should go and look after them more.”

Afterwards, I was called to meetings at municipal and district levels from time to time. At first, I did not understand much, but gradually I acquainted myself with the work through experience.

Q: Why did you agree to go to the Sunshine Home?

Cao's mother: I agreed to go after some consideration... They had noticed that I had been taking very good care of Dan Cao. That leader said, "Many parents would reject their kids if they had such problems. Now at the Sunshine Home, there are also many parents who neglect their kids. Sometimes we would talk with these parents, telling them that they cannot treat their kids this way. As soon as a kid is born, it's a form of life, so we have to treat the kid well."

We had put (Dan Cao) in the Children's Home. There seemed to be foreign friends visiting them every day. Anyway, there were frequent interactions between them and foreign friends, twice or three times per week. He felt very happy. I told him, "The community has told me to support the work of the Sunshine Home. There are not many students in the Sunshine Home, so they recommend you go there." He said, "I don't want to go. I feel very happy at the Children's Home."

At that time, the Sunshine Home was newly established, and there were no meals provided. In each community there was a Sunshine Home and we belonged to the Jiaying Subdistrict. However, our house was the farthest away from the Sunshine Home of Jiaying Subdistrict. The street opposite to us belonged to Chuanbei Subdistrict. I said to our subdistrict leader, "It's not that I'm unwilling to send Dan Cao to the Sunshine Home in our community. It just that they have to provide meals, so that I can send him there in the morning and pick him up in the afternoon. At the moment, I have to pick him up at noon for lunch, and then take him back after lunch. I have to go to and fro four or five times a day, and each trip takes more than half an hour. I cannot do that. He is now very used to the life in the Children's Home." The community leader insisted, "You are the chairman of CAPIDR. There are a few students at the Sunshine Home in our community, so there's the possibility that it would be merged with another Sunshine Home in another community. You'd better transfer Dan Cao into it."

The Sunshine Home of our community was originally situated on Old Hongzhen Road, and it was later relocated to Tianbao Road. The community leader then told me, "We offer meals now." I said, "I support your work, and we will send Dan Cao over. There are winter and summer vacations at the Children's Home, so after the summer vacation starts, that is, from July 1, I'll send Dan Cao to the Sunshine Home every day until August 30 to have a try. Let's see whether he feels more comfortable at your place or at the Children's Home. If he gets used to life at the Sunshine Home, I'll let him stay and quit from the Children's Home. Actually, the Children's Home charges 400 to 500 yuan per month while your place is free of charge. However, we have to see which place he feels more comfortable and wants to stay at. I would never neglect my kid's feeling just for the sake of saving some money."

During the summer break, I told Dan Cao, "Today I will take you to the Sunshine Home to play with other kids. It's up to you to decide whether you would like to stay for half of the day or the whole day. At home, you always watch TV all day long. How boring is that. I have many things to do, such as cooking and doing laundry. I

don't have time to talk to you. At the Sunshine Home, however, there are many other kids. I will wait for you there, and I will be with you." He said, "I don't know them, and they will look down on me." He always says that people will look down on him. I told him that would not happen because the kids there were in the same condition as him. He agreed, "Okay, let's go then."

After he went there, the first day was fine, but the next day he felt awful. That was because the Sunshine Home was at the same venue as the Sunshine Psychiatric Garden, which was for people with mental disorders. He said, "Mom, I don't want to go..." I said, "Why? You don't need to talk with the kids in the Sunshine Psychiatric Garden; you can just talk to the kids in the Sunshine Home."

However, there were a few kids from the Sunshine Psychiatric Garden who kept looking for him to talk and to... "If they talk to you, do not reject them. If you turn them down, sometimes their mental disorder may recur in spring."

Even today, as the Chairman I am still lobbying to the community together with the Vice Chairman of our Association on this matter. I said, "You have to find ways to separate the kids with mental disorders from the kids in the Sunshine Home. It will be terrible if accidents occur." I did not propose this because I was the Chairman. In fact, I was also worried about the other kids, because you don't know when the disorder will recur—they appear normal when their mental disorder is suppressed. Yet if it recurs, it's hard to tell the consequences. The kids in the Sunshine Home were different. They won't attack others, physically or verbally.

Once, a kid's mental disorder recurred, and he punched Dan Cao twice in the chest. Dan Cao told me, "I was just sitting there watching TV. He came up to me and punched me twice." At first, Dan Cao didn't even bother to tell me, but when I was picking him up, his teacher had to tell me, just in case something went wrong later. The teacher told me to bring Dan Cao to the hospital if he felt his chest congested. I asked why, and the teacher told me that Cheng punched Dan Cao. I asked, "Why did he punch Dan Cao?" The teacher said, "Today Cheng's disorder reappeared, and we couldn't control him." In the evening, I asked Dan Cao if anything went wrong. He said he was fine, so I just let go of it (giggles).

Q: So for this reason, he didn't want to go to the Sunshine Home at the beginning, but later on he got used to it?

Cao's mother: Exactly. He got used to it later on.

Well, (I told him) not to be in contact with them too often, but he was sociable and very friendly. According to him, he felt bad rejecting people when they approached him for a chat.

Later on, after 2 months of staying there, he got used to it and got along well with the kids there. Therefore, I didn't let him return to the Children's Home, instead he stayed at the Sunshine Home.

Q: Does he go to the Sunshine Home by himself every day?

Cao's mother: No, I take him there. From our house, we need to pass Hailun Road and Wuhua Road, and then walk farther down a little bit (to arrive there). There are many cars on Hailun Road. What's worse, now there's the tunnel, and there is no traffic light, so I don't trust him going there alone. He always tells me that he is old enough, so I don't need to walk him anymore. However, I tell him that I (don't feel

comfortable). Once a kid from the Sunshine Home was trying to cross the street at Hailun Road, but he was hit by a car, and the car just drove away. How can I trust him going there alone? I feel concerned. That's why I take him there and pick him up every day.

Q: He has never been anywhere by himself so far?

Cao's mother: No.

Q: You always fetch him here and there?

Cao's mother: Yes.

Q: What are the daily activities for him at the Sunshine Home?

Cao's mother: On Monday, there's a singing class by the President of Little Apple Art Troupe; on Tuesday, there's an English class by a foreign teacher; on Wednesday, there's a painting class by an artist from the Art Association; on Thursday, there are lessons by me and Teacher Zeng; and on Friday, Teacher Zhou has now found a coach who will teach them how to play wisper ball (See Fig. 1).

Q: Quite some activities.

Cao's mother: We do have lots of activities at the Sunshine Home. I was there the whole morning today (giggles) to take them to watch movies. The Sunshine Home also organized for them to sing at Prince and Princess KTV in the afternoon.

Q: What do they do in addition to classes?

Cao's mother: Sometimes, the teachers at the Sunshine Home will teach them how to string beads, or do some simple handcraft work. However, Dan Cao is very clumsy. You know what has made me feel touched most? Once their teacher was teaching them how to string beads, and the smarter kids already knew how to make



Fig. 1 Dan Cao doing exercise at the Sunshine Home

artwork such as shoes. I said to the teacher, “Dan Cao (doesn’t even know) how to string beads. He can never get the beads on the string!” That teacher was very patient. He said, “Today I am going to teach your son, and we are going to have a competition later.” “How are you going to teach him?” I asked. He said he would teach my son to string one bead at a time. I doubted that Dan Cao could get the string through even one bead. You know why, I know my son too well. His brain can’t control his hand. So if you ask him to hold the string in one hand and the bead in another, and then get the string through such small holes, there is no way he would be able to do that. The teacher told me, however, just to sit aside and be quiet. He also mentioned that they had taught Dan Cao several times, and that Can Dan could already string a lot more beads. I was very curious to see. So I sat at another table, observing how the teacher taught him.

They each got a little basket. The teacher said, “Dan Cao, you are competing now. Try to string a lot of beads so you can come in first place...” Then, Dan Cao started to string the beads and it was this long (with hand gesture)—the string went through the tiny beads, one after another. I was so touched that I was about to cry (giggles). He never knew how to do that before.

I praised him! I told him, “Dan Cao, you are amazing! Now you can even string beads.”

He said, “I am really happy today, Mom. I got an award. I got a pack of liquid detergent.” We have stuck all his award certificates on the fridge.

Q: Does he tell you about what he does at the Sunshine Home after school?

Cao’s mother: Yes. Since we want to train his memory, I have told him to report to us what he has for lunch every day. Every day after he gets home, he would tell us what he ate for lunch, such as dumplings or noodles... I require him to even tell us the filling of the dumplings (giggles). Well, he is able to tell us that. I told him, “We ask this not merely for the sake of knowing. Make sure that you don’t give us the wrong information. I’ll call your teacher to check. You can’t fool us.”

Q: What will you do on days when you don’t go to the Sunshine Home? Do you go out to play?

Cao’s mother: Yes, we take him out to play sometimes. In fact, these kids are lonely; so are their parents. We like to organize parent–kid field trips. This time we organized with Teacher Zhou and parents from the Sunshine Home to go on a 3-day trip from the 15th to the 17th. There is a kid named Liu in the Sunshine Home, and his parents are both middle school teachers—one compiles math textbooks and the other teaches Chinese. I once asked the boy whether he enjoyed his recent trip with his parents. “It was boring...” he said, “I was on my phone for 3 days.” When I asked why, he said it was all old people who he had nothing to talk about with (giggles). So, Teacher Zhou proposed that we should organize our own trip with the kids, so that the kids can play among themselves. Later on, I said to Liu’s dad, “When you brought Liu on a trip, it was just old people, but this time we are going to organize our own trip. Are you coming?” He said of course he is (giggles).

In fact, the kids communicate a lot among themselves. They may even ask, “What is your father doing today?” “What do you eat at home?” “How’s your mom doing these days?” They will ask after each other and they care about each other.

Q: Does Dan Cao take the initiative to communicate with others?

Cao's mother: He usually doesn't talk to strangers. However, after he gets to know you, he would become extremely friendly.

He usually doesn't talk much. Once there was a kid with autism, but every Thursday when we gave them lessons, we would ask him to answer questions. Sometimes he didn't want to, and I told him that he couldn't be like that, because everyone had to answer questions. You know I wanted him to talk a bit more. Anyway, he took Dan Cao as his good friend. They could sit wherever they liked during lunch, but he always sat with Dan Cao. "Mom, don't underestimate Han. He is really good at table tennis," observed Dan Cao. "He may not talk with many others, but he is really on good terms with me. He calls me brother." Brother Dan Cao (giggles).

Q: That sounds good. Does he go with you for grocery shopping?

Cao's mother: He does.

Q: Then how about taking a walk?

Cao's mother: Yes. Sometimes I would offer to take him to the supermarket. "I'll go if you take me." He had unpleasant memories in his childhood, you know. There was a small store down in the alley where we lived. Sometimes I would tell him to buy a bag of salt or a bottle of wine for cooking and he ran such errands quite well. Every time he would ask me if there would be any change. We know the owner of that little store, so I would say, "Just give him the money, and if he gives you change, bring it back home." He did that kind of shopping at least a dozen times. At that time, he was very young, maybe about 4 or 5 years old. One day, I ran out of vinegar, so I said to him, "Dan Cao, take the money and go buy a bottle of vinegar for me. Today just a small bottle will do." So he went, but his money was robbed, just in the alley. I don't know where it happened. He just ran back crying, and told me that someone pulled the money out of his hand. I asked him if he knew the guy, and he said no. Anyway, he was traumatized. He's refused to do shopping for me since then. He would say, "No, I'll be robbed."

After the robbery, he refused to use money and he did not want money. Sometimes we would give him money, but he would refuse to take it. He said, "If I want something, I will let you know."

Q: Have you ever tried to help him get rid of this bad memory?

Cao's mother: Yes, but he just doesn't want to do shopping. If he wants something, he will say, "Mom, let's go to the supermarket to buy this or that." I would say, "Next time, you go to buy it yourself." Then he would say, "No, I won't go by myself. I'd rather not have it."

Q: Has he ever tried to work?

Cao's mother: No, he has never worked. He is not able to (giggles). He definitely can't work.

In fact, the Children's Home also ran a factory. Someone offered my son a job there, but I rejected their offer. Why? Because I know my son is bad at doing things with his hands. Other people don't know, because he looks perfectly fine by appearance. However, I am aware that he doesn't have the ability to do that. I told them, "I have visited the school-run factory, and every job is hand related, such as screwing nails..."

My son can't do such things. You guys don't know, he can't even write his name. His brain really can't control his hands."

Q: Do you think there are any aspects that the Sunshine Home could improve on?

Cao's mother: One thing that could be improved is that it would be better if it could be separated from those with mental (disorders). I always feel concerned: what if someone gets hurt?

Another thing is that hopefully, senior-care solutions could be offered to people with ID and senior nursing homes could be built for them. To be straightforward with you, people with mental disorders can be normal when they are not having their episodes. People with ID, however, are always muddle-headed. They are always at a disadvantage even if they are with people with any other type of disabilities.

I thought about having my sister's daughter take care of him, which should be a good idea. However, it's become impossible now, because she got married and is now living in Australia. She said she would try to take Dan Cao to Australia in the future. However, Dan Cao's nationality is Chinese and all of his connections are in Shanghai, so it is not possible. We are really worried about his life when he gets old.

Q: Have you thought about what to do in the future?

Cao's mother: I have discussed this with my husband. My opinion is that we have to plan well now. In the future, we are not going to rely on anyone. And if either of us two passes away first, the other one, even if still in good health, shall go to the senior nursing home with Dan Cao, and give all of our properties to the government. Why? This would allow Dan Cao a transition period to adapt himself. The two of us know him very well, but when we both pass away, he would be at a loss by himself. He is also very shy in unknown environments.

Q: Have you ever thought about him getting married?

Cao's mother: No, never. He has never thought of this, either. He is not like those kids who may have the urge when they reach a certain age (giggles). He's not like that.

Q: Do you have any other expectations on society? Do you have any other plans?

Cao's mother: Nothing in particular, but I do hope to set up a senior nursing home for them.

Q: Are you enjoying any national welfare policies?

Cao's mother: Every month he is entitled to 1,000 yuan as a subsidy for the severely disabled and unemployed, which is used for his living expenses. When we first obtained the Certificate of Disability, the subsidy was only 100 yuan per month. I remember there has also been a monthly subsidy of 280 yuan for 10 years. The amount has been gradually increased in recent years. A flush toilet has been installed for us. No extra allowances for us for holidays or festivals. Oh, there was an extra allowance of 500 yuan for the Spring Festival last year.

Dan Cao has had high blood pressure, maybe inherited from me, for many years. We check his blood pressure on a regular basis and he takes medicine every day. Now he's getting better. Starting from this year, his medical expenses can be reimbursed in full. Up till last year, it seemed the maximum coverage per year was only 800 yuan.

The Sunshine Home is free of charge. Lunch was offered for free in the past. Later on, though, there seemed to be complaints from other communities, so now we pay a little amount, but it is only 60 yuan per month.

Special Olympics Was Super Fun

Cao's mother: I attend the district-level council meetings twice a month. There is a director Teacher Zhou who proposed that we should make more effort to develop the intelligence of these kids. I suggested that we could organize a waist drum team. She asked how we could make it (successful) because even normal people don't know how to play the waist drum. She asked me (how to teach them). I said, "Let's do it one step at a time." So far, the drum team has enjoyed a history of more than 10 years. We really taught them by holding their hands to play the drums, bit by bit, and gradually they mastered the skill. So, Teacher Zhou said to me, "Wang, you are really impressive." (giggles).

I have always taken Dan Cao to participate in the waist drum team of Hongkou District. I also play the big drum for the team, because we as teachers have to lead the kids to play the drums. We first learned to play the drums by watching others play. Then we would try them out ourselves and ask others questions that we had. Finally, we were able to teach the kids by ourselves. At that time, the main purpose was to develop the children's intelligence by slowly improving their hand-brain coordination. However, even to this day, Dan Cao's coordination is still very poor. He is not good at this. Some kids can already play very well and they can even do some tricks, just like normal people. We have taught them these skills and tricks.

Q: Was this before or after Special Olympics?

Cao's mother: It was established about 2 years before Special Olympics. Later in 2007, we played waist drums at the opening ceremony of Special Olympics. During the first 2 years, we didn't expect that we could finally make it to the International Special Olympics to be held in Shanghai. We thought it was impossible for us. We just tried our best to provide them good training—to play in an orderly manner and be able to show off their tricks. Half a year prior to Special Olympics, we began to apply (to participate in the opening ceremony). We have a teacher who plays the cymbals while I am the big drum teacher. I would first strike the drum three times, and that teacher would then start to play the cymbals, "bang bang." I told the students, "You all have to play neatly so that we can apply (to participate in Special Olympics). If not, how are we supposed to qualify? There is a qualification test, as well."

Q: How do you train the waist drum team?

Cao's mother: The training was quite demanding. (In order to make it to Special Olympics), extra training was required. Sometimes we started the training early in the morning. The drum team was made up of kids selected from eight different communities of Hongkou District. On Saturday and Sunday every week, we would go to the District Committee (for training). Saturday and Sunday would be dedicated to waist drum training. On weekdays, there was also bowling training. We were very busy during that period.

Since there was no school on Saturdays and Sundays, we used the playground of Miyun School and we had training there for 5 or 6 years. During those years, the

neighbors made many complaints, because the noise was extremely loud when so many kids were playing at the same time. If they played neatly, it was somewhat musical. However, when they did something wrong and you were in the middle of teaching them, that type of noise was really annoying to the neighbors. Now we mainly do the training in a room at the District Committee with the doors and windows shut, lest people complain and regard us as annoying.

The TV station would always come and shoot to track our progress. Later on, when we were at the opening ceremony in the Shanghai Stadium, Kefan Cao, the host of the ceremony, said to me jokingly, “Teacher Wang, my ears were almost deafened by your drums (giggles).” I said to him, “I actually didn’t want to have you stand side by side with me—we are both so fat (giggles).”

Q: Did you train Dan Cao by holding his hands to teach him to play?

Cao’s mother: Of course. I could never teach him enough (giggles). Sometimes, he would get annoyed when we held his hands, so he would smash his sticks on the ground (giggles)! He would say, “Oh I’m bored to death! I don’t want to participate anymore and my hands are sore.” I would respond by saying, “It’s okay if you don’t want to participate, but don’t get jealous when other people are there—tons of people want to participate.” He would say, “Alright, let’s continue.”

We taught every kid bit by bit, with no exceptions. It was a time-consuming process. After it was confirmed that we would appear at Special Olympics, we not only trained on Saturdays and Sundays, but also every Tuesday as well. Sometimes we trained for a full day on Saturday and Sunday. It usually started at eight in the morning, with some water and washroom breaks in between. Sometimes, it would last until two or three in the afternoon. It was indeed tough.

For each extra day of training, we had to tell the teachers of each Sunshine Home in advance so they would prepare enough food for the students to come back for lunch. We gave them a break in the afternoon... You have to train these kids repeatedly, or they would forget everything the next day.

Q: When Dan Cao was with the rest of the kids from the district, did he make new friends?

Cao’s mother: Absolutely.

The kids were very happy when they were together. They would say hello to each other and would have lots of things to talk about. In fact, they sometimes communicate less with us but talk a lot more among themselves.

He would tell his peers “you played this wrong; it is supposed to be like this (giggles).” He sometimes would even say, “If you keep playing it wrong, my mom will tell you off again.”

Q: Has he ever complained that it was too tough for him to continue?

Cao’s mother: Yes. He complained it was too boring and tough. I said, “This is like nothing and you are calling it tough! (giggles)”

At the same time, he found it kind of fun as well. You know why? He got other kids playing with him. To be straightforward with you, these kids are lonely at home, right? Sometimes, when we gave them a break for half an hour, they seemed very happy and very relaxed—it was so much fun for them to play and talk with each other.

Q: Had you guys been to the venue prior to the opening ceremony of Special Olympics?

Cao's mother: We first went to train at the venue, and then we also rehearsed there about four or five times. The chartered bus of the DPF at the district level sent us there a few times, which we really appreciated. Sometimes after training elsewhere, we had to go to the venue to rehearse our positions. If that was the case, we would not be at home until 11 p.m., which was a very long day for the kids.

If the performance during rehearsal was not up to their standard, they would still reject you. Therefore, we would always remind the students, telling them that "you've been playing hard and you're very tired, but us teachers are actually more tired than you guys. We have to buy costumes and may need to add some patterns onto the costumes as well." At home, I borrowed two sewing machines and several teachers would come over and make changes to the costumes together.

Q: Did the kids say that they were nervous on the day of the actual performance?

Cao's mother: The kids did say they were nervous, but that was only for a short while (giggles). They were more excited than nervous, actually. Although they said they were nervous, after talking with each other, they would become excited again at the thought that they would perform on stage soon. Dan Cao said to me, "Mom, we cannot mess up today (giggles)." And he also said, "I know it. I will play a bit quieter, so I definitely won't mess it up (giggles)." He is pretty wise.

We were the first performance at the opening ceremony because waist drums are loud enough to enliven the atmosphere. When we finished our performance, we all went out and had dinner together.

On the day of the last official performance, my mom was already in a critical condition (sobbing). At that time, my family was very supportive of our performance at Special Olympics. My mother was critically ill and she was in ICU at the hospital for several days. My sister didn't even tell me about it. On the last day, my sister started calling me, but she couldn't reach me. She called my husband only to be told that I wasn't home... I got home at midnight that day. As soon as I got home, my husband told me, "Call your sister right now. She called you several times during the day, but she didn't tell me the reason. I did tell her that you took Dan Cao to perform." When I called my sister, she cried, "Mom has been seriously ill for several days. Please come over."

I went straight there that night, but before that I helped Dan Cao shower and then put him to bed. My husband offered to go with me, but I said no, "Dan Cao is home. If you come with me who will take care of him?" I called a taxi to get there. When I arrived, my mother was already unconscious, unaware of anything anymore.

My sister said, "I know you had to take Dan Cao to rehearsal and training for Special Olympics recently, so we didn't call you. Mom has been sick for a long time anyway. I know today is your last day, but I didn't know what time you'd be back, so I have been calling you." Sighs...

After the opening ceremony, my mother remained unconscious for a long time, and finally she turned into a vegetative state. When Special Olympics ended, the District DPF invited us teachers on a free trip to Nanjing in recognition of our efforts. I decided not to go because of my mother. My mother had given me most of her care

and help because of my son. She had never taken care of the third generation, she just helped me to look after my son. She would help me when I was at work. I had an amazing relationship with my mother, so it was impossible for me to leave her behind.

The waist drum team was like a non-government organization. We didn't make money or get anything else from it. We were all just volunteers and we tried to help each other. I was in the waist drum team for 10 years. Many kids were taught by us teachers step by step. Usually, we had to pay for the chartered bus of the District DPF. Dan Cao and I each had to spend 200 yuan on transportation. Finally, I decided to quit the drum team.

Q: Does Dan Cao still know how to (play the waist drum)?

Cao's mother: Yes, but he forgets things really easily. He will forget how to play the drum if he doesn't practice often.

Q: Did he participate in any games at Special Olympics?

Cao's mother: Yes, he participated in throwing balls, which he chose himself. Since I was the Chairman of CAPIDR of our community, I knew all the stories behind Special Olympics.

Q: How did teachers train him? Did he receive a lot of training at that time?

Cao's mother: I sent him to the bowling club for training. Since I was the Chairman of CAPIDR, I would take the students there with other teachers. I did not simply follow-up on Dan Cao, I took care of other kids as well. We have the responsibility of taking care of them all.

His teacher made him the team leader to get the other kids in line (giggles). I also took several kids with me, asking them to walk in line together.

Q: Would he look for you when he couldn't see you?

Cao's mother: Yes, he would. However, I told him, "You can't do that. I can't always be with you. You should stay here with your friends, I need to take care of the other kids, too." He said okay.

Q: How was time split between training and schooling at the Sunshine Home?

Cao's mother: We worked with teachers from the Sunshine Home to choose a few good kids for training at the bowling club. They would receive training for 2 h each day and at noon they would return to the Sunshine Home by bus for lunch. We had to pay the bowling club, so we asked the District Committee for help. I told them, "If you want us to qualify, please give us support. Otherwise how can we make it?"

The training lasted for about a month. There were two games a day, about 2 h in total. It was not cheap for a 2-hour training session at the bowling club. We advised teachers of the Sunshine Home to prepare some empty water bottles filled with sand for the kids to practice in the afternoon. The teachers followed our advice.

Q: Did the teachers take them outside of Shanghai for competitions? Or was it just in Shanghai?

Cao's mother: It was just in Shanghai. We were not good enough to get a ranking, so we didn't go to games outside Shanghai.

Dan Cao didn't make it to the International Special Olympics. He just participated in community-level games. Players for the International Special Olympics

were selected from the community. Dan Cao's performance was not as good as others. We had to make sure that only the best ones got selected. So, five kids were selected from our community and Dan Cao got eliminated (giggles). I said, "No worries. He was never guaranteed a place just 'cos he's my kid, it's okay."

You have to be fair when you work for CAPIDR. For example, there was a calisthenics competition every year. I would always tell them, "If Dan Cao is not qualified, don't put him in just because of me." There would always be gifts if you go to competitions at the district or municipal level. Because of this, some leaders in other communities would send their own kids to such competitions, whether they were qualified or not. In my opinion, that would literally drag the team down and I didn't want that to happen. We would make sure that only the best ones in our community would be selected. This principle also applies to Dan Cao. If he was not good, he was disqualified. People respect me for that. They said, "Teacher Wang, you are very fair." I replied, "I have to be. I won't squeeze my kid into the game just for the sake of some little gifts or benefits. I am not doing my job for that."

With no ranking he felt frustrated. His teacher told him, "It doesn't matter. Try harder next time." He said yes (giggles).

Q: Did he tell you about Special Olympics at home?

Cao's mother: Yes. He told me someone sweated a lot and he wiped tears off someone else's face.

Also, a kid tripped over because his shoelace was undone. Dan Cao helped him to get on his feet and dusted off his clothes. "I also comforted him, telling him not to cry," said Dan Cao.

In fact, he knows how to (help others). I often tell him that you guys need to help each other out. He remembers, and he knows what to do.

Q: Did he ever say it was tough and tiring and that he didn't want to go on anymore?

Cao's mother: No, he never said it was tough or tiresome. Sometimes he told me he was very excited. He liked this sport, thought it was fun.

I realized that he became more friendly when he was with his friends. He said, "Mom, I think it's a lot of fun when I am with them. We don't argue with each other." I said, "Right. Don't argue. You have to unite together (giggles)." I said that they have to be together like a family with no arguments (laughs).

Q: Has he enlarged his social circle? I mean, is he in contact with more people?

Cao's mother: Yes, we also want to help him to meet more people.

In fact, their circle is not big—it's rather small. They are only in contact with other people with mental disabilities. It is strange that they talk a lot more when they are with the same type of people and talk a lot less with normal people. He especially likes to spend time with his buddies at the Sunshine Home.

Actually, he likes to take the initiative in doing things. He likes to play with people of similar personalities. He likes to play with Cheng, Han, and Zheng at the Sunshine Home. However, there are also other types of kids at the Sunshine Home with whom he doesn't like to mingle. I just asked him about Lu. According to him, Lu is rather tricky, so he doesn't like to play with him.

Q: What do you parents think of Special Olympics?

Cao's mother: We think it is great.

We are happy as long as the kids are happy. Don't you agree? We do everything for the sake of him.

I believe Special Olympics can change them. It is true. Had there been no Special Olympics, they wouldn't have experienced so much, right?

Q: Do you think there are any areas Special Olympics could improve on?

Cao's mother: I feel that Special Olympics could be made accessible to more people. Those kids who are even less competent... They should be given the opportunity to participate, too. I don't have many suggestions (giggles).

Q: Are there any other sports activities that you wish your kid could participate in?

Cao's mother: I actually want him to participate in every activity. In fact, everyone wants their kids to try things out.

Q: If he had the chance, would he take the initiative and participate in these activities, or would you be the one to push him to participate?

Cao's mother: He would like to participate. Eh, sometimes it's down to the Sunshine Home's choice. If you are not good enough, they won't let you participate.

Interview with Dan Cao's Teacher

Interviewee: Teacher A

Interviewer and writer: Zhang Di

Interview date: December 7, 2016

Interview place: Sunshine Home of Jiaxing Subdistrict, Hongkou District, Shanghai

Teacher: Our Sunshine Home is the most active in Hongkou District. There are volunteers from Monday to Friday, as well as tons of activities. The kids here are really happy. Over the past few years, our kids have all made progress—in the past they would lose their temper at home, but now they can control it. For example, if he is happy at the Sunshine Home in the morning, he will also be in a good mood when he gets home. Take Dan Cao as an example. In the past, he always needed his mom to bring him upstairs, but gradually his mom would only need to bring him to the entrance and would let him come up himself. Now, he only needs to be brought to the crossroad, and he can walk here himself. Anyways, they have all made huge progress.

Also, our Sunshine Home is together with the Sunshine Psychiatric Garden, so the supervision is relatively strict. Our parents have set up an Association of Family Members and Friends, which even includes our teachers like our dance teacher and Teacher Zhou. If the parents have any concerns, they may first turn to the Association, and we will try to solve any problems, if we can. This also helps our communication. There are no such organizations that are free of charge in other countries, so parents there need to pay a lot.

Q: What do you think about Dan Cao's performance at the Sunshine Home? How does he get along with the other students?

Teacher: He does okay.

Dan Cao has severe intellectual disability. You may see that he cannot control his own actions. However, the progress is still huge. He previously came from the Children's Charity House where everyone there had severe intellectual disability. Technically he was not allowed to come here. People like him will only receive rehabilitation treatment. Students just take him as a little kid, because he doesn't understand a lot of things.

Q: How long has he been here?

Teacher: He came around 2007,³ during Special Olympics. He could only learn how to bounce a ball at that time. Even today, he can still only bounce it several times.

Q: He knew how to bounce balls after Special Olympics? Are there any other changes?

Teacher: His self-care ability has improved a bit. Unlike at the beginning when he didn't know how to wash bowls or cups, he has learned how to do these things after coming here. We can teach him a little bit of self-care.

Previously, it could be that other people were communicating, but he just sat there without uttering a word. Now, although people can't understand him, they still talk to him.

Q: Does he show interest in any particular things?

Teacher: He just likes to talk. When you sing, he also follows you, and these are all okay. However, he can't sing by himself.

Q: Why did he not bring paint today?

Teacher: Well, when it comes to paint, he doesn't know how to deal with it. We can't even teach him. He should stay home because of his severe intellectual disability.

Q: I heard from his mom that he was taught to string beads, and he has learned a lot of hand-related activities.

Teacher: For stringing the beads, you just use one string and pass it through beads. He has learned how to do it now. Previously he could not pass the string through the beads, but he finally has mastered the skill. We had to teach him by holding his hands and helping him do the job. We have to repeatedly teach him, and let him practice over and over again. For him, he can only learn by practicing repeatedly.

Q: Is there anything about him that leaves a deep impression with you?

Teacher: He can now do some laboring work, and is willing to. In the past, he was not willing to move desks, chairs and such, and he even asked others to fill up his water bottle. When he needed water, he just demanded others by saying, "Help me fill this up," exactly like a prince, but now he can do it himself. He is talkative. His mouth was not sassy before, but now it is. This can also be regarded as an improvement, right?

³Dan Cao came to the Sunshine Home in 2005. He participated in the qualification tryouts and waist drum practices etc. before Special Olympics.

Q: Did he have any arguments with his classmates? Based on his current condition he shouldn't have any major problems with his personality?

Teacher: It's just that... students with mental issues will tease him, and he will get mad. Sometimes he just attempts to fight back, but nothing else.

Q: Do you think he will stay long-term at the Sunshine Home?

Teacher: They can only stay at the Sunshine Home till they are 35 years old! If he can be like he is now in society, it is already pretty good. That is because his brain doesn't function well—if you ask him to do something, he will start to make noises. Can't do anything about it, because his brain can't control his actions and thoughts.

Q: In the future, he can basically only stay home or at the Children's Charity House?

Teacher: Yes, his parents have taught him things like how to sweep the floor, and that's all. You can't let him buy stuff with money, not possible. We can cook food or place the food on the table, but he can only pick the vegetable leaves. His hands are not able to do anything else.

Interview with Dan Cao's Classmates

Interviewees: Dan Cao's classmates

Interviewer and writer: Di Zhang

Interview date: December 7, 2016

Interview place: Sunshine Home of Jiaxing Subdistrict, Hongkou District, Shanghai

Q: Do you often communicate with Dan Cao?

Student 1: Sometimes we talk to him. It is just that he usually doesn't understand what we are saying. He is always like that, and he doesn't learn when we try to teach him. Sometimes he doesn't know the questions we ask him, so he simply does not answer.

Q: Are there any other things that he can do himself? Are there any aspects that are particularly good about him?

Student 1: His massages are very good. Back knocking and massage. He does back-knocking massage for our teachers. Yes, there are (good aspects). For example, he sometimes helps us girls. How to put it, it's a kind of feeling that is hard to describe. However, he can't do much, so at most we would let him give us a massage when we are sore.

Q: Does Dan Cao always sit by himself?

Student 1: Yes. I always have to go up to him to talk to him. Then he just gestures for me to take a seat in his room. I walk in, and he always finds me a seat even if I don't want one...

Q: Is there anything about him that leaves a deep impression?

Classmate 1: No... The only deep impression about him was that we let him bounce the ball, but he just couldn't do it. I learned how to bounce balls with him and

another student who also didn't know how to bounce balls. The other student and I have both learned the skill, but not him. Also, it always takes the teacher forever to get him to bounce the ball. "Dan Cao, you have to bounce the ball!" He just bounces it several times and stops, and then the teacher has to tell him again so he would continue to bounce the ball. When the teacher is not looking at him, he would just leave. Later, the teacher would ask for him again, because he would just stand at the back, and the teacher doesn't know. Sometimes we ask him, "Dan Cao, what do you want to eat in the afternoon? You have to bounce the ball in order to eat." However, when the teacher is not paying attention to him, he just won't bounce the ball. I don't even know what's up with him.

Q: Are you good friends with Dan Cao? I see you guys holding hands, right?

Classmate 2: Yes, we are both in the same class. We play games together.

Dan Cao: Xiaomou Huang, his name is Xiaomou Huang. He is tall, very tall. You got me? This is my new classmate. Well, he is very nice, and he always plays with me.

Q: What do you often do when you are here?

Dan Cao: String beads and bounce balls. I bounce balls.

Q: Will he come up to you or teachers to say hi?

Classmate 1: Sometimes yes, but very rarely. We always have to say hi to him. He will only say "Good morning teacher," and "Bye." That's all.

Student 1: He always makes an old man in the Sunshine Psychiatric Garden fill up his water bottle, and has been caught by our teacher multiple times. I don't think this is appropriate. He knows how to do it, but he doesn't want to, so he asks others to help him. I always tell him to do it himself.

Classmate 3: He sometimes will, or classmates will help him to fill up his water bottle. He massages very well. You can even ask him.

Dan Cao: Massage, I always massage my mom.

Classmate 1: He gives great massages.

Classmate 3: I sometimes help him cut his nails.

Dan Cao: We are all classmates. Have to help each other.

Interview with Dan Cao

Interviewee: Dan Cao

Interviewer and writer: Di Zhang

Interview date: July 18, 2017

Interview place: Dan Cao's home

Q: Were you afraid of staying at home alone when you were young?

Dan Cao: Yes. There were mice, this big (illustrating the size with his thumb and forefinger). I was frightened to death. I was afraid that the mice would bite me. I was afraid of caterpillars, mice, cockroaches, a lot...

Q: Did you ever want your mom and dad to stay home and accompany you?

Dan Cao: Yes! But they worked very hard, very busy, fully tied up. I was always at home, watching TV and playing games.

Q: Did you blame your mom and dad?

Dan Cao: No, how could I blame them? They were busy at work! What's more, Mom was always with me when I went to see a doctor or took medicine.

Q: Your grandpa didn't go to see you when you had surgery. How did you feel at that time?

Dan Cao: Sad. I cried, sad...I wanted to see him. How was his illness? I wanted to see this old man and take care of him...

Q: When Mom and Dad were not at home, you would watch TV alone. Did you want to go out and play with other children?

Dan Cao: Yes, very much. There was no place to go. How could I get out? No one would play with me. What should I do...

Q: Your mom mentioned that a guy once ate up your meal, you...

Dan Cao: I hate him. He ate up my meal. Unlucky, very sad. Isn't he a bad kid? I no longer play with him.

Q: Do you remember going to school? Which schools have you been to?

Dan Cao: Yes, the Children's Home...

Cao Mother: He certainly would not remember the elementary school, because he went there for only 1 month and then got rejected.

Dan Cao: Rejected. They did not want me. I stopped going to school.

Q: Do you like to go to school?

Dan Cao: Yes, how could I not like it. Too boring, and I could not concentrate during the class.

Q: Are you happy at the Sunshine Home? What do you do there?

Dan Cao: Yes. Walk there. Walk around and look around. Do some exercises. Handcraft work, singing, playing, playing cards, ball games, table tennis, wiser ball games, and so on.

Q: Do you still remember your participation in Special Olympics?

Dan Cao: Yes. I chose bowling, which is a very interesting ball game (hand showing a ball-gripping action). The ball rolls in and the bottles would fall.

Q: Did you find the balls heavy?

Dan Cao: Yes, very heavy, one kilo in weight, this big (hand gesture showing size). "Ping," you throw the ball over there and you make it!

Q: How was the training at that time?

Dan Cao: For bowling, first with bottles. We lined up on the training field to play one by one. Use your hand to get go with force. "Clatter"... you win when... fall.

The training of bowling was tough, very tough. I could hardly hold such a big ball and would drop it... Then I won. I practiced hard and I could finally hold the ball. I was not afraid of tough training nor did I feel tired. I was confident that I could accomplish the mission.

Q: Didn't you go to games out of the city?

Dan Cao: No, I was not chosen. No problem.

Q: Any other interesting activities that you took part in?

Dan Cao: Waist drum, the waist drum team! “Rub-a-dub,” playing the waist drum, so happy! A veteran player, among those who joined the team the earliest.

Q: How long did you receive training at that time?

Dan Cao: One year, one year and a half.

Q: Did you feel tired?

Dan Cao: Of course. I sweated a lot, and my waist felt sore and hurt. Such a long stick, and my hand felt too sore as a result of practice to hold it.

Q: Did you find it difficult to learn?

Dan Cao: Yes, you have to remember the new lessons, and you have to practice so that you could play it well. You have to. You have to play the whole (song).

The waist drum is this big (showing the size with hand gesture around the waist), and it is tied to your body by a red rope. All the players have to line up and I stand at the very front. You hit the drum once and then the team changes to X formation, and then you play the drum with T-shaped steps.

Q: What if you forgot what you’d learned?

Dan Cao: My hand would be hit by my mom, very painful.

Q: Did you ever think about giving it up?

Dan Cao: No way, I had to complete the task!

Q: Do you like playing the waist drum?

Dan Cao: Yes, I do. Playing waist drum (is) very happy. “Rub-a-dub,” the sound is so pleasant to the ear! Very happy and it makes me feel proud.

Q: Then did you feel it more fun or more tiresome?

Dan Cao: More fun. In my heart (I feel very happy), the kids play the waist drums together, enjoying time together, jumping, enjoying themselves, how wonderful!

Q: Would you teach new players who couldn’t play?

Dan Cao: Yes, or I would call teachers for help and... “Go to play.”

Q: Do you still remember the opening ceremony of Special Olympics? Was it exciting? Were there many people?

Dan Cao: Yes, I remember and it was exciting. There were many people, and every one of us appeared in the performance. We ran onto the field. We were the first to perform. We ran forward and then “rub-a-dub,” we started to play the drum.

Q: Do you think you played well in the performance?

Dan Cao: Yes.

Q: Do you want to take part in this kind of activity again? Do you want to take part in the Special Olympics Games again?

Dan Cao: Yes, of course! I do want to take part in it, but I have to play it well so that I could appear in the performance. It’s a sports event, so things have to be done right. Have to be good.

Observation of Dan Cao at the Sunshine Home

Observation date: 9:00–15:00, December 7, 2016

Observation place: Sunshine Home of Jiaxing Subdistrict, Hongkou District, Shanghai

Observer and writer: Di Zhang

Time	Activity	Activity of the observed
8:55	Staff members make preparations in advance	Watches at the side and greets other students
9:00–9:10	Do the “Ninth Set of Calisthenics to Radio Music” A parent volunteer, who’s concurrently the dance teacher, guides the students to do the calisthenics; students who know how to do it are put in the first row to demonstrate to the rest together with the teacher	Dan Cao goes to his usual spot and looks at the students in front of him. He stretches his hands and feet, and then looks around again. When he has eye contact with others, he immediately beams with a radiant smile He stands at the very back. When others raise hands, he raises his hands; when others stretch their bodies, he twists his as well. Soon he is not able to keep up with the rhythm, so he stretches out his arm or bends over at his own rhythm. His actions are not coordinated, but are done in a very serious manner. If he notices that someone is looking at him, he would beam with his signature smile and show his moves to them
9:11–9:20	Joint Exercise of 25 Moves	Dan Cao is still not up to the beat, so he moves at his own will. Sometimes he can manage to keep up with the teacher, but after a few moves, he would start to look at the ground or at someone else. He cannot focus. When the Joint Exercise is over, he quietly goes to get his coat by himself and then stands at the side watching the teacher teach a few students to dance. According to the teacher, only a few students can join the dance rehearsal. Dan Cao is not able to do these dance moves, so he doesn’t participate

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Time	Activity	Activity of the observed
9:20–9:30	The teacher brings a few students to play table tennis, and calls Dan Cao to join	<p>Very happy and keeps smiling, though he is just standing aside watching others</p> <p>Starts to look around again</p> <p>The teacher teaches him how to play. Mumbling “play table tennis, I don’t know how to play table tennis,” he takes the racquet handed over to him smiling</p> <p>He cannot extend his arm very straight, and when the ball comes he is not able to get it very well. The teacher holds his hand to play. He is then able to get the ball a few times. He is very happy</p> <p>After playing a few rounds, he decides to get off the court and stand to the side watching the teachers play</p> <p>He looks around, and suddenly stares at the edge of the wall. Then he picks up a string of wool. He wipes the dust on the wool like a little kid and then puts the wool back</p>
9:30–10:15	Seven or eight students are still rehearsing the dance with the teacher, and the teacher asks Dan Cao to watch them. Dan Cao stands at the back with other students, watching	<p>He is able to listen and follow the teacher, and stands there without moving randomly</p> <p>Talks with another student from time to time. The conversation is started by the other student and they are discussing the thickness of their coats</p> <p>Dan Cao shows his coat to the other student, and says repeatedly, “Wool, thick, not cold...” The other student tries to warm his hands by putting them at the side of Can Dan’s coat. Dan Cao shows no objection and they continue to talk from time to time</p> <p>Seeing that I’m writing, he asks me simple questions like “What are you writing? Why are you taking pictures?” He would take the initiative to talk to people he knows. Also, he would point his fingers at dancers to signal people to watch their dances</p> <p>He watches the dance quietly, and would occasionally come up with a topic for conversation, but only with a fixed group of students. Their conversation has been centering around “whether your coat is thick or not”. He would always show his coat to others and would smile whenever there’s eye contact with others. He rarely chips in when there’s a large group of people talking</p>
10:15–10:20	The other students finished rehearsing. Time for recess	<p>He takes his water bottle to get some water to drink, and then stands there with his bottle</p>

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Time	Activity	Activity of the observed
10:20	The desks and chairs need to be returned to their original positions	<p>He takes the initiative to help move chairs and desks. He is excited that he is able to help and tries to gather other students when walking, "Come on!"</p> <p>He is enjoying the work. He starts to run and appears to be very active</p> <p>Another student needs to move a desk. Dan Cao puts down his chair, and immediately turns around to help. The two of them lift the table together and place it in the appropriate spot. He rarely talks to the other student during the process but is very enthusiastic</p>
10:25	Dan Cao watches other students playing table tennis	<p>Would talk to other students, and is in a very good mood</p> <p>When the players do well, he would praise them by giving them a thumbs-up</p>
10:37	Lunch is delivered to the classroom, and everyone is ready to eat	<p>He follows the teacher's instruction to get his bowl and chopsticks ready for lunch. However, he seems a little nervous now and stands aside waiting when there are only a few students taking the food</p> <p>He gets his spoon. There aren't many students taking the food, so he stands silently not too far away and quietly watches</p> <p>When there are more students going to take the food, he goes up to get some</p> <p>He sits down in the last row. After he places his food on the table, he waits in the line to get soup</p>
10:45	Lunch time	Eats the food by himself, brings his lunchbox to the teacher, and washes the spoon
12:00–13:55	Recess	<p>Communicates with friends, and gets ready for an afternoon nap</p> <p>Takes his coat and blanket and rests on a few chairs</p>
14:00	After recess, time for class	<p>Puts away his own coat and stuff</p> <p>Doesn't put on the clothes previously taken off</p>
14:00	Art lesson: The Secret of Colors	<p>Dan Cao sits at the desk in the second last row beside the wall near the window. Before the lesson begins, he puts blank paper, pen and pencil case on the desk, and sits still with a pencil in his hand</p> <p>He stands up with the other students at the beginning of the class and they chorus "I know I can." He can't speak very clearly, but he knows to participate</p> <p>After clapping hands, he sits down and flips his blank paper over and over again. He lets the observer look at his stationery, pulls out an origami that he made himself and says to me, "Take it away."</p>

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Time	Activity	Activity of the observed
14:02	The teacher asks everyone to bring a rock to the next class for color painting	He is able to understand the teacher’s words and keeps repeating “I need to bring a rock.” The other students ask the teacher about any other requirements, but he doesn’t communicate with others
14:05	The teacher starts the lesson	He sits upright in his seat with his hands around his chest, looking around—seems to be attentive to the lesson Someone passes by the walkway, and his eyes follow him. When the teacher interacts with the students, he can respond, but he only talks to himself without effective interaction with others His eyes won’t stay on the teacher’s actions for more than 1 min
14:09	The teacher asks students to draw two balls of the same size	He does not draw anything, but sits there and stares at the teacher instead He starts to fiddle with the flowers on the windowsill Other students are able to find tools such as coins or use the bottom of water bottles to draw two circles. However, he does not move his hands. I don’t know why, but all the students have paint except him. He just silently watches others paint
14:14	Drawing	He watches the student next to him draw. The teacher is guiding that student on the next step. With a pencil in his right hand, Dan Cao stares at the blank paper in front of him, but apparently he is not in the mood for drawing. He does not put his pencil to paper
14:20	The teacher is helping others	His eyes follow the teacher and he flips the blank piece of paper in front of him. Sitting next to him is the student he mentions a lot, but still, he doesn’t take the initiative to talk with him When someone asks a question, he would turn his head and look towards that direction
14:30	The teacher gives a simple instruction asking students to stop	He puts down his pencil, but unlike other students, he doesn’t talk
14:32	The teacher explains the flavors that different colors represent With 23 students in the class, the teacher is not able to give enough attention to Dan Cao	He hears other students talk and repeats some words himself, such as “bitter coffee” and “lemon, sour.”

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Time	Activity	Activity of the observed
14:36	The teacher explains the flavors that different colors represent	He keeps repeating things based on common sense in his daily life. He also talks to himself with no intent to communicate with others Some students look at him, and he smiles back as a response When students in the rows behind him call his English name "Mark," he immediately responds to the
14:40	The teacher explains the flavors that different colors represent	Finally, he grabs a pencil and draws a straight line When he hears other students say something wrong, he would correct them; for instance, telling them that "lemons are sour." However, he doesn't make eye contact with anyone. He just faces the front and he would not take the initiative to start a conversation
14:43	Other students are cleaning up for the art class	He draws a rectangle and a few horizontal lines (copying the pattern of the observer's notebook) He looks around again
15:00	End of class	Stands up and claps his hands
15:03	Organize stuff after class	He organizes his pen and paper, and enters another room to get his bag. Then he sits at his desk, waiting for his dad to pick him up A student comes up to talk to him, and he starts to communicate with them He walks with a student in the classroom
15:10	Waiting for parents to pick up	When he hears other students say bad things about him, his mood suddenly becomes bad However, he is instantly happy again when a student mentions he is good at back-knock massage

Translated by Zheng Si.

Edited by Andy Boreham and Zijian Chen.

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A Square Dancing Celebrity



Peifeng Wang

Interview with Mr. LZ's Parents

LZ, male, born in 1983. The only child in his family. Level IV intellectual disability. Studied in a regular class in the Shanghai Jiangwan Junior High School and graduated in 1999. Enrolled in a subdistrict Sunshine Home in Shanghai in 2005. Transferred to another subdistrict Sunshine Home in the district in 2010.

Interviewees: LZ's parents

Interviewer and writer: Peifeng Wang

Interview dates: November 13, 2016 and January 3, 2017

Interview place: LZ's home

Born Amid Hardships

Q: How did you meet?

LZ's mother: We are both senior high school graduates of 1966–1968. After graduating from high school in 1968, my husband was sent down to work on a farm in Dedu County, currently Wudalianchi City, in Heilongjiang Province in 1969. I was sent down to a farm in Nenjiang Region (currently being incorporated into Qiqihar City) in the province a year later, that is, in 1970. We returned to Shanghai a decade later. Our classmates introduced us to each other in 1980. Thanks to a similar experience in Heilongjiang Province, we got along well and (fell in love) smoothly. We got married in 1982. We just started to work and were busy. We were eager to learn more to serve the country better.

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I majored in finance in a secondary technical school. As a result, the post in the Finance Department was in my field. On the contrary, my husband had done a variety of jobs before he served as a teacher and was selected to work in the Finance Department. I gave birth to LZ in 1983. I was at an advanced maternal age. I was sent down to work on the farm when I was 22. We got married at 32 and had a baby at 33.

You should know that life was not easy on the farm. My health may have deteriorated there. After returning to Shanghai, I had to work hard to make a living. Being underpaid, I could hardly make ends meet and restore my full health. At the seventh month of pregnancy, I could faintly hear the baby's heartbeat. I went to the designated hospital, the First Maternity and Infant Hospital, and found that the baby's heartbeat was slow. I thought that may affect LZ's brain development. I inhaled oxygen and the baby's heartbeat became normal. As a result, I no longer worried about the issue and worked as hard as I did before. I would never ask for leave. The Finance Department was busy. We focused on work and cared little about our state of health.

I gave birth to LZ in January 1983. It was actually a normal delivery. Prepotency was not publicized at that time. Babies were delivered naturally. I was at an advanced maternal age and exhausted. Nonetheless, the doctor encouraged me to have a natural birth. I was in great pain in the process. It might have also affected the baby. My water broke before labor started. As a result, LZ lacked oxygen during his birth. He did not cry the moment he was born. The doctor slapped his back and he started to cry. The doctor was relieved. LZ behaved normally after he was born. I stayed at my mother's during postpartum confinement. LZ grew up gradually and learned to talk later than other kids did.

My mother reassured me that it was normal for baby boys to learn to talk late. We did not pay attention to that, either. Both of us were inexperienced. LZ was our first and only child. No one could take care of LZ. I have three siblings. So does my husband. Our parents were too busy to give us a hand. We had to work hard during the day. As a result, LZ was babysat by our neighbors, a couple in their fifties or sixties. They kept taking care of him until we moved when LZ was in Grade Three. They treated LZ well. We did not notice anything abnormal about LZ. He talked little but could speak Shanghainese fluently.

LZ's mother: He went to school at school age. Learning to talk late, he barely spoke at the nursery. The teacher might ask him whether he had pooped. If not, he would be required to poop in the bathroom. He did not cooperate and cried violently. He was hard to handle. Nor did he have regular bowel movements or was capable of self-control. He could not remember homework and reacted slowly in kindergarten. LZ had a tough time from the nursery to the elementary school.

Q: What about LZ's state of health in his school time?

LZ's mother: He was healthy.

Q: He didn't get sick easily when he was small, did he?

LZ's mother: That is true. It was easy to look after LZ when he was little.

Confronting Reality and Finding Out the Truth

Q: When did you suspect that LZ may have an intellectual disability (hereinafter ID)?

LZ's mother: His teacher from kindergarten remarked that LZ could hardly string two coherent words together. His brain was not developed as well as his peers. Two of my close friends also mentioned that LZ might be reacting slower. Moreover, he learned to talk late. All of these pieces of evidence indicated that LZ had an ID. We were not highly sociable at that time. We thought the condition would improve after LZ grew up. Our parents also thought that boys (learn to talk) late. (All will be well).

We started to notice that something was wrong with LZ when he enrolled in elementary school. LZ was able to read and write Chinese characters. He could also memorize math formulas. However, he could not solve problems requiring logical thinking such as word problems and mixed basic arithmetic operations. For example, he could not work out a formula for a word problem. I tutored him at night. Still, he could not do that. I was exhausted and scolded or beat him.

LZ's father: He barely passed Grade One and Grade Two. He fell behind obviously in Grade Three. I noticed that he worked hard. Other kids might be naughty and not (perform well). LZ could get down studying. However, he could not think logically and solve problems. After a long while, my wife got impatient and scolded him. However, it was useless. With great reluctance, I started to suspect that LZ had issues here (pointed at his head).

Q: You realized that LZ may be with ID?

LZ's mother: Yes. LZ performed poorly in arithmetic. The teaching process was much slower back then. Students made progress step by step. LZ could not solve word problems in Grade Three. Nor did he perform well in the test required in order to transfer him.

LZ's father: I was the first to suggest that he be examined.

LZ's mother: My husband suggested going to the hospital. I agreed. We had him checked twice. The first time was in 1994 when he was in Grade Four. He stayed at my mother's, which was located near the Children's Hospital of Shanghai.

LZ's father: It would be troublesome if something was wrong with this part (pointed at his head). I was unwilling and restless with anxiety to think of the issue. However, I had to face it and find out the truth via scientific means.

Q: LZ's case was confirmed in 1994, wasn't it?

LZ's mother: That is correct. He was examined at the Department of Children's Healthcare at the Children's Hospital of Shanghai. On seeing the result, the pediatrician remarked that what LZ achieved was below the normal value. Here it is (shows the result of the Wechsler Individual Achievement Test). LZ got 44 points on average. He got 55 points in language and 50 in manual dexterity. Nonetheless, the pediatrician also mentioned that it was too early to reach a conclusion. LZ was little. He might go backward and be slow to understand things. We were asked to talk more to him and teach him patiently to help him grow faster.

Q: Did you see doctors far and near after the examination?

LZ's mother: Of course. Some doctors commented that LZ could not learn due to the attention-deficit hyperactivity disorder. LZ took a variety of brain supplements such as Naolijian. However, he had issues here (pointed at her head). These supplements did not work.

Q: Did you realize that LZ might be with ID?

LZ's mother: You may say so. We were embarrassed and tried to solve the issue by ourselves. We didn't want to accept the results and were unwilling to tell others about it.

LZ was in Grade Five in 1995. He fell behind even more along with more courses he had to take. His math teacher told my husband that LZ might affect the class's enrollment rate as a whole. She wanted to take LZ to the hospital to test his IQ so that she could explain the situation to her boss and exclude LZ's performance in her assessment. That was also what my husband wanted. We had done it the year before. We wondered whether the situation would improve a year later. As a result, accompanied by the teacher, my husband took LZ to Xinhua Hospital.

LZ's father: LZ fell behind apparently in math. In fact, he worked hard and was well behaved while the teacher paid more attention to him. However, the results remained unsatisfactory.

In comparison, his performance was acceptable with respect to English and Chinese. LZ managed to move up to the next grade. Some students failed to pass exams and stayed down. The math teacher tutored LZ because she had dealt with students reacting slowly. She worried that LZ might affect the class's total enrollment rate. After all, it was the criterion applied to assessing a teacher's performance.

I told her that LZ had been tested the year before. The result showed that he reacted slowly. I wished that it was because he grew up slower than his peers did. In the current case, I had to ask the teacher to be more patient with LZ. She thought that we were reasonable. Some parents might not cooperate. She didn't know that I was (open-minded) and had already taken the initiative to have LZ tested.

I also told her that it was too early to jump to a conclusion. The doctor remarked that the test result was for reference only. She commented that it was rare to see parents as reasonable as me. She was glad that I actively cooperated with her. In fact, both of us wanted to find out the truth. She suggested that we go to the hospital together to have LZ tested. I was happy to. The result from the second test might be more convincing than that of the first one. Moreover, we were to go to the Xinhua Hospital, which was renowned for the treatment of pediatric diseases.

Children could have IQ tests on certain days there. I could not recall the specific date. A female pediatric specialist wearing glasses asked me about LZ's condition. Then she took LZ into a room to test him. We waited outside.

After the test was done, the specialist talked with me alone. She was nice and wondered whether I took LZ to be tested voluntarily or under the requirement of the teacher.

I told her that both the teacher and I wanted to find out LZ's state of health. The specialist understood me. She said that many (parents) were against taking their kids to be tested at the hospital. They complained that some teachers have children tested for their own purposes. Some teachers even took children to the hospital without the

parents. I explained that I was okay with the situation and just wanted to learn about LZ's state of health.

Hearing that, she told me that something might be abnormal about LZ's brain development. Nonetheless, the symptoms were mild. I mentioned that LZ was in Grade Four. She commented that our family must have worked hard jointly so that LZ could go this far. She said that she would explain the situation to the teacher separately.

I asked for advice. She prescribed traditional Chinese medicine benefiting brain function and asked me to have LZ examined a year later. The medicine cost as much as over 1,000 yuan per month or half a month. I can't remember clearly. We could only earn over 100 yuan per month. We were under great pressure.

LZ's mother: A course of the treatment lasted for about 3 months. We could not afford that.

LZ's father: The cost was 1,000 yuan for 3 months of medicine. LZ might have taken the medicine for a whole year (thinking back).

LZ's mother: That is true. We had (little) savings. I used up the money my mother had given me.

LZ's father: LZ accepted a course of the treatment and was tested again.

LZ's mother: The medicine worked slightly.

LZ's father: Slightly.

LZ's mother: The improvement was not obvious.

Q: Is there any relative in your families that is with ID?

LZ's mother: No.

Q: For generations?

LZ's father: No one in our families suffers from it.

LZ's mother: It might be because we have overworked or suffered from malnutrition when being sent down to work in Heilongjiang Province. However, we have ensured sufficient nutrition for LZ.

Q: How did you handle it after knowing the truth?

LZ's mother: We were anxious but had no solution. Back then, we would be off duty after six o'clock in the evening.

LZ's father: We depended completely on ourselves.

LZ's mother: My father-in-law had passed away long time ago. My mother-in-law and my parents were too old to (take care of) LZ.

Busy Working Hard at School

LZ's mother: On seeing the result of LZ's IQ test, my husband suggested enrolling LZ in a special school. Miyun School, a special school, had been established in this district. My husband asked around and was informed that the school only admitted students at Grade Three or lower. We had no other solution but enrolling LZ in a regular class and leaving things to chance.

Q: What subjects were available in the elementary school?

LZ's mother: They may have included Chinese, math, English, PE, music, history, and geography. They used to be easier and less complicated in comparison with those given now. LZ could still tell what he has learned from geography courses.

Q: Which one was his favorite?

LZ's mother: English. He was also good at Chinese.

LZ's father: Memorization is (significant) to learn English well.

Q: Was LZ good at English?

LZ's mother: His performance was satisfactory with respect to English. I focused on tutoring him math.

Q: Was math the most challenging subject for LZ?

LZ's mother: Math it is. He has performed increasingly poor in math.

LZ's father: He could not think logically.

Q: What was taught at math courses?

LZ's mother: Basic arithmetic operations.

Q: Did the teacher teaching math treat LZ as well she had done after accompanying you to have LZ tested at the hospital?

LZ's mother: She was under less pressure and pressed less hard on LZ. However, LZ was a point from passing the math exam to be admitted to the middle school. He had to stay down and repeat Grade Five.

LZ's father: LZ is with ID. The teacher might go (too far) to fuss about one point. LZ used to get along well with his classmates. After he stayed down, he was known as the student who stayed back. It would hurt a kid even if it was merely one point.

LZ's mother: LZ could not go up to the next grade if he only got 59 points in the exam. The headmaster asked to let LZ stay down. I have come around. After all, LZ failed to lay a solid foundation for further learning.

Q: What about his Chinese?

LZ's mother: Just so-so. LZ could not write a composition independently. He would pass the exam by memorizing one.

Q: One has to understand the topic before writing a composition. Was it hard for LZ to comprehend the topic?

LZ's mother: Of course. Only 30–40% of the content at most would meet the requirement.

Q: Did you mean that he could not complete the composition or digress from the topic?

LZ's mother: He could hardly stick to the topic.

Q: Did he stray from the point easily when writing a composition?

LZ's father: His composition was illogical.

Q: What about vocabulary and reading comprehension?

LZ's mother: He could do word dictation and complete reading comprehension. However, he was impatient to listen to you reading a book from cover to cover. He liked recitation but couldn't write a composition.

Q: Was the handwork course available at elementary school? Would LZ perform better at the course?

LZ's mother: Not at all.

LZ's father: He might bring the homework home and my wife gave him a hand.

LZ's mother: Exactly. LZ could only complete a rough handwork and I helped him to process it into a delicate one.

Q: Did he perform well in any of music, PE, and drawing courses?

LZ's mother: His performance was acceptable but inferior in comparison with that of normal students. He performed worse in PE because he spent most of the time in finishing his homework.

Q: Did you merely tutor LZ as a way to accompany him at night?

LZ's mother: We had to. He could not follow teachers in class. We had to teach him again at home after dinner. He probably sat by the desk steadily with a pen in his hand. He (seemed to be) studying but actually just dawdled. I tutored him math and my husband Chinese. We did not go to bed until he completed all of the homework. He was cooperative and tractable and memorized content he was required to.

Q: Did you train LZ specially when he was medicated?

LZ's mother: No, we merely tutored him. He might take a break on Saturday or Sunday. We would accompany him to go to the park to exercise when the weather was good during spring and fall.

LZ's father: He was not pressured and had to do a small amount of homework. Back then, students would merely need to pay attention in class to perform well in exams. They did not go to various tutoring institutions.

Q: Did LZ like to play?

LZ's mother: He loved to when he was little. However, he had to do homework first.

Q: What would LZ do after having dinner and completing his homework?

LZ's mother: He would read. We also bought him toys. However, he didn't have time for them. I recall that he spent all his time on doing homework while his peers played after doing homework.

Q: Did LZ ever agonize about that and want to give up?

LZ's mother: No, he didn't dare.

LZ's father: He suffered internally. When my wife scolded LZ, I thought that I had been way naughtier in my childhood. On the contrary, LZ worked hard. Why couldn't he perform well? As a result, I put forward first the suggestion to have him examined. It was useless to punish LZ if we didn't know the reason of his poor performance.

Q: Did LZ work hard because he realized that he performed worse than his peers did or merely because he was asked to?

LZ's mother: He did realize that. He may have been bullied, but he didn't tell anyone. For example, he would not tell us even if he was hurt (at school).

LZ's father: In fact, it was common among boys.

LZ's mother: He was (aware of) that (but) could not answer back. He would merely take it if he was called stupid. LZ never responds even if we talk tough. Nonetheless, he will talk to me if anything occurs at the Sunshine Home. He does not communicate with his father much. Nor would he obey his father's instructions sometimes. I told him that he should not put up with everything alone. I asked him to communicate with parents and teachers in time. Being the class monitor at the Sunshine Home, he needs to report problems in the class to teachers and get along well with classmates.

Q: What about his performance after repeating Grade Five?

LZ's mother: The situation changed slightly. He could barely write an eligible composition and perform moderately in Chinese. Regarding math, I asked him to solve all types of word problems and memorize them. It was the only solution. He has a good memory. That is how he could get 80 points in English. In the end, he got 67 in the math exam and enrolled in the Shanghai Jiangwan Junior High School. It was possible that some word problems he had memorized were exact test questions.

Finishing Middle School Smoothly, but Discouraged at Vocational School

LZ's father: Many students might fail the law and morality course in middle school. However, LZ could memorize the whole textbook, which impressed his teacher. He could also memorize a speech rapidly. His good memory could at least mitigate his shortcomings in other aspects.

LZ's mother: He met a nice teacher in Shanghai Jiangwan Junior High School. The teacher would teach him patiently and ask other students to treat LZ well. The class director treated LZ better. We explained LZ's condition and entrusted LZ to him. He felt pity for us. I gave birth to LZ at an advanced maternal age. He was honest and understood our difficulties and paid special attention to LZ.

Q: Which subject did the class director teach?

LZ's mother: He taught politics.

LZ's father: That is true. He just started to work at that time.

LZ's mother: We still think about him now.

Q: Was LZ interested in the politics course because of him?

LZ's mother: He could basically recite content taught in the course fluently. The teacher liked him. LZ took care of others, which (surprised) the teacher.

Q: Did LZ study in a regular class in middle school?

LZ's mother: He always studied in a regular class. He was also tutored by teachers after school. As a result, he was able to (keep up) and perform (moderately).

We may have worried less if he had enrolled in a special school at first. However, LZ could not learn so much. At the special school, teachers would hardly teach anything. They merely (make do) and organize students to do some handwork. I have been a teacher at the CAPIDR¹ for over a decade. Students graduated from the special school differ greatly from those graduated from the regular school. For example, students who graduated from Miyun School were less educated. They could not do basic arithmetic operations, causing great inconvenience to them in their daily life. The school has been irresponsible.

Q: Except for academic achievements, do students studying in the regular class also have an advantage in respect of social communications?

¹Association of Persons with Intellectual Disabilities and their Relatives.

LZ's mother: Certainly. Students from the two types of schools behave completely different when communicating with others.

LZ's father: But the academic pressure is also huge in a regular school.

LZ's mother: LZ might be pressed hard regarding his studies. The silver lining is that it is easier for him to fit into society after graduation.

Q: How did LZ get along with his classmates at school?

LZ's mother: Well, he made several friends in his class and did homework and played games with neighborhood kids.

Q: Did LZ have any close friends?

LZ's mother: Yes, several honest boys. We have kept a close eye on him. On one hand, he had to do a mountain of homework. On the other hand, he didn't have any pocket money.

Q: LZ would rarely have conflicts with others, right?

LZ's mother: He would never take the initiative to have words with others. It was the other way around. I was fully aware of that. In that case, whenever some students blamed LZ for a quarrel, the teacher would assert that it was their fault.

Q: How many years did it take for LZ to finish middle school?

LZ's mother: He spent 5 years in elementary school and 4 years in the preparatory class in middle school.²

LZ's father: Back then, we were advised by the teacher to not apply for a (Disability) Certificate for LZ, which would be unfavorable for LZ. We did it later. It was all right that LZ didn't go to a college. He could still learn cooking and make a living.

LZ's mother: Previously, people like LZ were looked down upon. Currently, the situation has changed along with social progress.

Q: Did LZ learn cooking after graduating from the middle school?

LZ's mother: In fact, LZ only got a Middle School (Diploma). Later on, he enrolled in Shanghai Chunshen Tourism Secondary Vocational School.

LZ's father: His performance was too poor to enroll in high school. (The teacher) persuaded us to apply to this vocational school. LZ would certainly (do that) because he had no other option.

Q: Did LZ pass the entrance exam and enroll in the vocational school?

LZ's mother: Of course.

Q: Is Shanghai Chunshen Tourism Secondary Vocational School a regular school or a special one?

LZ's father: It is a regular school admitting students with poor performance.

LZ's mother: The school has also admitted deaf students. LZ met the minimum age requirement to go to the vocational school but was weaker in his performance. A chef needs to chop vegetables. We were asked to prepare two kitchen knives to let LZ practice cutting potatoes and meat into shreds. However, LZ failed and cut his finger. Being not interested in it, he skipped school several times and quit.

²The 9-year compulsory education system is the "five-four system" in Shanghai. Students are taught in elementary school for 5 years and 4 years in middle school. Grades in the middle school include the Preparatory Grade, Grade One, Grade Two, and Grade Three.

Q: Did he tell you about him skipping school?

LZ's mother: He had no other place to go but my younger sister-in-law's, which was near the school. She asked LZ why school was over (so early). The teacher visited us several days later and said that LZ didn't go to school for a week. The head teacher told me that the school did not suit LZ. He could not continue studying there.

We agreed. It would be useless to pay the tuition while LZ escapes school. He could not do the assigned homework. We were fully aware that LZ had performed well to go this far.

LZ's father: We have to accept reality. The education system is a pyramid. The higher it is, the fewer people there will be. It is hard for LZ to go further. LZ has performed poorly with respect to manual work. After discussion, we agreed to withdraw LZ from the school. The tuition was 1,800 yuan for each semester. We paid for two semesters. LZ skipped school within the first month of the second semester. We wasted the money.

Q: What was your plan at that time?

LZ's father: I had no other option under the circumstances.

LZ's mother: LZ did not make any progress after a semester. He could not (go up to the next grade). He didn't want to be there anymore. He had insisted on studying at school when he was little.

Q: Did LZ himself say that he would never go to school again?

LZ's mother: That is correct. He told us that he would rather die than go there.

Learned Basic Skills to Take Care of Himself

Q: When did LZ start to look after himself, meaning washing up and brushing teeth?

LZ's mother: He could do that when he was little. The result might not be satisfactory at first. Nonetheless, LZ has made progress gradually. He was able to take a bath independently after he was 10. I had bathed him before that.

Q: LZ is with ID. Will you train him to take care of himself independently?

LZ's mother: We have taught him to take care of himself late. To be honest, it takes time for LZ to do these things by himself. My husband and I were busy going to work. I worked around the Bund while my husband worked near Xieqiao and Dapuqiao. The traffic was bad. The metro was not built yet. I needed to transfer twice and my husband had to transfer three times. It was exhausting. I would rather do it by myself than teach LZ. After all, I had to clean up in the end. I had no time to teach him patiently. After retirement, I can take it easier to teach him.

Q: You were busy. As a result, LZ was not trained to take care of himself in daily life. Is that correct?

LZ's mother: You may say so. I lowered my expectations. LZ could wash up roughly. I had no time to correct him. I would ask him to wash up carefully on Sunday. Currently, he is shy when I offer to scrub his back when he takes a bath. He refuses and does that all by himself. I further offer to wash his feet. I know that he

cannot wash his feet clean. He also turns me down. I have to let it go. I wonder what LZ would be able to do if he lived independently. He told me that he was independent. However, it is obvious that he is not capable of taking care of himself.

Q: Have you started to train him especially after retirement?

LZ's mother: Yes. He doesn't dare turn on the gas stove. We have to do it for him. He can take a bath independently. He can also (use) a rice cooker. He cannot cook.

Q: Is he capable of washing and cutting vegetables?

LZ's mother: Absolutely. He is more careful than I am. He pays attention to personal hygiene and washes his hands. He strives to keep healthy and develop certain recipes if he feels uncomfortable. He has learned that from his father.

Q: Do you have different opinions on LZ's development?

LZ's mother: No.

Q: Did you when LZ was little?

LZ's father: I had to find a reason for LZ's poor performance when LZ was little.

LZ's mother: I required LZ to complete his homework and my husband asked me not to beat LZ.

LZ's father: I could find specific solutions after I found out the reason.

LZ's mother: We have taken steps gradually. I do not think we have made many detours.

Q: You have worked in harmony, right?

LZ's mother: That is true.

LZ's father: We just (found out the truth) late.

Registering in the Community and Being Assigned to a Company due to the Disability Certificate

Q: Did LZ stay at home after withdrawing from the vocational school?

LZ's mother: He worked at Linong after withdrawal. He was 19 at that time.

Q: What is Linong?

LZ's mother: It means the community. He did nothing at home and became plumper day by day. I will show you a photo later.

LZ's father: I had never sorted help from the subdistrict office. However, I had to for LZ's sake. I explained LZ's condition. An officer named Wang, who was in charge, was nice and asked me to write and submit an application first. Then he could (accept and handle the issue).

LZ's mother: He advised us to check and prepare the needed materials. LZ could not do what normal kids do. As such, it was suggested that I (figure out ways to) apply for the Disability Certificate first. It had never occurred to us to apply for the certificate.

Q: Haven't you ever thought about applying for the Disability Certificate for LZ from the time you found out that he was with ID to his graduation from middle school?

LZ's mother: We never thought about it. We felt embarrassed. We have strived to help LZ to grow up as a normal kid and fit into society.

LZ's father: The disabled have to obtain the Disability Certificate to enjoy preferential policies. It is useless to reason about that.

LZ's mother: We were asked to bring LZ to be tested at Shanghai Hongkou District Mental Health Center on Wednesdays or Thursdays. A mental health center was established in every district. The disabled are identified there. It was 2001 or 2002. Officer Wang told me that LZ could enjoy preferential policies if he obtained the Disability Certificate. He advised me to exaggerate LZ's condition to obtain the certificate smoothly.

Instead, I told LZ at home to answer all the questions he could. In the examination, we realized that LZ did not suffer from issues such as color blindness. He could also complete basic arithmetic operations. The only issue was that it was hard for him to give direct answers.

The old doctor told me that the situation was complicated. LZ could do arithmetic operations. He can either be regarded as a person with ID or not.

I told him that LZ was absolutely with ID. I implored him to help LZ to obtain the certificate. My husband and I are older and will be retired soon. LZ, being with ID, could not go to school. We have to make plans for him. We would never come here if LZ could go to school as normal kids do.

The doctor felt pity for us. He said that he would consider it and asked us to wait for news at home. I begged him to lower LZ's scores.

Later on, LZ was assessed to meet (disability standards). About 2 weeks later, I was informed by a subdistrict officer that LZ could come over and take away his Disability Certificate. I went there and found that LZ was assessed to be with mild ID. I was relieved that LZ was at least recognized to officially be with ID. People with mild ID did not obtain any allowance at that time. Only those with moderate and severe ID would receive an allowance of about 300 yuan or 400 yuan per month. I complained that my efforts were in vain. Well, I explained to my husband that the stamped result has been rigid and hard-and-fast.

After a while, a subdistrict officer asked me whether LZ obtained the Disability Certificate. I told him that we were in a dilemma. LZ could not enjoy any preferential policy even after obtaining the Disability Certificate. He mentioned that LZ could obtain subsidies from the subdistrict office if he works in the community. A new property management company just replaced the former one after the serving term expired. LZ could work there as a cleaner. I agreed. LZ got chubby at home. He could work and practice in reality. The officer wondered whether LZ could endure the hardships. I assured him that he could. It was not complicated to be a cleaner. He explained that the payment was not much. The property management company paid 100 yuan while the subdistrict office covered 150 yuan. The payment totaled 250 yuan (he laughed at the amount because the number 250 means a stupid person in Chinese). I said it was not a problem. After all, LZ could work as a way of (physical exercise), otherwise he would be idle at home and come down with diseases such as a fatty liver at a young age. LZ worked hard. He cleaned the street as carefully as he did at home. Then he would have lunch. He was praised for his excellent performance.

After over a year, I discussed with my husband that now that LZ worked and was paid regularly, he could enter the social insurance scheme. We consulted an officer named Cao from the subdistrict DPF. He learned that LZ was with mild ID and calmed us down. He said that LZ was only 24 years old. A new policy would be released by the federation to benefit people who had mild ID and (who) could not receive any allowance. I listened and left him with our contact information.

The new policy might be released after the Spring Festival. Major companies must offer certain posts for people with mild disabilities. If they could not set these posts, people with mild disabilities could be assigned to them and get paid but not need to work. LZ was lucky to be among the first batch of disabled people assigned to major companies. Later on, LZ ceased to work as a cleaner. On one hand, it was exhausting. On the other hand, the property management company was restructured. He has been assigned to a company from then on.

Life from Bitter to Sweet after Joining in the Special Olympics Movement

LZ's mother: After LZ was assigned to a company, the subdistrict DPF went through an election after expiration of a term of office. The former Chairman and Vice Chairman of the Subdistrict CAPIDR were in their seventies. Younger persons were wanted there to run affairs. I had joined the association recently. As a result, I was elected.

Q: How did you join the association?

LZ's mother: The DPF has five affiliated associations, that is, the Association of the Blind, the Association of the Deaf and Hard of Hearing, the Association of Persons with Psychiatric Disability and their Relatives, the Association of People with Physical Disabilities, and the CAPIDR. The disabled persons participate personally in the Association of the Blind, the Association of the Deaf and Hard of Hearing, and the Association of People with Physical Disabilities correspondingly. Persons with ID must have guardians to participate in the CAPIDR. I joined the association as LZ's guardian.

Q: The subdistrict office sets up the Subdistrict CAPIDR but does not force people to participate. Is that correct?

LZ's mother: Of course. The associations have been managed in a hierarchy system. The disabled people play a part in activities held at the subdistrict level, the district level, and the city level step by step.

I was selected to be in charge of the Subdistrict CAPIDR in 2002. I would attend meetings at the district level and the city level first. Then I would convey what I heard to the district level. Hongkou District used to be divided into ten subdistricts. The number is reduced to eight now. Each association has one Chairman and one Vice Chairman. We gathered together to figure out new ways to hold activities in these associations. The Chairman of the Hongkou District CAPIDR was called Wang. The Vice Chairman was called Zhen Ni. He used to be an officer at the Hongkou District

Commission for Discipline Inspection. Under the guidance of Mr. Ni, our activities were famous in a limited scope in 2005. Mr. Ni was reported in newspapers in 2006. Shanghai hosted the Special Olympics World Summer Games in 2007. This was LZ (pointed at a photo) in 2006.

Mr. Ni said that kids with ID have been kept at home. He investigated the number of people with ID in Hongkou District. There were over 100 in our subdistrict. It was very beneficial for them to join outdoor activities. They could not fit into society if they stayed at home. He suggested establishing a choir. LZ was among the first batch of members in the choir.

Q: Were people with ID organized to sing?

LZ's mother: Each of us took a lead to teach our kids to sing and gathered them to sing in the choir. However, these kids could not carry a tune. I noticed that few children with ID have been good at singing. Neither Mr. Ni nor the rest of us had the confidence to continue the choir after two activities. The children were also reluctant to sing.

Under these circumstances, Mr. Ni suggested we organize these children to play the waist drum as a way of intellectual development. It has been common to see senior people playing the waist drum. As a result, a waist drum team has been set up for people with ID in Hongkou District. At the beginning, we recruited 18 children with ID. LZ was one of them. A retired lady from Ouyang Subdistrict, who was a member of a waist drum team, was invited to teach them. The team used to practice at Miyun School on weekends. They might learn something today and forget most of it the next day. Nonetheless, they kept learning and practicing.

Q: Was LZ interested in the activity?

LZ's mother: He could not play the waist drum at first. I accompanied him there by bus. After a while, he became interested in it. Having mild ID, he could understand the teacher better and learn how to play the waist drum. Then he would teach other members. He has practiced every day and made (progress) gradually. The activity was recognized at the district level. After the team finished rehearsing a complete program, we were organized to attend a municipal meeting, during which the team became famous in Shanghai. Being supported by municipal leaders, we have been more confident in continuing organizing the activity. Parents have brought their children to participate, too.

Mr. Ni also asked me to play the waist drum and teach others. He joined us as well. We, Chairman and Vice Chairman of the Subdistrict CAPIDR, spent a lot of effort to learn to play the waist drum. Then we taught others. LZ has become more confident after playing the waist drum for a while. He has outperformed others in imitation. After participating in the activity, he has made obvious progress and has been capable of communicating with others better. He was the first to join the team under the instruction of Mr. Ni.

(Holding a photo) This is Mr. Ni, the Vice Chairman of the Hongkou District CAPIDR. He led us in the activities. He said, "Lin, we should be engaged in this field for several years together." I followed him from 2002 until now. The waist drum team established by Mr. Ni has held activities on weekends.

It became famous in 2005. Back then, it was already known that Shanghai won the bid to host the 2007 Special Olympics World Summer Games. As a result, we started to prepare. Each of us would learn a set of moves and develop a new waist drum program for people with ID exclusively.

Our original intention to organize the waist drum team was to encourage children with ID to do exercise and enjoy themselves. After the team became famous, we paid more attention to running it well. (Pointing at a photo) This is Ms. Zhou teaching the waist drum team. She was the mother of a team member from Jiaxing Subdistrict. She taught LZ.

LZ: Xiaodong Yu.

LZ's mother: Her son had cerebral palsy. LZ and her son are good friends. Shanghai was to host the 2007 Special Olympics World Summer Games. However, none of us was good at English. Ms. Zhou volunteered to teach us. She also tutored LZ in English. Her son can speak German and French. Mr. Ni, who is fully aware that Ms. Zhou is (competent), recommended her to be the Special Olympics Global Ambassador. Naturally, Ms. Zhou has become one of the Special Olympics Global Ambassadors.³

Being the family leader, she thinks she is obligated to take the lead to launch the *Special Olympics Oral History* project in the district. She has collected various materials. We could only provide limited information. You could turn to her for anything you need.

She also told me to be at ease during the interview. She has helped me a lot. We get along well with each other. She volunteered to teach children with ID English and dancing. LZ has learned English and dancing from her.

LZ: Don't forget about the Special Olympics Athlete Leadership program.

LZ's mother: Exactly.

Q: Is LZ also an athlete leader?

LZ's mother: That's true. A boy and a girl with ID were selected in Hongkou District to participate in the Special Olympics Athlete Leadership program to be prepared for the 2007 Special Olympics World Summer Games. LZ was lucky and (selected) by playing the waist drum. I must thank (those that have devoted themselves) to training children with ID such as LZ.

At that time, all work was centered on the 2007 Special Olympics World Summer Games in Shanghai. Athlete leaders needed to rehearse a dance to appear on the stage of the 2007 Special Olympics World Summer Games. This is LZ (pointing at a photo) dancing. He has developed various interests gradually. LZ became interested in dancing from then on. He was fully aware that he wanted to dance.

LZ: (pointing at a photo) This is dancing.

LZ's mother: They danced together.

LZ: The badge of the athlete leader.

³The official title is "the Special Olympics East Asian Family Leader for the 2007 Special Olympics World Summer Games in Shanghai".

LZ's mother: He would learn from senior citizens to dance in the community park. He is a big fan. I am not. He has learned and remembered moves. It is really helpful. He is confident in doing that.

We started to participate in the Special Olympics movement since 2007. LZ has participated in all of these activities. Regarding sports he is not good at such as table tennis and basketball, he would practice at home. (Showing a trophy) I urged LZ to participate in an activity held in the community and he won this trophy. Whenever there was an activity, he would ask me to join. I would not. Instead, I took LZ there. He won first prize in a dance competition and became famous in the community.

LZ: Mongolian folk dance.

LZ's mother: (holding a photo) LZ performed a Mongolian folk dance (covers her face and laughs). He got the costume as a gift. (Continues viewing photos) This is Bingbing Li. Seeing our waist drum team, she contacted us in private and donated over 80,000 yuan.

LZ would participate in all the activities he was capable of. He likes to do exercises. Once, Mr. Ni was selected as a municipal advanced individual and went to Beijing to accept the prize. He took LZ with him.

Q: Which Special Olympics activities did LZ participate in?

LZ's mother: LZ has participated in a variety of games such as running, basketball, and unified running.

LZ: Sorry (brought a box of medals).

LZ's mother: LZ won these medals by participating in (numerous) games. This one is the gold medal for an abacus and mental arithmetic competition. This is from a unified running event. This is from the games of the disabled persons.

LZ: Don't forget rhythmic gymnastics.

LZ's mother: Sure. He won a silver medal for that.

Q: LZ won so many medals, didn't he?

LZ's mother: That is true. LZ has sorted them all by himself. (Holding a medal) LZ won the gold medal from the unified running game in 2014. He won a silver one this year (chortling). He was lucky in the game in 2014. The fastest team broke the rules and had a fall. As a result, LZ and his team overtook them and won.

Q: Has LZ been trained to participate in games such as dancing or unified running?

LZ's mother: Of course.

Q: Are there any professionals to guide them?

LZ's mother: The professional teachers usually undertake certain games. Next, they pick eligible persons. For example, if ten players are needed in a game, two extra players will be selected as substitutes. Things are (arranged) in advance. All of these players will be notified a month earlier, because they needed to be trained in a certain place. Then they practice and receive coaching.

Q: Is the training program launched punctually every day?

LZ's mother: Players are coached by professionals at first. Then, they (practice) according to requirements. It is not easy. Some children's feet were worn out. After a while, they were able to practice with high proficiency.

Q: Did LZ ever show reluctance under these circumstances?

LZ's mother: LZ is eager to (play a part). He never even flinches. On the contrary, he is afraid that he may be rejected. For example, tall persons have been selected to play horse. LZ did not fit. I told him to keep practicing. He was fully aware of that. Four men and four women were selected to participate in basketball shooting. LZ was not chosen. He knows well that he has been weak in the game. He is also aware that he may get a chance next year. He engages in activities actively. All of these people are aware that it is beneficial to do exercises.

Q: Have players gone to places outside Shanghai to participate in Special Olympics Games?

LZ's mother: Correct. But LZ hasn't. These players may join in games held nationwide. For example, players who go bowling have competed in games held in Hong Kong and Wenzhou.

Q: Did parents accompany them?

LZ's mother: These players go with the teacher.

Q: Would they share experiences with parents willingly after returning home?

LZ's mother: Absolutely. They have been talkative. They may also share with encountered acquaintances. For example, they would claim that it was too hot. They were too tired to perform normally. They also enjoy any special treatment. They attend an annual 4-day summer camp in Songjiang District in Shanghai.

Q: Is there anything worth mentioning in your mind about the camp?

LZ's mother: Certainly. LZ would tell me anything he could think of. For example, they might fold clothes in the dormitory. The teacher would bathe them and scrub their back. These children are innocent. Children with ID in Hongkou District such as LZ have participated in a variety of activities. They are more sophisticated than those from other districts. Children with ID don't dare go out and depend heavily on their (parents) if they always stay at home.

Q: What are other activities are held in the summer camp?

LZ's father: Physical examination.

LZ's mother: That is another program. LZ tells us everything. These children do not need to take anything to participate in the summer camp. They will be granted clothes and towels from the authorities concerned. The food is also great. They receive better benefits now. Moreover, they also attend classes. LZ, can you talk about the classes available there?

LZ: The etiquette class and the writing class. I could play the role of a journalist or an environmental volunteer. (Proudly shows a certificate of merit) I was selected as a star talent in the training camp.

LZ's mother: LZ wins a certificate of merit every year.

LZ: And Special Olympics activities.

LZ's mother: Which activities?

LZ: Well, supermarket, that is, shopping.

LZ's mother: I see. They are shopping in a simulated supermarket.

LZ: We pay and redeem products.

LZ's mother: They can have a shopping experience via the game. They also learn to spend money and calculate change. Can you do that?

LZ: Well, the teacher would calculate change.

LZ's mother: Oh, the teacher would help them.

LZ: I have also written articles which have been posted on the walls.

Q: What are they about?

LZ: Environmental protection.

(LZ proactively opens his exercise book.)

LZ's mother: He is showing an article on environmental protection he (wrote).

LZ: I did not want to be a journalist this year. I just wanted to play the role of the group leader. I went to bed on the first night. However, I was asked to write articles the next night. I would not be dismissed until I wrote one. It turned out that the article was wonderful (very proud). The teacher thought highly of it and told me that it would be selected to go into a book. I have already determined the illustrating picture, in which I stood (next to) the bronze statue of Franklin Roosevelt, a former US President.

LZ's mother (cheerfully): He likes to talk about such nonsense.

LZ (angrily): Well, the President.

LZ's mother (echoed): Yes, the President.

Q: Are these things LZ has experienced as a journalist?

LZ's mother: Yes. His article is published with one of his photos on the page. He stood next to the bronze statue of Franklin Roosevelt in the photo.

LZ: He served as President for four terms in succession.

LZ's mother: LZ is famous now. He also enjoys a reputation in square dancing. He told me that he now has fans when dancing at night. He said that I was blessed to have him as a son. That is true (laughed a hearty laugh). He mentioned that we, as a couple, should be proud to be parents to him (clapped her hands and roared with laughter). I am relieved as long as he enjoys doing these things and is happy. LZ likes to dance in public. He enjoys performing on stage (See Fig. 1).

Q: Have you completely supported him participating in Special Olympics activities?

LZ's mother: Of course. We have witnessed LZ's progress. He was not so active before participating in these games. Our friends know that LZ likes dancing. They sent him a pair of boots as a gift after a trip from Xinjiang. He brought them home and told me that he would wear them in his performance. He likes wearing folk (costumes) and performing ethnic and folk dance.

LZ: I am from an ethnic minority.

LZ's mother: LZ joined in a global Special Olympics activity. A party was held for Special Olympics teams all over the world in a hotel in Hongkou District. LZ was thrilled to be there. An actress was there from Inner Mongolia in China or Mongolia.

LZ: Wulan.

LZ's mother: That is correct. Her name is Wulan. She wore a folk costume that night. LZ was excited and took a photo with her.

LZ's mother: (pointing at a photo) This is LZ delivering a speech. This is Mayor Li. LZ regarded him as his godfather and invited him to do rhythmic gymnastics together. I commented that LZ was good at communicating. Mayor Li had participated in a sports meeting in Hongkou District. Other kids had merely stood by and watched. LZ had come forward and taken a photo with him.



Fig. 1 Mr. LZ likes dancing

Q: Except for LZ's great progress, have you become less burdened now?

LZ's mother: I am relieved now. To tell the truth, I could hardly fall asleep in the past. LZ was a heavy burden on the family. He just stayed at home and got increasingly chubbier. I worried about his future. After all, my husband and I are getting older.

It is hard to go through those 10-plus years. LZ has made progress gradually. At first, he was capable of nothing. I forced him to join in activities. He did not want to play the waist drum and got blisters on his hands. I practiced and also got them. Nonetheless, I insisted on LZ practicing and getting the calluses on his hands.

After mastering the skill, LZ has started to enjoy it. Moreover, he also performed and won honorary titles one by one. No pain, no gain. Encouraged by these achievements, LZ could perform on a larger stage. He was even received by the Mayor and the Deputy Mayor and shook hands with them. LZ was thrilled and shared his

experiences. He would not even wash his hands and couldn't fall asleep that night. I watched his performance on TV. I had never thought that my son, a disabled person, could be on TV one day. Later on, he was introduced to perform in Beijing and take photos. You can see these (photos) in the Hongkou District CAPIDR. Things are getting better.

LZ's father: I think LZ would not be as outgoing as he is now without these activities. He used to merely stay at home.

LZ's mother: I have gone through the process. I am satisfied that LZ has made such achievements and has been happy. His living conditions have also improved. Previously, he could only earn 250 yuan per month. Now, he has been assigned to a company and receives a statutory minimum wage of 2,190 yuan per month. Thanks to that, LZ can support himself. I think things will be better with an increasingly powerful country. We are really grateful to the government.

LZ is busier than us. On weekdays, he goes to the Sunshine Home before nine o'clock and returns home around three or four o'clock in the afternoon. After dinner, he performs square dancing and returns home at half past eight. Then he washes up, plays on the computer and goes to bed. On Saturday, he practices dancing in Hongkou District Cultural and Sports Training Center for Persons with Intellectual Disabilities. After learning all the moves, he also helps teaching others. He is busy and sweats profusely and takes a bath at home. He also joins in activities and watches *The Ultraman* on weekend afternoons. He likes watching it.

Q: Where does LZ perform square dancing in the evening? Who are his partners?

LZ's mother: He basically dances with neighbors in Liangcheng Park.

Q: How did LZ start to perform square dancing? Did he do it to keep fit or out of interest?

LZ's mother: He used to be chubby and stroll around in the neighborhood. As a result, he was encouraged to join in the activity. Just at that time, a person that used to promote Amway products in Liaoning Province stayed in Shanghai and had experience in square dancing. He set up a group to perform.

Q: Does LZ merely like watching *The Ultraman* or does he buy Ultraman toys?

LZ's mother: He likes collecting Ultraman toys.

Q: In which aspects do you want him to improve?

LZ's mother: I certainly hope that he can develop more interests instead of focusing on one hobby. It may be dull to watch *The Ultraman* constantly. He has also worked hard every day to play table tennis.

Q: Do you wish for more activities?

LZ's mother: The more, the better. Numerous activities are already being held now.

Q: Will you always support him in participating in all types of activities?

LZ's mother: Absolutely. I will accompany him to join in activities if I am needed. I also regard it as a way of physical exercise. LZ is more famous than us now. When we engage in an activity, I may be asked whether I am his mother. I support him. In turn, he makes me happy (smiles with relief).

Shouldering Responsibilities at the Sunshine Home

Q: When did LZ go to the Sunshine Home?

LZ's mother: In 2005. He was among the first batch of students in the Liangcheng Subdistrict Sunshine Home. It was small. The Quyang Subdistrict Sunshine Home has been operating well in the years since then. He was needed there. As a result, he has been transferred to the Quyang Subdistrict Sunshine Home. More activities are held there.

Q: Why did you send LZ to the Sunshine Home?

LZ's mother: The municipal government has established the Sunshine Home as a rehabilitation site for people with ID. These people can learn and exercise. It is a place for people with ID to cultivate themselves.

LZ's father: It also serves as a platform for people with ID to communicate with society.

Q: LZ withdrew from the vocational school in 2001. Why didn't he enroll in the Sunshine Home until 2005?

LZ's mother: The Sunshine Home was not set up in 2001. Shanghai won the bid to host the 2007 Special Olympics World Summer Games in 2002. In 2005, the Sunshine Home was launched as a practical project for the Shanghai Municipal People's Government to be prepared to host the 2007 Special Olympics World Summer Games. That is to say, the Sunshine Home (might) not have been set up if Shanghai had not won the bid to host the (2007 Special Olympics World Summer Games). The Quyang Xincun Subdistrict has been a model in Shanghai. Xiaoping Deng,⁴ a former paramount leader in China, visited Quyang Xincun Subdistrict. After a few years, Jintao Hu, former President of China, and Jinping Xi, current President of China, also visited the subdistrict separately.

LZ's father: The Quyang Xincun Subdistrict has been the first large residential area built in Shanghai and equipped with relatively complete social amenities. Xiaoping Deng used to visit the place. It is still convenient to live here.

Q: Did Quyang Xincun Subdistrict have anything to do with the Sunshine Home at that time?

LZ's: No, it was merely a large subdistrict. Mr. Hu visited Quyang Xincun Subdistrict after the establishment of the Sunshine Home in 2005.

Q: Has LZ been enrolled in the Sunshine Home from 2005 till now?

LZ's mother: Of course. He enrolled in the Liangcheng Subdistrict Sunshine Home in 2005 and transferred to the one in Quyang Subdistrict later (pondering).

LZ: April 8, 2010.

LZ's mother: LZ remembers the date. More activities have been held in the Quyang Subdistrict Sunshine Home. It is also regarded as a sound example among Sunshine Homes in Shanghai.

⁴The Quyang Xincun Subdistrict, which is located in Hongkou District, was the first large residential area built in Shanghai since China's economic reform and opening up and matched with relatively complete social amenities. Xiaoping Deng visited families and the farmers' market there in February 1983.

Q: Did LZ suggest that he be transferred?

LZ's mother: Yes. To be honest, the Quyang Subdistrict Sunshine Home has been equipped with more complete facilities.

Q: How did LZ know that the Quyang Subdistrict Sunshine Home was superior?

LZ's father: It was reported in the newspaper. Mr. Hu has also visited the place.

LZ's mother: We read it in the newspaper. Residents in Hongkou District are fully aware of that. The Quyang Subdistrict Sunshine Home has shared the place with a Sunshine Workshop⁵ to involve students in practical operation. I worried that LZ might be inferior in actual operation. He assured me that he wanted to do manual work. He started from the simplest work and aimed to make money. I helped him contact the Quyang Subdistrict Sunshine Home. He was approved to be transferred. After all, he speaks fluently and can play the role of a guide to accompany (visitors) in activities held by the Quyang Subdistrict Sunshine Home.

Q: Can students select a Sunshine Home at will?

LZ's mother: They can only do that in their districts. For example, LZ is registered in Hongkou District. He cannot enroll in the Sunshine Home in Huangpu District. It is free of charge for LZ to go to the Liangcheng Subdistrict Sunshine Home. He is charged 60 yuan per month to be transferred to the Quyang Subdistrict Sunshine Home. Nonetheless, I am willing to pay to let LZ stay at the Quyang Subdistrict Sunshine Home. He can learn more there.

Q: Is the Sunshine Home open from Monday to Friday?

LZ's mother: That is correct. If students are free, they will play the harmonica. Students have established a band and play on Tuesday afternoons. When do you have singing courses?

LZ: Monday morning.

LZ's mother: A variety of activities are held in the Quyang Subdistrict Sunshine Home. Students wear school uniforms and play the harmonica on Tuesdays, try paper cutting on Wednesdays, and dance on Fridays. Being established as a model, the Sunshine Home is also visited by peers at home and foreigners.

LZ: Children from the Sunshine Home can go to the training camp. Those from the base cannot.

LZ's mother: There are certain regulations.

LZ: I am from the Sunshine Home.

LZ's mother: The Sunshine Home and the Sunshine Workshop are different. Students are treated differently in these two institutions. In theory, LZ is a student at

⁵The Sunshine Workshop, also named as the Sunshine Base, is formally known as the Sunshine Occupational Rehabilitation Aid Base. According to *Shanghai Almanac 2011*, it was a practical project for Shanghai Municipal People's Government to create 100 Sunshine Occupational Rehabilitation Aid Bases in 2010. In fact, 170 have completed construction. The base is not a formal labor and employment organization providing occupational rehabilitation aids. It is operated on the basis of "subsidies from the government and enterprises and work of disabled persons" to provide the minimum subsistence allowance for moderately disabled persons. In the Sunshine Base, unemployed disabled persons are gathered together to receive vocational training and work. The Sunshine Workshop, the Sunshine Home, and the Sunshine Psychiatric Garden are called the three Sunshine Institutions.

the Sunshine Home and does not need to work. However, he, together with several other agile students, may be asked to give a hand in busy seasons in the Sunshine Workshop.

Work is regarded as a top priority. Students participate in activities in their spare time. They are busy. They need to prepare programs to participate in joint performances at the district level. They also need to perform in numerous competitions such as the radio calisthenics competition.

Q: Has LZ received subsidies to work in the Sunshine Workshop?

LZ's mother: Sure. LZ likes to work there. He wants to make money (laughs heartily). He is aware of that. He is willing to work hard and seriously.

Q: What does LZ do?

LZ's mother: He makes sponge balls and sponge brushes for a manufacturer in Taiwan. Sponge brushes can be applied to washing cups.

LZ: Commodities.

LZ's mother: He is accomplishing simple tasks such as making labels for Oishi and toothpick wrappers and preparing post sent by the post office⁶ and double-sided tape.

LZ: And posters.

LZ's mother: Did you mean flyers?

LZ: One, two, three, and four. The assembly line.

LZ's mother: They receive small payments to make appropriate handwork. The main point is to involve them in practical operation. They are paid quarterly according to their speed at work. The minimum payment is 60 yuan per quarter. LZ can make over 200 yuan. The best ones may earn 300 or 400 yuan. These students are delighted to work and earn money. They do not care much about the amount.

Q: Does LZ spend the money he earns?

LZ's mother: He earns and spends money as he wants. He saves his money to buy a major commodity in the future.

Q: Can LZ go shopping all by himself?

LZ's mother: He can only do simple calculations.

Q: Has LZ bought you any gifts after participating in activities held in places outside Shanghai?

LZ's mother: LZ merely stays in Shanghai. Some kids may buy toys or local specialties. He will if he goes to other places.

Q: It seems that you are satisfied with how the Sunshine Home and the Sunshine Workshop operate. Is there any aspect they can improve on?

LZ's mother: What is your opinion, LZ?

Q: Is there any shortcoming in the operation of the Sunshine Home?

LZ's mother: LZ likes to go there.

Q: How does LZ get along with his classmates there?

LZ's mother: Are you happy? How do you get along with your classmates?

LZ: Fine.

LZ's mother: He is happy and gets along well with his classmates.

⁶Ads and notices printed by the post office. They need to be folded and sealed.

Q: Does LZ have any friends at the Sunshine Home?

LZ: Yes.

LZ's mother: He has a lot of friends. Here is the photo (showing a photo). This is them performing at the TV station.

LZ: Cao.

LZ's mother: Yep, Cao and Shi.

Q: Does LZ have any cousins? Are they close?

LZ's mother: Certainly. It is not hard for LZ to communicate with his cousins. They are polite and close. Some children with ID would be looked down upon and abused and beaten. As a result, they might lose confidence to communicate with others. LZ is confident.

Q: Does LZ contact his cousins proactively?

LZ's mother: Of course. He can communicate with them smoothly in family get-togethers. Of course, they will be less in touch if his cousins get married.

Being Grateful and Letting Nature Take Its Course

Q: Have you considered the issue of marriage for LZ?

LZ's mother: It seems that LZ has no such (physiological need).

Q: We have noticed that young people with ID also have this kind of physiological need when working at a special school as interns.

LZ's mother: LZ's need is not obvious. I discussed it with my husband a long time ago. Many people at his age may want to find a partner and get married.

Q: Is LZ 30 this year?

LZ's mother: Born in 1983, he is 35 nominally. However, he has no such (need) indeed. We are not avoiding (the issue). In fact, we are both (anxious). On one hand, LZ is with mild ID. It is impossible for any girl in a better physical condition to take a fancy to LZ. On the other hand, LZ, being a man, has to shoulder more responsibilities at home. Even if someone doesn't mind LZ's condition and falls in love with him, can they get along and spend the rest of their lives together? Who will be in charge of money in the family? These issues are real. Consequently, we decided to let nature take its course as long as we can (take care of LZ). LZ also expressed that he just wanted to live with us and not get married. We will start to think about it if LZ wants to. Women performing square dancing with LZ would like to introduce some girl to LZ frequently. LZ refused and remarked that he should start a career before getting married. He has plans (chortles).

He watches TV and knows about love and affection. We have recruited a great many girls with ID in our art team. Some of them want to get married and some do not. Regarding those getting married, some haven't applied for a Marriage License; some have already divorced; some have been tricked to marry normal people and suffered a lot. Two persons have to be capable of supporting themselves to live together. However, LZ still depends on us. I am in my sixties. I have to provide a

house and take care of LZ even after he gets married. What if we are too old to take care of him?

LZ's father: It does more harm than good for LZ to get married.

LZ's mother: We have to think about the issue. It is possible that LZ may marry a girl. What if she left after giving birth to a baby? What if the baby was also with ID? I have discussed the issue with several teachers and reached the conclusion that it is better for LZ to live all by himself.

Q: Which preferential policies are enjoyed by LZ?

LZ's father: LZ receives the statutory minimum wage in Shanghai every month.

Q: Is the amount 2,190 yuan?

LZ's mother: LZ is capable of supporting himself. He lets me keep his monthly income of 2,190 yuan as his living expenses. He hardly spends any money.

Q: Is there anything else except the minimum wage?

LZ's mother: That is all. LZ is with mild ID. People with moderate ID or above are identified as the severely disabled and receive state unemployment benefits of about 1,680 yuan now (uncertain facial expression).

LZ's father: Not all people with ID can be assigned to a company. Major companies in Hongkou District have offered a small number of posts. LZ is lucky to get one and be paid without the need to work.

LZ's mother: Of course. A small number of people with mild ID can be assigned to companies now. Regarding the rest, they are covered in the social insurance scheme via the Sunshine Base. Students graduated from Miyun School have mild ID. Currently, any student enrolling in the Sunshine Base can be covered in the social insurance scheme.

Q: LZ both receives income from the Sunshine Base and the statutory minimum wage. Is that correct?

LZ's father: Exactly. It was thought that people with ID assigned to certain companies could work as normal people do and be self-supporting after being trained in the Sunshine Home for a while. In that case, it would reduce the burden on cooperative companies. However, these people fail to get a job. They cannot compete with normal people such as college graduates.

In fact, companies are required to offer certain posts to people with mild ID. These people do simple tasks and get the statutory minimum wage. These companies, which have no other choice, would rather pay the statutory minimum wage to keep people with ID away.

Q: It may be troublesome if these people truly work there, right?

LZ's mother: In comparison, we are lucky to be in Shanghai.

Q: It seems that you are content about efforts made by society and the government to help the disabled. Do you expect more?

LZ's mother: We mainly hope that the disabled can get more help. One day when we are too old to take care of them, they won't be able to support themselves with the current allowance.

LZ's father: We are getting older while LZ is growing up. A company may be mandated by the government to pay LZ for nothing. However, I don't think it is a permanent solution for either the company or the government. Here is the original

intention of the government. People with mild ID, after being trained for a while, should be more competent to work normally and support themselves. We parents also wish for the same result. However, under the current circumstances, I am pessimistic on this actually being realized.

Q: Do you have any sound ideas?

LZ's father: It is hard to realize them (smiles to ease embarrassment). As a parent, I certainly hope that LZ can fit into society and have an appropriate job to stand on his own feet. However, we are fully aware of LZ's capabilities. He is a slowcoach indeed. It is impossible to act in haste to help him grow. We are content that LZ can receive the statutory minimum wage as the allowance. After all, LZ is not the only person in need in China. We can also take care of him. LZ is carefree.

LZ's mother: Independence is significant. We cannot test him to see whether he can live independently for several months.

Q: LZ is lucky to be your child. We have communicated with parents because of our major. We have found that children's development is greatly impacted by their parents' outlook.

LZ's mother: I think it is a demanding major.

LZ's father: What is your major?

Q: Special Education.

LZ's father: It is indeed challenging.

LZ's mother: It has been a pleasure talking with you. I have never met a person who majored in Special Education before.

Q: Let's just conclude here today. Thank you for your cooperation. We will keep in touch.

LZ's mother: You are welcome. Thank you for your effort.

Interview with Mr. LZ's Teacher

Interviewee: Teacher

Interviewer and writer: Peifeng Wang

Interview date: January 3, 2017

Interview place: A Subdistrict Sunshine Home in Shanghai

Q: What about LZ's attendance at the Sunshine Home?

Teacher: He attends the Sunshine Home regularly.

Q: What about his performance?

Teacher: LZ is smarter and keener than his classmates. He is more energetic in participating in profitable activities such as artistic performances. On the contrary, he has no passion for routine manual work. Being the class monitor, he should take the lead in sweeping the floor. However, he merely watches others doing it. He may also be just posturing if he is caught by a teacher.

Q: What are LZ's strengths and weaknesses?

Teacher: He performs poorly in math but is good at recitation. For example, he cannot take 50 yuan to go shopping. He is not capable of telling right from wrong but can play something by ear.

Q: What about LZ's social adaptability?

Teacher: He is tractable and confident and likes to push himself forward. On the whole, he is good at art and literature and can dance to music.

Q: How well do LZ's parents cooperate with teachers?

Teacher: LZ can understand teachers well and explain (teacher's requirements) clearly after returning home.

Q: Which issues may be faced by the Sunshine Home and the Sunshine Base in operation?

Teacher: They are well funded but cover a small area, making it hard to install equipment and launch psychiatric rehabilitation programs. Teachers are underpaid with few benefits and unable to do as well as they wish to. They seem to enjoy the treatment provided for civil servants but actually work as a high-class babysitter. They are under great pressure. On one hand, students have poor memory. They have to be taught the same information repeatedly. On the other hand, students' safety is the top priority. These students may quarrel and fight frequently. Teachers have to handle these issues as quickly as possible. More parents send their children to the Sunshine Home to save trouble. They tend to protect their children and blame the Sunshine Home and teachers for any accidents. As a result, the Sunshine Home must offer courses on emotion management.

Q: Do teachers work fulltime or part time?

Teacher: Fulltime. Teachers are recruited via social recruitment and go to work after being trained. The Quyang Subdistrict Sunshine Home shares a place with the Sunshine Base and the Sunshine Psychiatric Garden. They are called "Three Auspicious Sunshines" jointly and are set as a model in the sector. The Sunshine Home is visited by visitors from home and abroad throughout the year. As a result, full-time teachers are required to receive them.

Q: What is the source of funds for the "Three Auspicious Sunshines" to maintain normal operation?

Teacher: Funds allocated by the government, subsidies from the DPF and donations from well-wishers in society.

Q: What are sources of work tasks available in the Sunshine Base?

Teacher: We contact enterprises to cooperate and produce products, most of which are giveaways sent by these enterprises to their clients.

Interview with Mr. LZ's Classmate

Interviewee: Mr. S

Interviewer and writer: Peifeng Wang

Interview date: January 3, 2017

Interview place: A Subdistrict Sunshine Home in Shanghai

Q: How long have you known LZ?

S (looks at LZ with an inquiring look): Since about 2005.

Q: Do you like LZ?

S: Sure. He is like my elder brother and a great dancer.

Q: Does he teach you dancing?

S: He likes helping others. He teaches me to dance and speak Japanese and English.

Q: What about your common hobby?

S (confused and in thought): Hobby?

LZ (looks at S and tries to give him a hint): Righteous heroes.

S: Ultraman.

Q: What do you think are LZ's shortcomings?

S: He is perfect. That is his only shortcoming.

Q: Is LZ liked in the class as the class monitor?

S: Everyone obeys him. He is clever.

Interview with Mr. LZ

Interviewee: LZ

Interviewer and writer: Peifeng Wang

Interview date: January 3, 2017

Interview place: A Subdistrict Sunshine Home in Shanghai

Q: When do you go to the Sunshine Home?

LZ: Sometimes earlier and sometimes later. I return home after three o'clock in the afternoon.

Q: How do you go home? By bus?

LZ: I walk to the Sunshine Home in the morning as exercise and go home by bus in the afternoon.

Q: Do you like going to the Sunshine Home?

LZ: It's fine. It has a sound environment with rich oxygen, just like a fairy tale world.

Q: Do you like the teachers here?

LZ: They are good.

Q: Who is your favorite?

LZ: Ms. Lu. I nicknamed her "Junko Ojika," the heroine in *Moero Attack*, a Japanese TV Drama.

Q: Why?

LZ: She is pretty and also a fan of Japanese animation.

Q: Which courses are offered at the Sunshine Home?

LZ: A large number of activities are held here. We sing and string beads on Mondays. We play the saxophone and the harmonica on Tuesdays if we do not need to work. On Wednesdays, we participate in activities held jointly by the Sunshine Home and the Shanghai Beijiao High School and learn paper cutting from teachers

from the Hongkou District Cultural Activities Center. We play diabolo and learn Chinese calligraphy on Thursdays and dance on Fridays.

Q: How do you feel about the food here?

LZ: Chow Mein on Wednesdays is greasy. I like other dishes such as rice cakes and egg fried rice.

Q: Do you participate in activities held at the Hongkou District DPF on weekends?

LZ: Sure.

Q: What do you do at home?

LZ: I watch TV, learn Japanese,⁷ write Chinese characters,⁸ dance, and surf the Internet sometimes.

Q: Do you chat with your parents at home? What do you talk about?

LZ: We talk about the school, dance, and Ultraman (whispered).

Q: Do you help them to do housework?

LZ: Of course. I wash my clothes, clear the table, do the dishes, and sweep the floor.

Q: Which parent do you love more?

LZ: I love both of them.

Q: Which one do you talk to more?

LZ: Mother.

Q: Which one is stricter with you?

LZ: Both.

Q: When do you start dancing in the evening?

LZ: From seven o'clock to eight o'clock.

Q: Do you dance every day?

LZ: Yes.

Q: Do you dance with fixed partners?

LZ: We have a team.

Q: Is there an audience?

LZ: People who pass by. The Spring Festival is around the corner. As a result, restaurants are busy.

Q: What do you do after returning home?

LZ: I go over what I have learned and exercise. I work if there are tasks. I am making red envelopes now. Last time, I made bubble stickers. I can both improve my manual dexterity and generate more income.

Observation of Mr. LZ in the Drum Team

Observation date: 09:00–11:30, November 27, 2016

Observation place: Hongkou District Disabled Persons' Federation, Shanghai

⁷LZ teaches himself Japanese out of interest and can communicate smoothly in Japanese.

⁸LZ has developed an intense interest in ancient Chinese poems and poets since he was little and he is fond of writing traditional Chinese characters.

Observer and writer: Peifeng Wang

Time	Activities	Remarks
09:13	Two formations combined into one	LZ, being the leader of the waist drum team, stood by and watched with satisfied facial expression
09:16	Two formations were adjusted with individual members being instructed by the teacher	
09:20	LZ joined in the team as the leader to perform the waist drum program called <i>Chinese Kung Fu</i>	LZ was confident and passionate and kept smiling and nodded in greeting to the observer from time to time
09:24	Time-out and the teacher corrected postures of individual members	LZ put his arm on S's shoulder and chatted
09:25	The activity ended and all students took a break	
09:34	Performed a group dance called <i>The Lotus Pool by Moonlight</i>	LZ danced proficiently and elegantly, winning unanimous praise
09:38	Performed a group dance called <i>Sunny Days in September</i>	LZ's moves were in place, with a smile on his face
09:40	Time-out and teachers corrected moves of individual students	
09:45	The activity ended and all students took a break	Observation subjects gave a glass of water to corresponding observers
10:00	Performed Jing Wu martial arts	LZ was full of energy and performed vigorously and robustly
10:02	The performance was over. The teacher asked: "What do you think of your performance?" The teacher corrected postures of the whole team and instructed individual students	
10:08	Performed Jing Wu martial arts again	LZ spared no effort all the way
10:10	The martial arts ended and students took a break	LZ sat down and drank some water and looked around
10:20	Performed the group dance <i>Little Apple</i>	LZ beamed and performed vigorously
10:24	Performed the group dance <i>Tao Ma Gan</i>	
10:26	Male solo	LZ performed robustly with moves in place; girls watched
10:30	Female solo	Boys watched
10:32	The performance was over	All teachers and students went to a bakery
10:40	The baking activity started	Students put on gauze masks, hats, gloves and aprons. LZ was deeply interested and focused on baking
11:30	Took a group photo	

(continued)

(continued)

Time	Activities	Remarks
11:40	The baking activity ended	The observation subjects sent baked cakes to corresponding observers to show gratitude
11:42	Completed observation.	

Observation of Mr. LZ at the Sunshine Home

Observation date: 09:00–14:30, January 3, 2017

Observation place: A Subdistrict Sunshine Home in Shanghai

Observer and writer: Peifeng Wang

The Spring Festival is close. Students at the Sunshine Home mainly make red envelopes for enterprises and public institutions.

Time	Tasks	Remarks
09:00	Made red envelopes (printed with Chinese characters: “2017 exercising and developing a healthy lifestyle”); packed three red envelopes in one pack and bundled up every 25 packs with rubber bands	LZ was skilled and efficient. He was energetic with a smile on his face, chatting with students next to him and working simultaneously. He nodded in greeting to the observer from time to time and stood up and looked around
09:55	LZ stood up and carried red envelopes to another classroom	Trotting
09:57	LZ continued packing red envelopes	Completed packs piled in a jumble. A classmate helped put them in order and LZ thanks the classmate
10:30	Took a break and drank some water	LZ showed the observer where the water dispenser was and gave a glass of water to the observer
10:40	LZ took the observer to watch a saxophone performance and introduced members in the band to the observer one by one	He expressed pride not only in words but also in his expressions
11:50	Lunch break	
12:40	Continued folding and packing red envelopes	LZ started to feel tired and slowed down in work. A while later, he pulled himself together and accelerated packing
14:30	School was over	Handed in packs and the teacher counted the quantity. LZ completed the most, reaching 336

Translated by Weizhen Yang

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A Splendid Life for the Chinese “Forrest Gump”



GuliMire

Interview with Mr. Xiaobo Wang’s Mother and Xiaobo Wang

Xiaobo Wang, male, born in 1983.¹ The only child in his family. Level III intellectual disability. Finished studying in a regular school (Shanghai Pudong Zhangyang Middle School) in 1998. Registered and studied in a subdistrict Sunshine Home in Pudong New District in Shanghai between 2005 and 2015.² At present, he studies at home and goes travelling. He is a member in the dance team affiliated to the subdistrict Disabled Persons’ Federation.

Interviewee: Xiaobo Wang and his mother (Ms. Zhangdan Yan)

Interviewer and writer: GuliMire

Interview date: November 29, 2016

Interview place: Reception room on the first floor of Quanji Hotel, Zhangyang Road, Shanghai

Reacting Slowly and Enjoying Himself in Kindergarten

Q: When did you get married?

Bo’s mother: May 1982.

¹Xiaobo Wang was a volunteer in the 2007 Special Olympics World Summer Games in Shanghai. He was hailed as “a Forrest-Gump-like volunteer” by major media in China. Both Wang and the protagonist in *Forrest Gump* have intellectual disabilities (ID). Nonetheless, both have been optimistic and marched forward courageously overcoming adversity to keep making breakthroughs in their lives. They have set a good example for people.

²Xiaobo Wang studies at home. As a result, this case does not involve the observation part.

GuliMire (✉)

Fudan University, 220 Handan Ro, Shanghai 200433, China

Q: Were you pregnant soon after getting married?

Bo's mother: That's correct. Xiaobo was born on February 27, 1983. It was the Lantern Festival.

Q: Was prenatal testing available at that time?

Bo's mother: Everything went well before the delivery. However, Xiaobo suffered oxygen deprivation for a short time when he was born. The doctor adopted oxygen therapy as soon as possible and Xiaobo cried out loudly after a while. On hearing that, we were relieved. "The result is not bad. It would be troublesome if the infant were deprived of oxygen any longer," remarked the doctor. Everything seemed to be normal at that time.

However, later on, we noticed that Xiaobo was not lively. He was obedient and had an ordinary appetite, but he reacted slowly from time to time. We went to a doctor and were told that there was nothing to worry about. Xiaobo would be livelier after going to kindergarten and making friends. He behaved normally in kindergarten. He also performed properly and passed the interview to be admitted to an elementary school.

Q: Xiaobo, how old were you when you went to kindergarten?

Xiaobo: As far as I recall, I was 4 or 5 years old.

Q: Which kindergarten?

Xiaobo: The kindergarten in Jing'an District. It was located near my home.

Q: Was it a boarding kindergarten?

Xiaobo: No, I went there in the morning and returned home after school.

Q: What about your performance in comparison with your classmates?

Xiaobo: I remember not being able to take care of myself as well as other kids did. I would need a hand from the teacher to get dressed sometimes. Except for that, I think I performed like the rest of the kids.

Q: After school, did you go home all by yourself or were you picked up by your parents?

Xiaobo: My parents picked me up at first. I started to go home all by myself after knowing the way. It was not far. I just needed to cross the road and turn a corner.

Q: How were you treated by teachers there?

Xiaobo: Some teachers were kind and gave me a hand when I was in need.

Q: How did you get along with other kids in the kindergarten?

Xiaobo: I recall that I got along well with most of them. I was playful and energetic and liked playing with other kids.

Q: Did you make a lot of friends there?

Xiaobo: Sure.

Q: Were there any unpleasant memories?

Xiaobo: Not any I can remember.

Q: Every child has a hobby. What was Xiaobo's?

Bo's mother: I think Xiaobo was in a good mood after getting a high score when he was little. He was outgoing and liked reading. He also communicated smoothly with his classmates.

Xiaobo: My parents would take me out on weekends when I was in nursery and kindergarten. I enjoyed myself and took photos. I was happy before I enrolled in elementary school.

Willing to Work Hard, but Unable to Catch Up Since Grade Four

Q: Which elementary school did you attend?

Xiaobo: An elementary school in Jing’an District.

Q: Were you challenged academically?

Xiaobo: I performed well in the first three grades. On average, I got scores of about 80 or 90 in Chinese, math, and English.

Q: What about other subjects?

Xiaobo: Other subjects were set to cultivate our interests. We didn’t have to take exams on these subjects in the 1980s. We learned to solve word problems in math courses in the second semester in Grade Four. It was obvious that I started to perform poorly in math. It was hard for me to understand and think logically to solve math problems.

Q: Did you still perform well in Chinese and English in Grade Four?

Xiaobo: The results were acceptable.

Q: How did you feel when you realized that you could not catch up?

Xiaobo: I was depressed and had a sense of inferiority. I thought I was not as good as my peers. I could not get a sense of achievement from my studies.

Q: How did your classmates get on with you?

Xiaobo: They preferred spending more time with well-performing students. I did not perform well in math and was not confident. Only a few students liked playing with me.

Q: Did your teachers treat you differently after you started to fall behind?

Xiaobo: I would consult them if I had any problems. However, they had to give classes. They couldn’t spend much time to tutor me in their spare time.

Q: Have you practiced more to perform well in English?

Xiaobo: I may have a talent for languages. My spoken English is good.

Bo’s mother: Xiaobo really could not catch up in math. He gave satisfactory performance in Chinese and English. For example, he could learn to sing an English song quickly. He might also be able to have a little chat with foreigners he met. He has been good at communicating with people. He has been outgoing and he had fun.

Q: Were you ever a course representative or a member in the class committee at the elementary school?

Xiaobo: Never.

Q: Being depressed, did you ever participate in any extracurricular activities?

Xiaobo: I liked these activities. I recall that I have registered in interest-oriented classes such as track and field and drawing. I might not have won any prizes, but I have tried to develop more interests. It was fun to enrich my life with extracurricular activities.

Q: Which one was your favorite? Which one were you good at?

Xiaobo: I preferred doing radio calisthenics.

Q: Why?

Xiaobo: I could stretch my limbs and extend my body to the greatest extent to boost my spirit. Our class used to participate in a radio calisthenics competition and win a prize.

Q: What about your performance in drawing?

Xiaobo: I merely drew some simple lines. Students are taught with more drawing skills now. I, on the recommendation of Mr. Tong, a novelist, bought a drawing book called *Cartoon Comic*.³ I have imitated drawing lines first and improved my skills gradually.

Q: How well can Xiaobo take care of himself?

Bo's mother: He can take care of himself well. I strived to cook meals at home for the sake of food hygiene. My husband and I had to work. We prepared meals before we left. Xiaobo could have meals, wash dishes, and go to school all by himself.

Father Insisting on Regular School After the IQ Test

Bo's mother: Xiaobo was in Grade Five and about to graduate. His class director suggested having Xiaobo tested in the hospital. She said that other kids might be naughty and perform poorly. On the contrary, it was hard for Xiaobo to learn and keep up even though he worked really hard.

My husband was told that it was normal for some naughty kids to fail to form good study habits and stay down. I also thought that some students performed as poorly as Xiaobo did or even worse. Nonetheless, it was obvious that it was hard for Xiaobo to keep up in his studies. However, we were embarrassed and kept it to ourselves. Hearing the teacher's words, I took Xiaobo to be tested at the Jing'an District Mental Health Center.

He got a score of 68, indicating mild ID. The doctor remarked, "Xiaobo would perform outstandingly in a special school. Why bother enrolling him in a regular school, putting him under so much pressure? Students are assigned jobs as soon as they graduate from the special school." I knew nothing about the disease and asked the doctor whether there was any medicine? Seeing that I was nervous, the doctor suggested I consult an expert. I had come around to the fact afterwards. The die was cast. It was unnecessary to see any more doctors.

I told the teacher frankly that the results of Xiaobo's IQ test were not satisfactory indeed. In fact, I wished to send Xiaobo to a special school. He would be less pressured and everyone would be happy. However, my husband was unwilling to do that. He was afraid that Xiaobo could achieve nothing in a special school. He also told me to keep Xiaobo's condition to myself.

³Lengren Zbigniew (1919–2003) was a famous Polish cartoonist.

Xiaobo: The special school was not equipped as well as it is now. I didn't want to go there, either. I felt that I could learn nothing there.

Bo's mother: We visited the special school. Neither Xiaobo nor his father approved of the idea. I didn't insist and Xiaobo remained in the regular school.

Q: What about Xiaobo's performance in the graduation exam?

Xiaobo: I barely passed it.

Bo's mother: Tutored by a home tutor, Xiaobo passed the exam and graduated from elementary school.

Haste Making Waste

Q: Which middle school did you attend?

Xiaobo: We were assigned to middle schools randomly by the computer, just like the way you get a license plate in Shanghai. I was lucky to be assigned to a sound middle school in Jing'an District. I was enrolled in a preparatory class before I started middle school study. After the preparatory class, the school was relocated. As a result, I was transferred to a middle school in Pudong New District.

I went there alone from the very beginning. I thought my classmates were clever and concentrated on their study. They did not show great enthusiasm about my arrival. Nor did I take the initiative to communicate with them.

Q: Did you ask your classmates for help when you had trouble in studying?

Xiaobo: I was introverted at that time. I would not consult others even if I couldn't understand. My classmates were busy after school.

Q: Did you turn to your teachers?

Xiaobo: Rarely. I was too embarrassed. Teachers charged for extracurricular tutoring, just like teachers do now. However, they would not necessarily teach students according to their merits.

Q: Would you consult your parents at home?

Xiaobo: My parents are not well educated. They could tutor me when I was at elementary school. Middle school knowledge was beyond them. Moreover, they had to work and could spare little time to tutor me. My father has worked as a technician and was busy. My mother prepared meals for me every day and was on the middle shift.

I often stayed at home alone, either doing homework or staring at trees out the window. I just muddled along in school and pretended to know. Gradually, I could not follow teachers at all and had an increasing sense of inferiority. Looking back now, it was really torture.

Bo's mother: It was harder for Xiaobo to do math homework than Chinese homework. He often went to bed after 11 or 12 o'clock. My husband had a high self-esteem. He worried about Xiaobo's performance. He went to work at five o'clock in the morning and accompanied Xiaobo to do homework till midnight. It was tough. For a while, he was not busy because the company he worked for was to be relocated to the suburb. As a result, he did not sleep at all, but studied all night with Xiaobo.

“Xiaobo, you will live a quality life if you work hard now. I hope you can live a better life than we do,” he told him. I replied, “You expect Xiaobo to perform well. However, Xiaobo cannot understand what he has learned at all. That’s very ironic!”

Xiaobo: My parents held high hopes for me and expected me to perform outstandingly. However, I did not do well in math, physics, and chemistry. It was impossible for me to meet their expectations all by myself.

Bo’s mother: Xiaobo was tutored by a home tutor until he reached Grade One in middle school. He was exhausted and slept little. As a result, we no longer forced him to study and let it be.

Q: Was Xiaobo tutored by other home tutors afterwards?

Xiaobo: I was tutored in English.

Bo’s mother: Xiaobo was tutored by an English tutor in the first two grades in middle school. We did that for the sake of his class director, who cared about Xiaobo’s performance and thought Xiaobo could catch up in English after being tutored. We were fully aware that it would put pressure on Xiaobo again. However, we followed the advice to spare her feelings. Moreover, we also thought that Xiaobo could perform better in English. In fact, I always believe that it was wrong to press Xiaobo to work hard. He could not sleep well because of that. However, we had no other choice.

Q: Did Xiaobo perform better after being tutored?

Bo’s mother: He could just pass English but still failed to catch up in math, physics, and chemistry.

Q: How did you get along with your class director?

Xiaobo: Just so-so. She thought that I performed poorly in study, but had a talent in sports activities. She would tell my parents when I was not myself in class. She had to press me to work hard. My performance might have affected the performance of the entire class. She also told my mother that.

Q: Did your mother tell you that after you returned home?

Xiaobo: Sure. My parents also hoped that I could perform as well as normal kids do. However, the reality was not satisfactory.

Q: How did you communicate with Xiaobo after talking with the class director?

Bo’s mother: I talked with Xiaobo about that. He was fully aware that he could not catch up. I understood him and said, “I know that you cannot catch up. You just try your best.” In fact, we knew that it was hard for Xiaobo to keep up because he has ID. My husband was reluctant to accept the fact.

My parents were college graduates. My mother worked as the class director in an elementary school in Hongkou District. My father used to be an official in Huangpu District Education Bureau. In 1957, he was sent down to Chongming. He worked there for 2 years. Later on, because of the family background, he was sent down to work as a manager in a restaurant in a grassroots work unit. He lied to me and my little sister that he asked personally to work there. He also cared about Xiaobo’s performance, “You should pay more attention and find the causes for Xiaobo’s poor performance,” said my father, “you must see to it that he performs outstandingly, otherwise he can only...”

We, like many other parents, liked to compare Xiaobo to other well-performing kids. Look, that child performs outstandingly. Xiaobo could not keep up and went to bed late at night. Consequently, he could hardly concentrate in class, resulting in a vicious circle. In retrospect, we pulled up seedlings to help them grow and caused damage to Xiaobo’s health unconsciously. We did not treat him well.

Xiaobo: I could barely get along with my normal peers. I just endured. There was no other solution for me to keep studying. We did not consider other options. Nor were we enlightened to follow another way to learn skills.

Bo’s mother: Xiaobo could not pass the graduate exam. The headmaster thought that Xiaobo could not make any progress even if he was asked to repeat a year. As a result, Xiaobo obtained his Certificate of Graduation of Middle School.

Xiaobo: I got scores of over 260 in all.

Q: What was the minimum passing score?

Xiaobo: I don’t remember.

I participated in few extracurricular activities. I recall that I was encouraged by a classmate to play a supporting role in a performance. The classmate was in charge of the performance and nice to me. Moreover, I would also ride a bike with my classmates in my spare time. I got along well with my classmates. My best friend was also my middle school classmate. On holidays, we would go shopping in malls and play table tennis and go skating. I was good at playing table tennis, basketball and golf and swimming. The teacher set me to lead the radio calisthenics in a contest because of my standard movements.

Q: Did you mean your class director?

Xiaobo: That is correct.

Doing What One Is Capable of and Becoming Confident

Bo’s mother: Xiaobo was relieved after graduating from middle school. However, my husband still hoped that Xiaobo could do further study.

Xiaobo: My father registered me in a vocational high school to improve my education level. However, I could not take it after 3 days. My mother persuaded my father, “We, as parents, must take it easy and be practical and figure out ways that are beneficial to Xiaobo’s physical and mental health. All roads lead to Rome.” My father came around to the idea and helped me to withdraw from the school. However, the tuition of over 3,000 yuan was not returned.

Bo’s mother: Later on, my husband convinced Xiaobo to learn electrical engineering in a technical school. He is a technician and works seriously. Today, he is still invited to train staff and give courses in other companies. My husband said, “Well, I will no longer push you with respect to academic achievement. Let’s take a step back and learn technical skills. Son, a sound technician is not replaceable.” “Xiaobo, it is beneficial to be a technician. You may not perform well at school. However, I will support you if you are willing to learn a technical skill. You have my word,” said my husband, funny and cute.

I didn't want Xiaobo to learn these technical skills. It was exhausting. Moreover, he would be frustrated again. I told my husband, "Xiaobo cannot perform well in school. Let's accept the fact. I think Xiaobo can learn other things. We must be flexible." My husband didn't agree and insisted on Xiaobo learning a technical skill. It turned out that Xiaobo could not do that well, either. My husband was depressed and no longer insisted on that.

Xiaobo: Well, I may not be good at that.

Bo's mother: The teacher remarked that his hands were too sweaty to learn electrical engineering. Moreover, he had an operation due to acute appendicitis. Xiaobo has been thin since he was little. He has also been exhausted by huge academic pressure and had bad digestion. I think it may also be the cause for the appendicitis.

Xiaobo: I was unhappy and aimless after the operation. I was unwilling to communicate with others.

Bo's mother: I took him to see a psychiatrist, who thought Xiaobo suffered from "schizophrenia" and prescribed medication. After returning home, Xiaobo told me that he would not take the medicine because the diagnosis was incorrect.

Xiaobo: We went to the Department of Forensic Psychiatry in a special hospital and the psychiatrist overturned the previous diagnosis.

Bo's mother: We were told that Xiaobo was just depressed after the operation. I was told that it was not serious. We should take him outside more often and he would be well. Well, Xiaobo was nearly diagnosed with schizophrenia. Thank God we believed that Xiaobo was healthy. We were lucky to meet a responsible psychiatrist the second time.

Q: Did you continue studying in a technical school after the operation?

Xiaobo: I withdrew.

Q: Have you received any rehabilitation therapy after the operation?

Xiaobo: My parents were anxious. They took me to Shanghai Research Institute of Acupuncture and Meridian, which is located on Wanping South Road. I accepted acupuncture, Tuina, applied plasters and had traditional Chinese herbs for several months. I gradually recovered.

Q: How long did you stay at home for recovery?

Xiaobo: Two or 3 years.

Q: How did you spend the time?

Xiaobo: I had an IQ test in a designated hospital and applied for the Disability Certificate. I was at a loss at first. My peers either went to work or did further study. When I was the most helpless, my mother was attracted by the serial story column called "A Tycoon's View" on *Finance and Investment*. Mr. Tong was the columnist.

Bo's mother: It is a weekly newspaper and released on weekends. Mr. Tong attracted readers with his humorous or incisive writing. I shared it with Xiaobo after reading it. What impressed us deeply was Chapter 21 of *Grandpa Caishen's Funny Stories* named *The Fallen Top and the Regretful Whip*. It tells the story of a girl in Grade Two in a key middle school. Unable to bear any longer her father's "whip-style" education, she committed suicide by jumping from the 18th floor. After reading the story, all of us felt that we would go through a difficult situation.

Xiaobo: The girl may have performed outstandingly. However, she must have been depressed and felt suffocated. That is why she chose to end her life. My mother was deeply touched. She thought that she had to stop pressing me anymore.

Bo’s mother: I contacted Mr. Tong via the email address published in the newspaper. He replied and encouraged us. He seeks a healthy and relaxed life, “Everything cannot be forced.” I think it means that “one just needs to go with the flow and not force anything.” After we came around to the idea, Xiaobo was no longer pressed and became more confident and happier. We started to live harmoniously and accept the world as it is. We have been content and happy and enjoyed a casual life.

Xiaobo: At that time, to cheer me up, my father bought the camera, the printer, and the computer to cultivate my interests. My mother took care of me and cooked nutritious dishes to help me recover as soon as possible. I am grateful.

Q: Did you learn anything, especially after you received these things, such as the computer?

Xiaobo: I signed up to a computer training school launched by Shanghai Jiaotong University to attend an office automation course at the primary level, which was given in our subdistrict. At first, I could not understand the theory. Nor could I operate in practice. The teachers were patient and tutored me. I gradually understood and could complete basic operations independently and pass the exam with a high score.

Q: Which basic operations?

Xiaobo: I am familiar with Microsoft Word and Excel and SQL solutions. I would input corresponding commands according to certain questions to input data and create a worksheet in Excel independently. The teachers appreciated my efforts and set me as the class monitor to encourage me. Afterwards, I also helped many other students learning computer skills and they were grateful. Consequently, I started to be confident step by step.

Q: Did you also learn photography especially?

Xiaobo: I had mastered basic photographic skills. Thanks to the introduction of the President of the subdistrict DPF, I could learn from Mr. Xue, Head of the Team Management Department in the Subdistrict Cultural Center, on improving my skills and selecting appropriate shooting modes. Later on, I practiced my skills by taking pictures in activities held by the CAPIDR.

Preparing for Special Olympics and Enhancing Capabilities through Home Visits

Bo’s mother: In 2004, the subdistrict DPF forwarded exciting news; that is, Shanghai would host the Special Olympics World Summer Games in October 2007. Athletes would be selected from all subdistricts to participate in the games.

Xiaobo: My mother and I saw regulations of the CAPIDR on the official website of the China Association of Persons with Intellectual Disabilities and their Relatives and knew that such an association had also been established in Shanghai. My mother

called the person in charge. Chairman Zhang of Shanghai CAPIDR told my mother that the association had also been established in Pudong New District.

My mother and I paid a visit to the Chairman of Pudong New District CAPIDR to find out more about it. She invited us to join in the Association.

Bo's mother: The slogan of Special Olympics was "Going Outside and Socializing." Her son had studied at a special school and been a Special Olympics Global Messenger and a Special Olympics athlete who participated in numerous Special Olympics Games and won awards. She invited me to be the liaison of the CAPIDR in our subdistrict. Then I was promoted to be Chairman there and organized people with ID in our subdistrict to play a part in activities held by Pudong New District CAPIDR.

Xiaobo: From then on, my mother has become the initiator of the Lujiazui Subdistrict CAPIDR. The first job she did was to pay a home visit.

Q: What kind of home visit?

Bo's mother: When communicating with Xiaobo, it came to me that the primary task of the CAPIDR should be to understand basic situations in families with family members with ID. Then it would be much easier to promote Special Olympics.

Q: When did you start to pay home visits?

Xiaobo: We were prepared in the first half of 2003 and started to do that from the second half of 2003 till the first half of 2004.

Q: How did you get these families' contact information?

Xiaobo: Officer Lu from the DPF of the Civil Affairs Section, after knowing about my situation, thought that my mother was eager to help me and other people with ID and willing to work as a volunteer in the subdistrict CAPIDR. He took out a list of people with ID in our subdistrict from a desk drawer and gave it to my mother. My mother returned home with the list and told me that it could help us change ourselves and encourage other families with family members with ID to join in the Special Olympics movements.

Bo's mother: We started to follow the list to pay home visits and completed them smoothly in about 3 months. Xiaobo visited families with family members with ID in five communities independently. He had been transformed from being introverted with a sense of inferiority to being optimistic and outgoing. His life has been enriched.

It was time consuming to pay home visits. We would have a boxed lunch and drink mineral water to keep up with the schedule. I said, "Xiaobo, we should complete home visits in several months." A member in the CAPIDR commented, "Ms. Yan, you are a doer. You and Xiaobo have done some substantial work." I also think that Xiaobo and I have done a marvelous job.

Back then, I didn't know how we were pushed to complete all these home visits. Generally speaking, it is rare to see volunteers do that. I appreciate that the DPF trusted me and gave me the list. We might have impressed the person in charge with our optimism and enthusiasm.

Xiaobo: My mother and I would keep a record and write down our feelings on the computer after every home visit.

Q: What is the purpose of your home visit?

Bo’s mother: First of all, we cooperated with the DPF to promote that Shanghai would host the 2007 Special Olympics World Summer Games. We encouraged people with ID to go outside and participate in the magnificent games.

In our home visits, some parents would complain that people with ID have frequently suffered prejudices and been looked down upon. They had been upset when their kids were stared at and judged by passers-by. Some families also had a sense of inferiority as we did. I am a mother to a son with ID. I knew exactly how they felt and went all out to straighten it out. I told them to care little about what others may think. If they could not stand it anymore, they can stare back. We burst into hearty laughter and agreed that it felt good to take things as they come. Later on, families in our CAPIDR have united and bravely gone outside.

Xiaobo: Once in an outdoor activity held by the CAPIDR, individual passers-by looked at us strangely and whispered to each other. We stared at them collectively and laughed heartily. They were probably embarrassed and soon dispersed. Parents felt happy and stress-free taking part in these activities. Consequently, we achieved the goal of the “SO get into it” advocated by Special Olympics.

Bo’s mother: Second, I was told to report needs of visited families to the DPF, which would meet these needs according to available policies. Xiaobo and I just did our duties to act as a bridge between the DPF and the disabled persons.

Third, I wanted to keep Xiaobo busy and enhance his communication skills. It was indeed the only option to train him to be independent. We did not do it out of lofty ideas. I am Xiaobo’s mother. When I was asked to assume the responsibility, I believed firmly it was God’s will.

Xiaobo: At that time, I felt that I was capable of making contributions for the group.

Q: What information would you share at your home visit?

Bo’s mother: I would introduce myself first. I told them that I was mother to a son with ID and the initiator of the subdistrict CAPIDR. I was there to promote Special Olympics. The Special Olympics Games have been held for people with ID. Any persons with ID and aged from 7 to 80 can participate in the Special Olympics Games. These families were thrilled on hearing the information.

Q: How did you feel in your first home visit?

Xiaobo: I was confident. I think I was destined to help my mother do it.

Q: Did you complete your first home visit independently?

Xiaobo: My mother accompanied me for the first time. I completed the rest all by myself.

Q: Did you run into any difficulties during your home visits?

Bo’s mother: At first, some parents were reluctant to participate in Special Olympics activities. They claimed that their priority was to support the family. I told them honestly that my son was also with ID. The living condition of the disabled persons would be improved gradually following the 2007 Special Olympics World Summer Games. On hearing that my son was also with ID, they began to trust me and joined in the Special Olympics activities.

They had no idea about Special Olympics. I explained it as a kind of sports activity. I asked about their available time so that I could send them the “activity notice” if any

sports activity was held by the Pudong New District CAPIDR. They were happy to hear that. A large number of persons with ID joined in sports activities collectively. Children with ID were crazy about these activities. They also had great potential. Our subdistrict houses multiple Special Olympics athletes that outperform Xiaobo.

Xiaobo: They are natural athletes.

Bo's mother: They won first prize in games, especially track and field events such as high jump, long jump, and shot put.

Xiaobo: They also performed well in playing badminton and basketball. Most Special Olympics athletes have a strong physique.

Bo's mother: The parents were happy. They believe that their children are gifted.

Xiaobo: These children used to watch TV at home, just like I did. They had nothing else to do.

Q: Did you complete home visits independently except for the first one?

Xiaobo: I accomplished home visits to families with family members with ID in five communities all by myself.

Q: Did Xiaobo share information about these families with you?

Bo's mother: Yes, he did. He mentioned that some children suffered multiple disabilities. They could not go outside because of their physical conditions. Consequently, their character would change. Some parents were upset about a small living area and hoped to send their children to a nursing home. Some parents required nurses to look after their children. Xiaobo started to think after getting the information. He said, "Mother, it is significant to keep fit. I must cheer up." I am lucky in comparison with other families with family members with ID. I think it is especially important to have a harmonious and sweet home. Parents must believe their children and encourage them instead of scolding them frequently.

Q: Did Xiaobo share his thoughts?

Bo's mother: Sure. He thought that his mind-set had changed and he knew the area better. First, he learned about landmarks near the community. For example, we were to visit a neighborhood committee. He learned in advance that a large supermarket was located opposite the neighborhood committee. In that case, we would not detour. He learned a lot from these home visits. It was a unique and marvelous experience.

Xiaobo: I would also record the conversation and demands of the disabled persons (on this notebook). It recorded a piece of my life and accompanied me to develop toward a promising future. I will always be grateful for the experience, just like I was with the experience of being a volunteer in the 2007 Special Olympics World Summer Games in Shanghai.

Q: What about results of your home visits?

Xiaobo: A large number of families remarked that what we did was meaningful and brought changes to their families. Thanks to our home visits, people with ID and their parents in our subdistrict were willing to participate in Special Olympics activities held at all levels. Children with ID have changed physically and mentally after playing a part in these activities. Parents worked as volunteer teammates to encourage and cheer up athletes in the field.

Q: How did you feel after completing home visits?

Xiaobo: I think we, that is people with ID, can do wonders. I have proved with my experience that a person has great potential. We can prove our value with enough courage and confidence. The spirit of the Special Olympics has made a significant impact on 280 families with family members with ID that we have visited.

Making Progress via Multiple Courses at the Sunshine Home

Q: How did you enter the Sunshine Home?

Xiaobo: My mother took me there first. She hoped that I could join in activities held there to be confident and go outside and make friends.

I did not like going there at first. It was called the Work and Rehabilitation Center. Everything was strange to me. Few people were in there. They learned to string beads. I was not interested in that at all. I could not make use of my talent.

The place has been called “Sunshine Home” since 2005. It was one of ten practical projects launched by the Shanghai Municipal People’s Government in 2005. Taking the opportunity of Shanghai hosting the 2007 Special Olympics World Summer Games, the Sunshine Home launched various activities and programs, attracting an increasing number of students. Mr. Yan Hongyuan was in charge of the Sunshine Home at that time. Knowing that I enjoyed crowds, he came to our door to persuade me to register at the Sunshine Home. I recall that we talked for half a day. I have realized that students can indeed change intellectually and physically step by step at the Sunshine Home.

For example, doing handwork is a vital step of rehabilitation to train flexibility of limbs. Several students had already been there when the place was called the Work and Rehabilitation Center. I saw them stringing beads. They did that patiently. I could not do it at first. Then, I was able to complete a small task. In the end, I could make a small accessory. In the process, I have become more patient, confident, and concentrated. My mind has changed slowly. I started to be included into the group gradually. I felt that it would be promising to study at the Sunshine Home. At present, the Sunshine Home has provided a variety of courses such as PE, handwork, singing, dancing, drawing, sign language, and Japanese. Other public organizations will also give courses there. I may need to go on trips. When I spend time there occasionally, students tend to share anecdotes during their study. I can see satisfaction and happiness on their smiling faces.

Q: What did you do at the Sunshine Home?

Xiaobo: I would participate in regular activities and take and share photos.

Bo’s mother: Xiaobo is also a member in the dance team under the subdistrict DPF.

Xiaobo: Ms. Zhou, an experienced dancer, has been recruited to teach us. She is also mother to a Special Olympics athlete. She has taught us dancing every week for a decade since the establishment of the dance team in 2007. The team has participated in countless large dance performances, variety shows, and municipal and district-level contests and won plenty of first prizes. We also won first prize in the radio

calisthenics competition for people with ID organized by the subdistrict DPF and the Pudong New District CAPIDR. Officials of the DPF were concerned about us. They were solicitous about our health during the rehearsal. We were delighted to dance.

Q: Are you still a regular student at the Sunshine Home?

Bo's mother: To be precise, Xiaobo is a member of the dance team under the subdistrict DPF. He does not go to the Sunshine Home frequently. He has concentrated on keeping fit, reading, watching films, and learning to do housework. The teacher may ask Xiaobo to attend in cases of major performances. Xiaobo will actively join if he is in Shanghai.

Having a Good Appetite and Being Healthy After Joining in Special Olympics Activities

Q: How did you start to take part in Special Olympics activities?

Xiaobo: Once, my mother and I went to the preparatory group of the 2007 Special Olympics World Summer Games. It was a simple office located on Puyu West Road. Mr. Jisheng Chen, who was physically disabled, worked there. He was the first person that told us that Shanghai would host the 2007 Special Olympics World Summer Games. In 2005, I participated in the first community-level Special Olympics Games organized by the subdistrict office in Dongchang Middle School Affiliated to East China Normal University.

Q: The Special Olympics Games at the community level?

Bo's mother: That's correct. The community-level Special Olympics activities were launched in 2005 to be prepared for the 2007 Special Olympics World Summer Games. In 2005, the Pudong New District CAPIDR also organized Special Olympics activities in the Shanghai Pudong Special Education School. In 2006, our track and field team represented Pudong New District to participate in the Special Olympics Shanghai Invitational Games. Athletes from our subdistrict ranked at the top in various games.

Q: Which games do you usually play?

Xiaobo: Primarily track and field events such as shot put.

Q: What about other events?

Xiaobo: I have also taken part in long jump.

Q: What are other events available at the Special Olympics Games other than track and field events?

Xiaobo: Canoeing and kayaking and archery.

Bo's mother: Our subdistrict CAPIDR has only organized track and field events.

Q: Where did you get trained before the games?

Xiaobo: At Jianping West Middle School. We cooperated with the DPF to contact the school. The school was very supportive and sent a coach to train us.

Q: What was the training schedule?

Xiaobo: Athletes would sign in on site before they were trained. Then, we were trained for 2–3 h. If it rained, we would run along corridors in the school building. We learned skills and essentials in running. Coaches understood us and would communicate with us equally and smoothly. They kept cheering us on. The motto of the 2007 Special Olympics World Summer Games was “I know I can!”. Back then, I did not think it was tough at all. Instead, I was totally engaged in training and enjoyed myself.

Q: What exercises did you do?

Xiaobo: We warmed up and stretched limbs. Next, we were trained for track and field events such as running and long jump and ball games such as table tennis, badminton, and basketball.

Q: How did you get along with coaches?

Xiaobo: The coaches appreciated us and affirmed our talent in sports.

Q: Did Jianping West Middle School make the training plan?

Xiaobo: Jianping West Middle School volunteered to train us according to our requirements.

Q: How long did the training program last?

Xiaobo: We were trained once per week. The program lasted for 2–3 months.

Q: Did you go there by yourself or accompanied by your parents?

Xiaobo: My mother, being in charge of the subdistrict CAPIDR, had to be there during our training. Some parents would also be there from time to time.

Bo’s mother: I needed to take photos which would be filed or shared with athletes’ parents.

Q: Has the training program continued or did it end after the 2007 Special Olympics World Summer Games?

Xiaobo: Training at Jianping West Middle School ended before the opening ceremony of the 2007 Special Olympics World Summer Games.

We also had to receive the US Special Olympics delegation to the 2007 Special Olympics World Summer Games. Our unified activities only lasted for most of the day. The delegation was energetic and got along well with us. We had to speak different languages. Nonetheless, we communicated smoothly in activities and cooperated well when playing basketball, tug-of-war, and badminton at Jianping West Middle School. A farewell banquet was also held at the Intercontinental Shanghai Pudong. I also attended it.

Q: Could they speak Chinese?

Xiaobo: They would merely say “nihao” (meaning “hello”). We would encourage each other via hugs.

Q: Didn’t you talk in English?

Xiaobo (smiled shyly): We might say “Thank you” and “Hello.”

Q: Which municipal or community-level Special Olympics activities did you join in?

Xiaobo: In May 2005, I took part in the Special Olympics activity held at Meiyuan Community Subdistrict and won second prize in the men’s football event. In September 2005, I won third prize in the men’s 200 m in the sixth Shanghai Municipal Special Olympics Games. In October 2006, I ranked third in the men’s 100 m and fourth in

the 4 kg shot put in the Special Olympics Shanghai Invitational Games. In May 2007, my team came third in the team basketball set shot at the Lujiazui Functional Area Special Olympics Games. I joined in the Pudong New District Special Olympics Games and won a prize in the men's 100 m (Group B) on November 11, 2008.

Q: How did your life change after participating in the Special Olympics events?

Xiaobo: Thanks to sports activities, my appetite was stimulated. So was my metabolism. My internal organs can function better when sweating. My limbs also became more flexible and better developed.

After I began to participate in Special Olympics activities, I could obviously feel that I was full of energy and confident and able to communicate naturally with others. All in all, I think I have more options in life. I have been raised to perform well and take the initiative to do whatever I can. When I paid home visits, I learned that some children with ID could not go to the Sunshine Home due to various reasons. Consequently, my mother and I came to them to do basic exercises such as passing and dribbling the ball. They were happy and asked me to accompany them frequently. These movements might be simple. Nonetheless, I think parents were happy to see that their children have a companion.

Being a Volunteer as Optimistic and Positive as Forrest Gump

Q: How did you apply to be a volunteer at the 2007 Special Olympics World Summer Games?

Xiaobo: I contacted first Mr. Bi, who was in charge of the Volunteer Center under the Pudong New District Spiritual Civilization Office. Mr. Bi knew that my mother was in charge of the subdistrict CAPIDR and I worked as her assistant. He contacted my mother to confirm it. My mother asked me whether I was willing to be a volunteer. I said yes. In August 2007, I was asked to complete an application form at the Volunteer Center and joined other volunteers to be trained. Among 40,000 volunteers, I was the only one that was also a Special Olympics athlete.

Q: What was the content of your training?

Xiaobo: We needed to learn plenty of things. For example, we learned to receive global Special Olympics athletes, provide services and matters needing our attention. We also had to learn the concept and history of the Special Olympics, available sports events, matters related to ethics and religion, and international etiquette. I have participated in the volunteer training multiple times. My mother accompanied me once or twice. I joined in the rest all by myself.

Q: Were you required to speak other foreign languages?

Xiaobo: I can express myself basically in English. I was to serve a Special Olympics athlete from Jamaica jointly with a teammate. This was my first time being a volunteer in a major international event. I was not familiar with the process at first. My teammate guided me until I got used to it gradually. Later on, I could serve the Jamaican athlete smoothly. My job was to help him carry a basket at the Pudong New District Natatorium.

Q: Carrying a basket?

Xiaobo: Exactly. It was loaded with swimwear, towels, mineral water, and light refreshments needed by him. My duty was to accompany him at the site, carry the basket before the game, cheer him on during the game and help wipe him down and change clothes and supply light refreshments. I also presented awards to swimmers. At first, the Shanghai Special Olympics Organizing Committee did not arrange volunteers to present awards for athletes. Knowing that I was the only Special Olympics athlete as a volunteer, they made an exception and gave me the honor of presenting awards to Special Olympics athletes and outstanding volunteers. I was greatly encouraged by the honor. It also encouraged Special Olympics athletes to go all out in competition.

Q: Did you communicate with the Jamaican athlete?

Xiaobo: I mainly greeted him in English. We hardly communicated with each other verbally. Instead, I supported and encouraged him via body language such as a smile, a thumbs-up, or a hug.

Q: What impressed you the most during your volunteer services?

Xiaobo: I was interviewed by major media. I was even invited once to attend a press conference arranged by the Shanghai Special Olympics Organizing Committee. It was raining moderately. My mother accompanied me to the press conference.

I sat at the platform and was interviewed. I thought I must be in a dream. Ha-ha. Then, my thoughts as the volunteer at the Special Olympics Games were reported instantly on major news platforms and media. I was known as the “Forrest-Gump-like volunteer.”

I released my thoughts on participating in the Special Olympics Games on Sina Blog in succession. One article named *The Forrest-Gump-like Volunteer* was published on a Special Olympics feature page on *Jiefang Daily* on Tuesday, October 2, 2007.

Q: Who came up with the name of the “Forrest-Gump-like volunteer,” you or others?

Xiaobo: I was the only Special Olympics athlete serving as a volunteer there. The media gave me that name naturally when interviewing me.

Q: Which media used that name?

Xiaobo: Media such as China Central Television (CCTV), Dragon TV, and Phoenix TV.

Q: Why would they call you that?

Xiaobo: They thought I was as normal as regular people and capable of providing services I can to foreign athletes. “Forrest Gump” may not get double digits in the IQ test. Nonetheless, he still grows up to be an optimistic, positive, brave, and sincere person. These media outlets may have thought that I have these merits.

Q: Did you feel different participating in the Special Olympics Games as an athlete and as a volunteer respectively?

Xiaobo: As an athlete, I became stronger and faster and my limbs became more coordinated. I could also help my teammates within my power. I felt happy. As a volunteer, I felt I shouldered great responsibility to serve the athletes. First of all, I

had to be careful when taking care of my teammate. I think I became more careful in looking after my teammate.

Q: What other volunteer activities did you join in?

Xiaobo: I've done a lot of volunteer work with photography and video recording. Mr. Xue, my first photography teacher, has also taken me to photographic activities at all scales such as the 2010 photographic activity to welcome the World Expo in Shanghai. I joined in the "Smiling under the Sunshine" themed activity held by the Pudong New District Sunshine Home in 2011. I primarily took photos and shot and won the honorary title of the "outstanding volunteer." From 2009 to 2013, I also undertook the task of taking photos and shooting the annual staff meeting of the Pudong New District "You and I Helping the Disabled Service Society."

During the 2010 World Expo, I, together with another Special Olympics athlete from Beicai Subdistrict, joined the "Pudong Family Blog Saloon" team to serve as volunteers in metro stations on weekends. We promoted the escalator etiquette of "standing right and walking left." I also gave directions when asked. I helped people in wheelchairs to places they wanted to go to. I further shared my volunteering experience at the metro station in my blog.

Being Tutored to Pass the Preliminary Contest of the English Competition Named "Star of Outlook"

Bo's mother: When I worked as the Chairman in the subdistrict CAPIDR, a group of college students from the Department of Navigation from the Shanghai Maritime Academy visited the DPF in our subdistrict and offered to provide disabled persons volunteer services such as the door-to-door tutoring services, counseling services, and company services. The DPF convened community disability service assistants to investigate the disabled persons and their relatives in need of free "door-to-door tutoring services." I got the list and contacted college student volunteers. The "door-to-door tutoring services" have indeed brought dramatic changes in families with disabled family members and have been welcomed in these families.

Q: How?

Bo's mother: W was the first person to receive door-to-door tutoring services from college student volunteers. Suffering intellectual disabilities, she merely stayed at home and watched TV all day long or went shopping with her mother. She barely communicated with the outside. Both I and these volunteers were shocked when we visited her for the first time. She cried easily. As a result, volunteers were careful with words to avoid embarrassment. Starting from the actual situation, they tutored W in logical thinking and language. She was tutored in math in the first semester to enhance logical thinking. In the second semester, W was tutored primarily on verbal communication. After nearly a year's effort, W could get along well with volunteers. Her parents feel that her mental health has improved dramatically.

These volunteers thought they should explore further (methods to help and tutor people with ID) according to individual characteristics. The subdistrict DPF, the CAPIDR, and volunteers discussed it and made detailed teaching plans. Moreover, volunteers further tutored W to write short compositions at the request of W’s father. A while later, W surprised us and made progress in all aspects. Her parents were grateful to these volunteers and invited the subdistrict DPF and the CAPIDR to send a silk banner to the Shanghai Maritime Academy. “The subdistrict DPF and the CAPIDR and Shanghai Maritime Academy cooperated to provide the service of tutoring disabled persons. It was timely help in our family. Thanks to door-to-door tutoring services provided by these volunteers, my daughter has become more optimistic and has made great progress,” written in a thank-you letter by W’s father to the Youth League General Branch of the Shanghai Maritime Academy.

As another example, Y was weak because of premature birth. She was shy and could not open up easily to communicate with others. She studied in a regular school and had a sense of inferiority because she could not catch up. Later on, she was transferred to a special school in Pudong New District and performed very well there. In 2004, Y was to graduate from the special school. At that time, she was studying *New Concept English 3* and hoped to pass the English exam smoothly. Knowing about her needs, the subdistrict DPF and the CAPIDR arranged college student volunteers to tutor her at her home. The Department of Navigation organized students good at English to tutor Y on Thursday nights. Consequently, Y passed the English exam smoothly and enrolled in a junior vocational and technical school in September. She graduated in 2007 and worked in an information service company after a recommendation from the subdistrict DPF. Before Y started work, her mother invited me to send a silk banner to the Department of Navigation at the Shanghai Maritime Academy to thank these volunteers.

In 2008, two volunteers that already graduated and working visited Y. They called Y and said, “We are no longer tutors and students. We are friends. We will cherish our friendship. You can call us if you need any help in work and life.” Both Y and these volunteers started work. Y’s mother was impressed by the consideration of these volunteers.

Xiaobo: I have also benefited from the service. On November 5, 2008, I read news on the education page of the *Shanghai Morning Post*: The CCTV “Star of Outlook” English Competition, which has been held for 9 years in succession, opened applications for the 2009 competition (Shanghai Division). I was interested in English recitation at school. Seeing the news, I wanted to participate and bravely express myself. My mother also supported my decision. According to requirements of the organization committee, every candidate should give a 2-minute speech without notes. I tried to select a topic. My mother also offered a sea of topics, which I thought was not suitable for me. Shanghai was to host the World Expo in 2010. In the expo garden, the “Life and Sunshine Pavilion” had been established for the disabled. As a result, I set the title of my speech as “My Wishes for the Shanghai World Expo 2010.” I think the title was the most appropriate there.

My Wishes for Shanghai Expo 2010

After browsing the official website of the Shanghai World Expo 2010 and visiting the Shanghai World Expo Display Center, I knew that the “Life and Sunshine Pavilion” will be established for the disabled at Shanghai Expo 2010. I am happy from the bottom of my heart that I live in Shanghai, a beautiful city.

During this period, we, the dance team under the Lujiazui Subdistrict “Sunshine Home” constituted by people with ID, were busy rehearsing a performance called *Haibao Dance*. The teacher was making tailored Haibao costumes for us. I think it will be a marvelous moment when we perform with these costumes.

I have a wish at Shanghai World Expo: in 2010, on a large and glittering stage covered with red carpet in the Life and Sunshine Pavilion for the disabled, all dancers with ID from the “Sunshine Homes” in Shanghai can dance and sing, in order to give a wonderful performance on behalf of Chinese people with ID for international friends on site.

I have a wish: I am a volunteer at the Life and Sunshine Pavilion for the disabled. I will do my best to serve the disabled persons, feel the theme of “equality, participation and sharing” in the pavilion, and get spiritual enlightenment, a vision of a better city life during the interaction and exhibition.

Q: How good was your English?

Xiaobo: I can express myself. I am confident. On November 11, 2008, Yang Zhimeng, a volunteer from the Department of Navigation, visited our home to tutor me in English speech. My first impression was that he was tall, easy-going, lively, and handsome with a sense of humor. He tutored me on pronunciation from phonetic symbols and taught me to memorize words according to their meaning in Chinese. I repeated after him and kept practicing. He was agile and smart, creating a relaxed study environment. Thanks to his tutoring, I could read correctly the speech several days later. Next, I managed to recite it.

On January 17, when I gave my speech of *My Wishes for Shanghai Expo 2010* in the preliminary contest, I saw myself expressing my talent to the greatest extent after brave efforts. I was confident and completed the speech correctly. With a storm of applause, I passed the preliminary contest smoothly. In the next contest, candidates were required to look at a picture and tell a story. I thought it was beyond me and quit.

Q: Were judges aware of your condition at the preliminary contest?

Xiaobo: Yes. I mentioned in my speech that “I am a student at the Sunshine Home.” Shanghai was to host the World Expo 2010. My speech was titled *My Wishes for the Shanghai Expo 2010*. The Life and Sunshine Pavilion in the expo garden was to display exhibitions related to disabled persons exclusively. As a result, I wanted to serve as a volunteer.

Bo’s mother (inquired Xiaobo Wang): How did your speech start?

Xiaobo: Distinguished guests, ladies and gentlemen. (Mother laughs proudly.)

Q: What were the comments of the judges?

Xiaobo: After the speech, I checked the result on the computer. It showed “congratulations on passing the preliminary contest.”

Q: Didn’t they comment on the spot?

Xiaobo: No. All competitors left the classroom after completing the speech. They would check the results on the official website. Those who passed could prepare for the following competitions. Therefore, I believe more firmly that helping others is helping yourself. The volunteer must be guided by God to help me achieve my dream of giving an English speech. I am grateful for all of these things.

Marching Forward Courageously and Contacting and Cooperating with Over 20 Work Units

Bo’s mother: We have benefited a lot from the door-to-door services provided by college student volunteers from the Shanghai Maritime Academy. We have also been motivated to seek cooperation opportunities with enterprises and public institutions.

After completion of the 2007 Special Olympics World Summer Games, Xiaobo and I, being endorsed by the DPF, started to look for cooperative enterprises and public institutions. During the decade when I served as Chairman in the CAPIDR, about 28 enterprises and public institutions have established cooperative relationships with the CAPIDR. Xiaobo and I learned to communicate with others in practice (see Fig. 1).



Fig. 1 Xiaobo Wang (in red) watching a billiards game in an inclusive activity

Shanghai Oriental Art Center was the first one we visited. It was on a National Day for Helping the Disabled. Pudong New District Disabled Art Troupe was about to perform there. The subdistrict office was allocated limited tickets. Families in the CAPIDR wished to watch the performance. Xiaobo and I went to negotiate with the Public Relations Department of Shanghai Oriental Art Center. We told them honestly our wish. Knowing that we were there to ask for tickets for the disabled group, the lady in charge was generous and brought out about 20 tickets from a drawer and gave them to the CAPIDR as a gift.

Q: How did Xiaobo contact these enterprises and public institutions?

Xiaobo: I searched their addresses and contact information on the Internet. Next, I called the persons in charge at the Human Resource Department and told them that we would like to cooperate with them. If they agreed, I would visit them personally and introduce the Sunshine Home briefly.

Q: How were you received? Did these people show a tendency for cooperation?

Xiaobo: Most of them were friendly and wished to offer public services.

I will list two examples. One was Shanghai Sibada Cultural Communication Co., Ltd. On July 17, 2012, it launched the “Sibada Cup Lujiazui Special Olympics Community Home” Summer Camp jointly with Special Olympics athletes and parents in Hongkou District and Pudong New District. We had a tug-of-war, kicked shuttlecock, and played table tennis and billiards. We got along well with each other.

Second is the New York University Shanghai (NYU). At first, I wanted to learn spoken English at NYU. As a result, I sent an email to the Office of Academic Affairs of NYU. Mr. Xu, who was in charge of public services, invited me to have a face-to-face conversation at the school and wished to launch activities at the Sunshine Home. I was highly thought of and shouldered the responsibility of connecting NYU and the Sunshine Home. I thought it was a mission from God. Everything went smoothly next. First, Chinese and foreign students from NYU visited the Sunshine Home and held a party. I recall that it was before Christmas. They got along well with students at the Sunshine Home. Second, students from the Sunshine Home were invited to a party in the classroom in NYU. We sang and performed a sign language dance. Students from NYU learned sign language with us. We could feel that they were inclusive and open-minded via body language.

I further contacted a business group. I met its president at a charity dinner held by Special Olympics East Asia. She was nice and appreciated my efforts.

Bo's mother: She was keen to offer public services. After Xiaobo contacted her multiple times, she took time to negotiate with the subdistrict DPF on cooperation. Regardless of success, we could feel her passion for charity.

Xiaobo: After the 2007 Special Olympics World Summer Games, we hoped that schools nearby would hold large Special Olympics activities for Special Olympics athletes. I turned to the Secretary of CPC General Branch of Dongchang Middle School Affiliated to East China Normal University, which was located nearby. The person in charge understood me and was willing to cooperate with the Sunshine Home to launch activities. However, its school time conflicted with ours. Their students could come to the Sunshine Home after half past three in the afternoon. However, the Sunshine Home is open from nine o'clock in the morning to half past three in the

afternoon. Lujiazui is known as a finance and trade zone that houses massive major enterprises and schools. Personally, or speaking from the perspective of Special Olympics athletes, it will be terrific if the Sunshine Home could cooperate with them to hold Special Olympics activities.

Bo’s mother: We have cooperated with numerous enterprises and public institutions to hold activities. For example, we watched *Swan Lake* at Shanghai Grand Theatre, listened to piano music at Shanghai Concert Hall, watched films free of charge at SFC Shanghai Cinema (Nextage Film Art Center) and visited Shanghai Ocean Aquarium and Shanghai Zhoupu Prison. Our Special Olympics athletes were trained at Jianping West Middle School. We have also cooperated with Shanghai Oriental Art Center and Shanghai Wild Animal Park.

When we went to Shanghai Flower Port for the first time, Pudong Public Transportation Co., Ltd. provided us with free shuttle services. We also visited Wusongkou Paotaiwan Forest Marsh Park free of charge. We were given a discount when holding the annual get-together of our association in Shanghai No. 1 Revolving Restaurant. We participated in an experimental and outdoor education program sponsored by Action Training in Qingpu District. We also had free lunch. Shui’ai launched Yoga training programs and held lectures at the Sunshine Home. Wuxing Ceramic Art Studio provided the venue and taught students at the Sunshine Home how to make pottery and sent ceramics to all students as a gift.

Xiaobo thinks that most enterprises are friendly and are willing to join in public welfare activities. He, on behalf of Special Olympics athletes, would contact these enterprises either by email or personally. His efforts are recognized by persons in charge of these enterprises. However, not all enterprises are willing to cooperate with us. I told Xiaobo, “You will encounter all types of enterprises. It is an opportunity to practice your patience.”

Xiaobo: I contacted a foreign-related enterprise. It is said that the enterprise is keen to do charity work in communities. But it is not true in reality. I visited the enterprise multiple times and communicated with the head of its Human Resource Department. He promised at first, they would try to launch charitable activities at the Sunshine Home. I was told that they had cooperated with a college club. They would cooperate with us at the right time. However, they kept paying lip service or putting off holding activities when I contacted them over the phone or face to face later on. Well, I think they could have been frank and told me the truth. It was unnecessary to fool me over and over. Despite that, I still communicated with them politely. From my communication with all types of enterprises, I can feel clearly their attitudes toward Special Olympics athletes and unified movements. I am also aware that it is not stipulated that enterprises must hold public service activities for the disabled. I have learned a lot when communicating with enterprises.

Bo’s mother: It is also a way to learn. Xiaobo can expand his vision and deal with all sorts of people.

In fact, in my opinion, if the enterprise does not want to cooperate with the DPF or the Sunshine Home, it can be frank with Xiaobo, “Wang, we have no such plans at present. We will contact you when we do.” Do you agree? On the contrary, they were misleading and just beat around the bush, dampening Xiaobo’s enthusiasm.

I comforted Xiaobo that it was a test by God. He should be honored to be tested. A large number of enterprises are willing to cooperate with us. This is the only enterprise that is not friendly. Xiaobo even visited its headquarters once.

Xiaobo: I was told that the enterprise was keen to do charity work in the community and suggested trying again.

Q: Did the headquarters contact the enterprise and ask it to cooperate?

Xiaobo: I was told that it was an independent enterprise.

Bo's mother: After this experience, I think Xiaobo has become more patient and can understand others when solving problems. I am happy to see his growth.

Xiaobo: Society is sophisticated. We need to have a strong mind.

Q: Does any of the cooperative enterprises mentioned above still hold activities jointly with the Sunshine Home?

Xiaobo: We still cooperate. NYU is busy and does not hold any activities at the moment. Students at the Sunshine Home hope that I can serve as a bridge and contact it again to launch activities jointly.

Q: Do enterprises need to sign cooperative contracts?

Bo's mother: We will (sign contracts) if these enterprises ask to. For example, we have entered into a contract with the Shanghai Maritime Academy.

Xiaobo: We may also enter into long-term cooperative contracts with enterprises such as SFC Shanghai Cinema (Nextage Film Art Center). People from the subdistrict CAPIDR and students from the Sunshine Home have been organized to watch films regularly.

Q: What is the impact of these activities on students at the Sunshine Home in your mind?

Xiaobo: Staff from these cooperative enterprises and public institutions and students from the Sunshine Home jointly made handwork, drew pictures, went on trips, and learned sign language. Thanks to their efforts, these students can enjoy a colorful life, find and develop their potential and talents, and become confident. They pass on positive energy and are optimistic.

Q: What do these activities mean to the Sunshine Home?

Xiaobo: Thanks to these activities, enterprises and public institutions can know students' mental state and routine study and life at the Sunshine Home. We can also tell them our needs and interests. They will do everything they can to help us and enrich our lives and encourage us. I think it is a virtuous cycle.

Q: Xiaobo, how did you change in the process of contacting these enterprises and public institutions?

Xiaobo: It makes me feel that I am competent when I start to communicate with potential cooperative enterprises and public institutions. On the one hand, I have contributed to better operations of the Sunshine Home. On the other hand, I can enhance my capabilities in communicating smoothly with all sorts of enterprises and express our intension exactly.

Q: You and Ms. Yan mentioned repeatedly the word "empowerment." When did you get to know the word?

Xiaobo: My mother and I learned it from our communications with an enterprise. It used the word as a sign of trust on the basis of my optimistic and aspiring words

and deeds. I could not understand clearly its meaning at first. After searching on the Internet, I knew that it is a new concept that refers to measures designed to increase the degree of autonomy and self-determination in people.

Bo’s mother: I think Xiaobo has done a good job. He is eager to practice and improve social communication skills. In his words, thanks to the platform of the CAPIDR, he has learned things he could not learn in class. If the CAPIDR is compared to the “Whampoa Military Academy” and cultivates special talents, Xiaobo can stand up and exclaim proudly that he has already graduated from it.

Creating Opportunities for Everyone to Join in a Camp

Bo’s mother: Several years ago, the Shanghai University of Sport invited Special Olympics athletes from Pudong New District to participate in “Camp Shriver.”

Q: Where did you learn about it?

Xiaobo: We read about it on the Weibo account of Special Olympics East Asia and *Lingzhicao* (meaning “Snake Jasmine”), the internal magazine issued by the Shanghai DPF. I took the initiative to contact Professor Xueping Wu from Shanghai University of Sport. She was very supportive and asked me to write her an email, explaining that I wanted to participate in the camp. Then, I received the invitation from Shanghai University of Sport, inviting Special Olympics athletes from Pudong New District to join it.

As a Chinese saying goes, it is more joyful to share joy than enjoying yourself alone. It is better to invite people from Pudong New District CAPIDR to play a part. On hearing the good news, I was empowered by the CAPIDR to be in charge of it. Professor Wu wrote in her email that I needed to create an Excel table with athletes’ and their parents’ name, gender and ID card number and athletes’ age, height and weight. Uniform clothes would be prepared. My mother and I texted persons in charge of every subdistrict CAPIDR and asked them to collect information. Next, I created the Excel table and emailed it to Professor Wu.

Q: How many people with ID joined in the camp with you?

Xiaobo: All in all, 20 Special Olympics athletes from our subdistrict and Pudong New District CAPIDR went there. Moreover, 20 parents accompanied them as teammates to cheer on these athletes and provide logistics services.

Q: Did you join as the person in charge?

Bo’s mother: No, the person in charge was the Chairman of Pudong New District CAPIDR. I worked as a liaison to promote successful completion of the activity.

Q: What was the specific training content at the camp?

Xiaobo: We accepted basketball training together with student volunteers from Shanghai University of Sport. Instructed and led by coaches, we experienced activities such as dribbling the ball, passing the ball and doing a lay-up and back-to-back basketball relays. We also played games such as puzzle games or held hands with hits and exciting background music.

Q: How long were you trained every day?

Xiaobo: We took the shuttle bus provided by the Shanghai University of Sport and arrived there at eight or nine o'clock in the morning and ended at three or four in the afternoon. We had free lunch at the Shanghai University of Sport. The cafeteria provided nutritious meals according to our training intensity. It was really warm and considerate.

Q: Did you feel tired after a day's training?

Xiaobo: No. I was happy to play with my companions.

Q: How did the coaches get along with you?

Xiaobo: They applauded and encouraged us that we were the best. I think Shanghai University of Sport has done substantive work for Special Olympics athletes. I give it a thumbs-up. I hope that Camp Shriver can be held continuously. It would be better if similar activities could also be held annually at the subdistrict level and the community level.

A New and Relaxed Life Featuring Reading and Travel

Q: What about Xiaobo's plans in the future?

Bo's mother: He was exhausted at school and helped me greatly in the CAPIDR. Now, he is grateful and starts enjoying a comfortable and happy life.

Xiaobo: The top priority for me is to improve capabilities to take care of myself and manage money. I can basically deposit or withdraw money from the bank and go shopping online. I hope I can be more efficient and have more time to practice and learn.

Q: Do you still plan on being a volunteer?

Xiaobo: I follow the concept advocated by Mr. Tong; that is, "focusing on family life and reading extensively." I concentrate on doing things I am interested in and good at and keep learning to enrich my knowledge.

After knowing him since 2004, my mother and I registered in Sina Weibo and recorded and released our experience there. Instructed by Marshal Tong, I have started to read e-books on WeChat Read to improve my capabilities in cognition, reading and commenting gradually.

Bo's mother: Xiaobo has made great progress. He can speak fluently and has improved writing skills.

Xiaobo: That is also one of the obvious improvements after participating in the Special Olympics. I could not write well at first. I have collected rich materials when joining in the Special Olympics and activities held by the CAPIDR and been inspired to write.

Q: Why do you call Mr. Tong "Marshal Tong"?

Xiaobo: He reads a lot and his idea is novel and avant-garde. He helps me dramatically in life and studies. He is like Marshal Canopy to me.

Q: Has Xiaobo ever considered finding a job?

Bo's mother: He is skinny and particular about food. Regarding work, Xiaobo, after meeting someone when serving as a volunteer at the metro station, passed an

interview as a normal person to work as a part-time metro station assistant. He worked for 2 h in the morning shift and two more in the middle shift. He worked there for a whole year. It was windy. However, Xiaobo could not wear a hat or scarf according to regulations. As a result, he went to communicate with his leader and was transferred to a post at the hall. He also recorded his thoughts for the whole year. It can be seen that Xiaobo can fit into society well. It was both a work and a training opportunity. However, he is not in good health. His condition will be improved with an easier life. Taking this opportunity, Xiaobo would like to thank those enterprises giving him an offer after receiving his CV.

Q: Xiaobo and you have been to many places. Do you like traveling?

Bo’s mother: Sure. After I quit from being Chairman at the subdistrict CAPIDR, we were happy to go on trips. We can see different landscapes, customs and civilization in various cities.

During our trip, Xiaobo keeps saying, “Mother, I will protect you and help you with baggage.” It may be hard to buy water in scenic spots. Xiaobo will help me. He knows a lot about the route. He takes care of me. We take self-guided tours. When arriving at a place, Xiaobo will check the weather. If it rains, he will stay in the hotel and read and write down travel notes. If it is fine, we will go to scenic areas as he planned. Xiaobo observes carefully. He has many thoughts on seeing local customs and natural landscapes. He will record them after we return every day and share it on the Internet.

Q: Who makes plans before a trip?

Bo’s mother: Xiaobo is mainly in charge of that. For example, the day before we went to Guilin, he searched scenic areas on the Internet. We would follow his travel guides. He suggested going hiking in the Two Rivers and Four Lakes Scenic Spot. Two rivers mean Taohua River and Li River while four lakes refer to Ronghu Lake, Shanhu Lake, Mulong Lake, and Guihu Lake. We followed him. The trip was awesome.

Q: How do you usually go on trips?

Xiaobo: By air or by train. We take buses to go to urban scenic spots and taxis to remote ones.

Q: Is your schedule busy during traveling?

Bo’s mother: We don’t want to rush. We want to enjoy ourselves and taste local food, experience customs and see local art and natural landscapes.

Q: Where have you been?

Bo’s mother: We have been to numerous places such as the Three Northeastern Provinces, Fujian, Guangxi, Guangzhou, Shenzhen, Zhuhai, Hainan, Hong Kong, Macau, Taiwan, Hubei, Chongqing, Beijing, Hebei, Anhui, Jiangsu and Zhejiang. We have mainly taken self-guided tours.

Q: What is your favorite place?

Bo’s mother: These places are distinctive. I think highly of Shenzhen. It has a pleasant weather all year round. A large number of barrier-free elevators are installed in the metro station. Passengers can use them directly without the need to press a bell and wait for assistance from the staff. Environment is sound on the street with multiple ramp ways. Travel feels comfortable and convenient there. We have

also visited scenic areas such as OCT East, Shenzhen Lianhuashan Park, and the Window of the World in Shenzhen. I also think that Weihai is an inclusive and clean city. Drivers yield to pedestrians. We visited fantastic scenic spots such as Liugong Island, Weihai Park, Xingfu Door Garden, Yangmadao Square, and Chengshantou Scenic Resort. These cities are better developed.

Q: Do you have any travel plans now?

Bo's mother: No. We play it by ear and go on a trip if we want to. We will select a package tour if we go abroad.

Q: What is the main source of income in your family?

Bo's mother: My husband is an excellent technician. He has been appreciated by his company. He is even invited to give lectures in a former company. I have a retirement pension.

Q: Does Xiaobo receive any allowances?

Bo's mother: People with ID such as Xiaobo enjoy a permanent allowance from the Shanghai Municipal People's Government. We are contented.

Q: Xiaobo is single, isn't he?

Bo's mother: That is correct. I think Xiaobo is realistic and mature about the issue. He told me, "For example, if I sit in a coffee house with a girl and we look out toward the same direction, it means that we are destined to be together. It may not be the right time now. When it should come, it will come."

Xiaobo: I just want my partner to run the household with me. We can do housework and take care of each other. God will plan it.

Q: Are you a Christian?

Xiaobo: We are polytheistic. We respect religions but are not religious. We firmly keep away from any cult. I think gods will help me and empower me at the right moment.

Q: What are your expectations in the future?

Xiaobo: I just want to live a rich and colorful life. It is the most practical thing. I also hope to enrich my spiritual and cultural knowledge via constant reading and studying.

I have an idea. I hope that the Special Olympics can organize Special Olympics athletes to take a 2-week luxury cruise tour accompanied by their parents. Participants pay for the trip at their own expense. We, whether parents or children, are keen to travel.

Q: Xiaobo, who do you want to thank the most for your achievements now?

Xiaobo: My mother. She has done a lot for me. You can't write that down. She is forthright, honest, and kind-hearted. She has raised me up as a normal kid and taught me to be independent and shoulder responsibilities in the family. She has also been engaged in helping other kids with ID. I also want to thank my father. He works hard. He may have been strict with me sometimes, but I know that he did that for my sake. I want to do the same for them. Moreover, I am grateful to the DPF at the subdistrict and district levels. I have been trusted and encouraged when I was at the most disoriented moment.

Q: What's your expectation of Xiaobo's future?

Bo’s mother: I am content with things the way they are. Xiaobo may be strict with himself and seek perfection. He may get that from his father. I told Xiaobo that he should let nature take its course. Now, Xiaobo can prepare his diet according to his needs and make deposits in the bank. These things may be trivial but essential in life. I am satisfied with his performance. I don’t expect more. Fortunately, after shifting focus on the family life, Xiaobo’s physical condition has been improved greatly. Regarding marriage, I believe in serendipity. I just hope that Xiaobo can be happy and healthy.

Xiaobo (laughs): Happiness comes from contentment.

Bo’s mother: That’s correct.

Q: All right, thank you, Ms. Yan and Xiaobo. I hope everything will be better for Xiaobo and he can be confident and live a happy life. I also wish that you will always be young and beautiful. Let’s conclude here today.

Interview with Domestic Worker in the Wang Family

Interviewee: Ms. Li (domestic worker)

Interviewer and writer: GuliMire

Interview date: December 20, 2016

Interview place: Wang’s home

Q: Ms. Li, when did you start to work at Xiaobo Wang’s?

Li: In around August 2015. My main task has been cooking. I have learned from Xiaobo’s mother which dishes to make and the family’s taste. It is a part-time job. I only work for 2 h. If there is still time after the meal is ready, I will do some cleaning, mop the floor, and clean the gas range and the toilet.

Q: What is your comment on Xiaobo’s performance during your work there?

Li: When I went there for the first time, I thought he was lively and cute. He was also diligent and capable of many things. He liked exercising. He would go to the vegetable market if he had time and buy some. He has been obedient and filial. He cares about his mother and pats her on the back. I told him that it was my duty. He said, “It’s okay. I will do that.” They take care of themselves well. Both Xiaobo and his mother eat Chinese yam and tomatoes. Their rooms and the kitchen have been kept in good order.

I am happy there. When I make dishes, Xiaobo may help me washing rice. After he is done, he goes to do exercises such as running. He may also play badminton with his mother if he is free. I think he has made progress every day.

Q: Except for work, do you spend any extra time with Xiaobo and his mother?

Li: We sometimes go to a karaoke bar if we have time. I like singing. Xiaobo’s mother is a good singer. She sings *Invisible Wings* the best. I recall that we went to Shanghai GalaCity a short time after I started working at their home. Xiaobo sang an English song.

Q: Will you keep the part-time job at Xiaobo’s?

Li: Of course. I've started to work in the domestic worker voucher company since 2001. I have (done) it for 7 years. I will certainly continue doing it.

Q: How long will you continue working at Xiaobo's? Did you sign any contract?

Li: We sign an annual contract. For example, we signed a contract this January. We will sign a new one next January. So is the contract with Xiaobo's.

Q: Did Xiaobo say anything considerate during your work?

Li: Yes. I ride an electric motorcycle to go to work. Xiaobo told me to drive slowly and be careful. Moreover, he also told me to think positively, eat well, and go to bed early. I am contented with these words.

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Addendum: Metro Line Two Halted During a Heavy Rainstorm



Xiaobo Wang

It was Friday afternoon, September 13, 2013. A thunderstorm hit Shanghai at lightning speed and removed all dirt. After having lunch, I wondered whether I could go to work in the heavy rain. I have to, another voice said in my head. Therefore, I wore a raincoat and slippers and went to work, with an umbrella in my left hand and a knapsack in my right hand (carrying my sneakers, socks, and a towel). Wow. I waded into the deep puddles on the street, hearing my footsteps. I was in a good mood in the heavy rain.¹ I could jump in the water puddles. However, some scenes were unpleasant. It was gross to see rubbish floating in these puddles. It was common in certain streets in Shanghai. I finally reached the metro station. I took out the towel, dried my feet and changed my sneakers when entering the Metro Line 2 Station.

I started my work in my orange uniform. It was raining heavily with lightning. We, metro station assistants, arrived in advance as usual to wear our uniforms and voice amplifiers. We were energetic and delighted to engage in work.

When I was promoting the escalator etiquette among passengers, I heard news broadcasted repeatedly: (general idea) Metro Line 2 has suffered a malfunction and will stop operation for a period of time. Passengers in a hurry can select ground transportation means. Those that have already bought a ticket may return the ticket in a nearby metro station within 7 days.

I suddenly heard that I was called by Mr. Yang, our Manager. It was raining heavily. Nonetheless, he still came to cheer us on. He has often encouraged us spiritually. In cases of emergency, all staff at the metro station worked at the front line under the instruction of the Manager to guarantee safety of passengers and normal operation of the metro line.

¹Xiaobo Wang likes reading and writing. This is an essay he wrote when he worked as a part-time metro station assistant. The editor has made no modification.

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After we were off duty after the evening peak, we could still hear news broadcast from time to time at the People's Square Station: "Metro Line 2 heading Pudong has stopped due to a malfunction. Passengers in a hurry may select ground transportation means..." I put away my uniform and voice amplifier in the Manager's office. I noticed that other assistants were leaving. There was no sign for us to work overtime due to the heavy rain. As a result, I followed them and left.

It seems that only Metro Line 1 and Metro Line 8 operated normally. Other lines were halted due to a reverse flow of rain. Passengers stuck at the People's Square Station waited in order and followed the instructions of staff. They either returned their tickets or waited for the metro to start again...

It was late. As a result, I followed other passengers and walked out of the metro station. I walked onto the street after the heavy rain, with my footsteps sounding like rapping bamboo clappers in a comedy. I walked for a long time and was hungry. I bought some light refreshments and milk and walked to the bus station of Tunnel Route 9. A bus came after over 2 h. It was dark, crowded and stuffy in the bus. It was rainy. As a result, the window was opened. The air conditioner was not on at full capacity. Despite that, all passengers, after waiting for such a long time, were exhausted and grateful that they were on a bus in the end. I was proud of myself. I was one of the office workers. We were patient and energetic to go out, work and return home through heavy rain. I could feel strongly that everyone believes in the same things and passes on the same power, that is, hope is not far. We will arrive at home in the end if we are confident and overcome obstacles.

I was home by 22:20. Zhangdan thought I worked overtime. I told her that I was off duty at 19:00. I had to take a bus and waited for over 2 h for the bus, just like others did. She replied that I was stupid. She said that I could take Tunnel 3 near People's Square and return home. She said, Xiaobo, we support you working, and hope that you can learn to handle emergencies and find solutions.

It was hard to go to work. I felt strongly about that today. It reminds us that we must keep fit. Thank God for every blessing. Today, my physical condition ensured that I could handle the emergency with ease.

After I returned home, Zhangdan filled the tub with hot water and prepared warm ginger water in the foot sauna. After a bath, I drank goji berry and millet porridge while taking a foot bath. I felt her warm love from head to toe. I had a dream at night. In the dream, I also experienced heavy rain with lightning.

Go in grace. I can finally lie in bed comfortably and fall asleep...

Written on September 14, 2013 Cloudy

Translated by Weizhen Yang

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Down Syndrome Boy Loving History Books



Fengzhi Liu

Interview with Mr. Wei Yang's Mother

Wei Yang, male, born in 1983. Only child. Grade III intellectual disability. Graduated from Miyun School (a special school), Hongkou District, Shanghai. Joined the Sunshine Home in Hongkou District in 2005.

Interviewee: Huiqin Wang (Wei Yang's mother)

Interviewers: Fengzhi Liu, Puyu Zhang

Writer: Fengzhi Liu

Interview dates: October 22 and December 27, 2016

Interview places: Wei Yang's home, the Hongkou District Disabled Persons' Federation

A Lucky Child

Wei Yang's mother: Before I got married in October 1981, Wei Yang's dad and I were engaged for 5 years. He was born on 13 August 1983 when I was 25 years old (lunar calendar age 27). Before I retired, I worked at the Sixth National Cotton Factory in Shanghai. His dad was an office administrator in a neighborhood factory that processed plastic bags.

Q: When did you find out about the child's condition?

Yang's mother: It was after he was born. But before then in my ninth month of pregnancy, the doctor said the baby might be underweight and asked me if I wanted to come into the hospital for the rest of the pregnancy. So I spent 2 weeks in hospital. Suddenly, one day I couldn't feel the baby moving and told the doctor. He said let's

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do a blood test. At that time the Maternal and Child Care Service Center wasn't very well equipped, and they didn't have the equipment, so they asked my family to take a blood sample to the First People's Hospital. But on that day, their test machine was out of service, and it had to be delayed to the next day.

When the result came back, they said it wasn't good news, the baby had fetal hypoxemia and I might need an emergency caesarean. All the doctors were off duty, so I had to wait for the next morning. The operation started at 8 a.m. and was finished by 11 a.m. The doctor told me: "Your child might have fetal hypoxemia, but he looks fine." We couldn't tell then, if the child had Down syndrome because he was a pretty baby, small eyes with double-folded eyelids, curly hair and white skin. Even the doctors couldn't tell if anything was wrong. As it turned out, the baby had two problems; one was fetal hypoxemia, another one was that he was very small. He was 2 weeks premature, weighing just a little over three and a half pounds. The doctor said to feed him well and that might bring him back to good health.

When I was discharged, they wouldn't let him leave hospital with me and kept him in an incubator. Once, when the nurse was feeding him, I saw a mark on his head (points to the back of her head with her fingers). It looked like a sore, the doctor dressed it later. After 3 weeks, the sore became infected, and I said to my husband: "It's not doing the child any good at all leaving him here for longer." Then he said to the doctor that we wanted the baby to come back home with us, and he agreed.

I looked at him when he was in my arms and I was very upset, so upset. By now, there was a big hole (makes a shape the size of a badge with her fingers) on the back of his head! His dad is a very caring and careful person and he changed the dressing every day, leaving the wound open to the air when he was home: the weather was hot, and we didn't want the wound to become infected again. After that, it healed in a week.

The doctor told us the child's light body weight was a birth defect, and I would need to care for him all the time. I got some help from his grandparents. When he was 4 months old, and ordinary children would start reacting to the sounds around them, my son didn't. In fact, he couldn't turn around. His granddad said: "Why doesn't he react when I knock a cup or a bowl?"

So I took him back to the hospital and the doctor said he couldn't see anything wrong with him. He said to me: "He isn't active at the moment because he's underweight. Compared to other newborn babies, he's too small." At that time, I thought to myself, if the doctor says he isn't healthy, I'll have another child. It might be hard work, but bringing up a child is always a handful, I can certainly bring up two children at same time! But the doctor said: "I can't tell if your baby has a serious problem, but you shouldn't have a second child." If he is diagnosed with Down syndrome, and I had a certificate of the official diagnosis to prove this, I would have been allowed to have a second child.¹ But the doctor wasn't able to give me that

¹Having two children was allowed by invoking a special phrase under China's long term 'one-child policy,' which was formally implemented in 1982, and ended in 2015. According to the national family planning policy, civil cadres and workers and other city residents, a couple is only allowed to have one child except when they have one of several 'practical difficulties', for example they will

document at that time. He said: “We’ll see the child again when he’s a year old and check his condition.” So I had to go back home without family planning permission.

He was a lucky child really, on his first birthday, August 13, he suddenly started understanding all kinds of things, just like other children of his age. He’d be sitting in his pram—the old pram was a humble thing in those days—if he needed to pee and of course he couldn’t say anything, he’ll erm... (She mimes a moving and struggling baby), then I knew he needed to pee. Another thing we noticed was, if we knocked on a bowl, he would start to turn his head around to see where the sound was coming from.

So I went to see the doctor again, and told him about these changes. He said the child should be fine, but his premature birth and light weight was making him develop slower than a normal child. This diagnosis changed my mind and I gave up on the idea of having another child.

He started to talk when he was one and half, almost 2 years old. But he still couldn’t tell us if he needed the toilet. Every morning, when I put him on the potty if he needed to poo, he wouldn’t stand up. Then I knew what he wanted to do, but he couldn’t tell me; he couldn’t walk either. But he looked as though he was able to understand something. If I put a horn recording radio² on his desk, he’d tap his hands here and there and move around.

Later, maybe when he was about 2 or 3 years old, his face started to change (the child started showing signs of Down syndrome facial characteristics). One day, I looked at his face, and the distance (shows the distance between the eyes) is getting wider. So, I took him for a blood test at Xinhua Hospital, and the result told us clearly that he had Down syndrome.

Now he was almost 3 years old, and I would be allowed to have a second child.³ The doctor said if I got a document from the subdistrict office, I’d be able to have two children.

At that moment I was thinking about this over and over. He’s a toddler already, if I had a daughter that would be fine, she’ll look after him when he grows up. But if it’s another son, what will happen to him? To raise a son, (she refers to the interviewer) you’re too young to understand this situation... you’re unmarried so you don’t know. A son will always be controlled by his wife after he gets married. I thought, this won’t work, if he has a young brother, he might not look after him once he gets married.

Also, I was worried that a second child might have the same condition—health and medical conditions were so far behind in those days—nowadays pregnancy tests can tell you everything. This kind of medical technology was unavailable at that time. What would I do if I had another disabled child?

be allowed to have two children if their first child suffers from a physical disability, mental illness, or an intellectual disability.

²The ‘horn recording radio,’ which she’s talking about refers to a large portable radio cassette player, a very popular family music player in the 1980s.

³According to the national family planning policy, even if a family meets the conditions for a second child, there has to be a 3- or 4-year gap between children.

At the same time, I was worried that I wouldn't be able to give much attention to my son if I have a second child; the little one would need to be looked after as well.

Although his grandparents liked him very much, even though his paternal auntie didn't, I don't think they would have loved him so much even if he'd been a healthy, normal baby. We didn't have much money, both my husband and I worked in the neighborhood factory. I worked in that factory for 10 years until they moved out of the neighborhood. When the factory asked if anyone wanted to be reemployed in a textile mill for more money, I took the opportunity.

If we had a second child, then I would have to spend a lot more money on his or her education and university tuition and have nothing left for the disabled child. I was thinking about all of these things, and eventually I made up my mind not to have a second baby, but to bring up the first as best I could. This is why we don't have two children.

Q: Did he live with his grandparents when he was little?

M: We all lived together in the same Tingzijian⁴ but it was divided in two—we were in the front, and his grandparents lived at the back. Wei Yang stayed with them when my husband and I were at work. When my son was older, he liked to lock the door to our space and wouldn't allow his grandparents in. Now both of them have passed away; his grandpa died 18 years ago, his grandma died over 20 years ago.

Q: Did his grandparents keep him company all the time or did they have other things to do?

Yang's mother: They stayed with him all the time. But Grandma wasn't very well, she developed Alzheimer's disease. Grandpa would take her and the child out for breakfast and buy food and vegetables for the evening meal. He would cook lunch and then they would go out again when he played mahjong. Grandpa took Wei Yang with him everywhere he went. They only came home when we returned from work. At that time, his dad was very busy, he was an official in the factory. My factory operated round the clock, three shifts, if I was on the afternoon or night shift, both my husband and I wouldn't be home in the evening, and his grandma would put him to bed.

Q: When he was young, except for his grandparents' company, did he have any professional help in a rehabilitation institution?

Yang's mother: No, he didn't. Once his paternal auntie introduced us to some medicine, I can't remember the name now. She said it would good for his condition, but it didn't work for him. We didn't send him to a rehabilitation institution for treatment because his condition was different, much better than other children who had the same condition. He could walk and talk, he was able to read, we didn't worry so much. While his grandparents looked after him, he wasn't stuck at home all day, which would have been bad for him; they took him out every day.

Q: Did you try to do anything to develop his intelligence?

⁴Tingzijian refers to a north-facing small room, usually a servant's room originally at the corner of the first level of the classic, well-known 19th century multi-floor homes, Shikumen. More information about Shikumen residences can be found at these links: <https://www.travelchinaguide.com/attraction/shanghai/shikumen.htm> or <https://en.wikipedia.org/wiki/Shikumen>.

Yang's mother: I would take him to the park when I was free. I didn't have the time to do any kind of intellectual development with him, because I was working three shifts. His dad was always very busy, too. He left home early but came back very late. My time was taken up with all kinds of housework, shopping, cooking, washing; we didn't have a washing machine or anything like that. When he was older, I didn't even have time to help with his homework. I only realized he could read when I saw him with a newspaper one day.

Q: Did you try to teach him?

Yang's mother: No, we didn't. But when I discovered he liked music I bought him some tapes to play with. When he was a child, I also bought his favorite cartoons like *Mr. Black*, *Little Dragon Mermaid*, and *Monkey King*.⁵ We didn't teach him in a formal way, but took him out often. His dad usually took him out to play; sometimes I'd join them as well. If I worked two morning shifts, two afternoon shifts, or an evening shift schedule, I was able to take him somewhere when I finished.

Q: Did he go to a nursery when he was young?

Yang's mother: He only spent one semester in a nursery, because he was excluded for bad behavior. He was very naughty back then, beating and biting other children (with a resigned smile). He liked to stay away from other children and play with his toys. If other children saw him and tried to grab his toys, then he would fight back.

One of the Best Students in His Special School

Yang's mother: He was very small when he was born, and he grew into a skinny boy, not as big as he is now. When he was nine and ready to go to school, I was afraid when he arrived to register that they might react to his condition and reject him. So I tried to talk to a teacher in an ordinary primary school and told her: "My son is the right age for school, but he isn't in Shanghai right now, can I bring him to your school next year, when he grows up a little bit more?" But I didn't tell her that he had Down syndrome. She was a very good teacher, and she said: "It's no problem, bring him to us next year, please."

He enrolled at that school the following year, but he couldn't study because he was still too young. His classmates were reading and studying in class and he couldn't understand what to do. One teacher said me: "Your son doesn't really fit in here; he needs a special education school." At that moment, I was... I cried again. I had to think about what to do next, every child needs an education. He had to go to school; he mustn't stay at home.

He could already read very well when he was school age. You might ask, how could he do that? It was because we subscribed to *Xinmin Evening News* when he was five, and one day I saw him holding the newspaper and he looked like he was

⁵All of these three are very popular TV programs from the 1980s. *Mr. Black* was a famous Chinese cartoon for many generations.

reading. I asked myself, how could he read? His dad said: “I don’t know either. He just picked up the newspaper and looked like he was reading.”

His grandparents looked after him until he was ready to go to school. His grandpa liked to play mahjong and my son would always sit next to him and play with his own game. He has a very good memory, he learned to recognize and remember the words on mahjong tiles after he heard people call them out such as: “East wind, whiteboard.”

At first, I couldn’t work out how he could read, but after I gave it some thought, I realized that he had memorized all 144 mahjong pieces! There are characters and numbers, like “fortune” and others, and this ability of his made me determined that he should get a proper education; he has to be independent one day.

After I was let down by the ordinary school, I took my son to the Hongkou District Welfare House. The teacher asked him a lot of questions like “Where do you live? What’s your mom’s name? What’s your dad’s name?” My son answered all of them. When he was younger, about six, more or less, he could talk to the doctor about his pain or symptoms without my help. After the interview, the teacher said: “You shouldn’t leave the child with us, we won’t be able to teach him very much. We’re just a kind of children’s nursery. You should take him to a special school.” I didn’t even know there was one! Then I found out that there was one on the Tianbao Road. The teachers enrolled him when they saw his condition.

Q: How long was he at the ordinary school?

Yang’s mother: Probably about 2 months, but he couldn’t stay there any longer. His face revealed everything, even though some children who were less intelligent than my son could stay on.

Q: You mean he had to leave because he had Down syndrome?

Yang’s mother: One thing was his condition, another was he couldn’t keep up with the other students.

Q: Is there a big difference between the two kinds of schools?

Yang’s mother: The teaching materials are similar; the ordinary school has its own standard textbooks, but the pace of learning at that school was difficult for him. The difference is that the special school, the Miyun Road School, has a much lower standard of learning, because those children with special needs have a slower learning ability. For example, my son is in his 30 s, but his intelligence is only equal to that of a young teenager. When he started school at 10, his brain was only developed to a level equivalent to that of a 5 or 6 year old.⁶ That’s why he couldn’t keep up in an ordinary school. The first year’s teaching schedule and material at the special school is the same as the final year in a nursery. They only start to study at the level of an ordinary first grade when they have reached the second grade in the special school. There’s quite a difference between the two kinds of schools.

Q: So the gap is 1 or 2 years?

Yang’s mother: Probably more than that, say 3 years. After he transferred to the new school, I stopped worrying about him. The teachers liked him because he was

⁶Down syndrome patients usually have intellectual difficulties that gradually increase with age; their IQ is usually between 30 and 55.

very well behaved in class, never screaming or running around like some of the other children, and he always listened to them.

At the same time, he was a good student; there were over ten in the class, divided into three groups: good, average, and poor. He was in one of the top groups. He always handed in his homework on time and finished it on his own. I didn't interfere with his study very much at all, because I thought being literate would be enough for him; anyway this school wasn't an ordinary school. Usually he finished his homework after he came back from school and then I'd take a look; the answers were always right. This really gave me peace of mind.

He liked to play mahjong with his grandma after he finished homework. He's liked mahjong since he was very young, and always bothered us for a set. But I didn't play with him.

When I went to parent's meetings, the teachers never discussed his homework, never said anything about it. But sometimes I was called to the school because he'd been misbehaving, fighting for example, but study was never an issue. As for his popularity, I never worked out a reason.

Q: Fighting with somebody? Was he a naughty boy?

Yang's mother: He can be very naughty; I had to pay compensation to some students several times. And I was a regular visitor to the teacher and the headmaster's office. His teachers usually called me directly if he'd bitten or beaten someone. The teachers still liked him a lot though, maybe because he was such a good boy, with good manners. At the present place, the district DPF center, all the teachers like him.

Q: What did they learn in the special school?

Yang's mother: Basic subjects, like music, math, PE, drawing, singing, and other things, at a very simple level. They didn't have a politics class because that would be beyond them.

Q: Which subject was his favorite?

Yang's mother: It seemed he was good at math, Chinese, and singing, but not so good at drawing and PE. His math and Chinese test scores were usually over 90%.

Q: Do you remember anything during his schooling which impressed you?

Yang's mother: Not really, but he seemed good at studying. The teachers always gave him good marks for his homework, he rarely asked me questions. Sometimes, if I saw a wrong answer, I would ask why he made that mistake and explained the question to him again.

Q: Did you reward him for good marks?

Yang's mother: Yes, of course. We would go out together or I'd buy him something delicious, although back then there weren't as many tasty snacks as today. About 2 years before he graduated, he asked me for a mobile phone, but back then very few children had one. Even me. But his dad had one and he passed this old phone to my son after he bought a new one. He used this old mobile phone, and remembered the numbers of all his family and relatives. The mobile phone made things easier sometimes, too, he could call us if he was going to be late. Like the time he called me when he got off the bus at the wrong stop and explained where he was over the phone. I told him what to do and he came back by taxi safely. It was a relief that he had a mobile phone, I have to say. Anyway, after school, he didn't like to hang out

with the other children, but came back home straight away, finished his homework and played later.

Q: Did he join in any activities when he was at school?

Yang's mother: The school organized all kinds of activities, visiting different places quite often; he was always joined in these events.

Q: Did they have some performances?

Yang's mother: I don't remember if they did, but they went to shows outside school sometimes. These children didn't draw so much public attention in those days, it's very different today. Now his school has a lot of student activities and performances. They never had such opportunities before, things have changed. Especially since Shanghai hosted the Special Olympic Games in 2007. It seems they are able to do better things and society pays more attention to them. It's very different from before.

Q: Did he play with his friends when he was younger?

Yang's mother: No, he didn't play with other children at all. Because he hardly went out, although he would never agree or argue when I told him to go out and play. He just stayed at the side and did his own thing.

He was a naughty boy when he was little. He's an introverted child, doesn't like his stuff to be touched or touch other people's stuff. If somebody grabbed his toy, he would fight for it and wouldn't let it go easily. Once, when he was little, he wounded another boy's hand when the boy took his toy. He was never interested in other children's toys either. His young cousin, his paternal auntie's son, would often leave his toys in the yard. If my son saw them, he would take them back to his cousin's place, and never kept any of them.

Q: Did he get on well with classmates at school?

Yang's mother: I'm not sure about his social relationships at school, but I understand that he's quite introverted there, too. He had good relationships with his teachers, and he would rather play with adults. If he saw an old man telling a story about an emperor in the street, he would get involved straight way. He didn't play with other children.

It's quite strange, he isn't an active person, doesn't like active games either, never liked football. He prefers quieter games like bowling, dancing, playing a drum, rather than jumping around like other children.

Q: Did he have a close classmate?

Yang's mother: He didn't like to play with other children, but he told me he got along quite well with the class monitor, a girl. But I don't know her name.

Q: Did he stay in the same class until he graduated?

Yang's mother: He changed places a couple of times. In the beginning, he enrolled at the Special School of Tianbao Road; 2 years later, he transferred to the school at Miyun Road and joined a bigger class with his teachers and classmates.

Q: Did his teachers encourage him to play with his classmates?

Yang's mother: I don't know. Because he's one of the good students, studying hard, taking homework seriously, the teachers didn't try to influence his social behavior. They knew he liked to play alone, and wasn't interested in playing with the other children.

Learning to Be an Independent Person as a Child

Yang's mother: When he was a child, around five, I started teaching him to go shopping alone at the local store. Sometimes, he'd come back and ask me for candies when he saw the other children were eating them. I'd say: It's rude to stare at other children when they're eating, they might get annoyed. Let me know if you want to have some snacks, and I'll buy them for you. He never forgot that lesson. In a situation like this, I just tell him: "It's all right, you can buy them yourself." The store was just on the corner; it was very convenient for him to go there for some snacks.

One time, I ran out of change and wasn't sure of the price of the thing he wanted, so I gave him a big note. When he walked away from the counter without change, the shop assistant stopped him: "Oops, little one, why did you forget your change? Are you a fool?" He was so annoyed and screamed to me when he got home: "Mom, they said I'm a fool!" And he insisted that I go back there with him to confront the seller. I couldn't work out why the assistant would insult a young customer like him, so we went back to the shop together. I found out what had happened and explained that the assistant had said that only because you forgot your change after you had paid.

Another time, when he was little, preschool age, he went to the barber shop alone to have his head shaved because he was losing his hair. But he came back home with a shaved head and eyebrows! I asked him where did your eyebrows go! He was very angry and ran back to the barber and shouted at him: "Why did you shave my eyebrows off, you have to give them back!" After that, he never let the guy touch his hair again. He loses his temper with some tiny things very easily, and won't let them go for a long time, "If you insult me, I'll turn my back on you," that's the way he's been since he was a child.

Q: When did he start being independent, like washing his face, or cleaning his teeth?

Yang's mother: When he was very young, he could wash his face and he could dress himself when he was very little: he's a tidy person. He started school quite late, at 10, but began washing himself around 8 years old. He'd shower every day, his dad would take him to the bathhouse every day because we didn't have a bath at home. When we got a bath installed at home some years later, he couldn't control the shower, but liked to wash himself after we ran the water for him. He's a tidy person, I remember one time he had loose bowels at school and ruined his pants; he ran all the way back home to take a shower. Fortunately, his paternal auntie was at home and ran a bath for him. I was surprised to find his dirty clothes on the floor when I came back at lunchtime; then his auntie told me what had happened: "Your son came back for a shower and now he's gone back to school."

Q: Did he ever cry when you left him at primary school?

Yang's mother: No, he was never a crybaby. He's grown into a strong boy, maybe because he went out quite a lot; to his grandparents for breakfast, or food shopping, or to grandpa's afternoon mahjong game every day. He didn't even cry when he was

a baby. He always had a very good appetite, I even had to make an extra hole on the nipple of his feeding bottle (she bursts out laughing).

When he went to school at Tianbao Road at first, we had to take him there, but soon he could walk to school alone. He could read and remember the names of the roads. Several years later, when he was in the fourth or fifth year, well, actually it was his third year, the school moved and merged with another. The new place was far, far away, a bus journey; the first couple of times, we went to school together and I kept explaining where the bus stops were at both ends, where to change, how many stops the journey would take, where the breakfast shops were.

You see, he used to have breakfast out with his grandparents, this morning he's at home only because of the rain. Even when he goes to the Sunshine Home these days, he still does this, buys his own breakfast every day.

On the third day at the new school, I told him to take the bus journey on his own, but I followed behind him. If he got on the bus through the front door, I would go in the middle door and hide from him, then I'd get off at the same stop. I could see that he was pretty good at taking the bus and stopped worrying. But I still followed him one more time before he really travelled alone. After graduating from school, he only asked for our help to pick him up if he went somewhere new for a performance. Usually he was independent.

Q: He is a pretty able child; do you think you're too strict with him?

Yang's mother: No, I'm not a strict mother; I just have some rules that I have to explain from time to time. For example, it's not very nice if you stare at people while they're eating, better to buy your own snacks. I don't have too many rules because he doesn't like going out very much. I just let him do things his own way. I show a lot of leniency, and I'm happy with his behavior and proud of his achievements.

He used to let me wake him up every morning, but wouldn't trust his dad in the same way. If I wasn't home this morning, he'd be nervous about being late. Usually, he heads off to the Sunshine Home at 8 a.m. I wake him before that, and then he washes and gets dressed, he leaves and has breakfast at the store on his way to the home.

Another thing is, because of his diabetes, he needs monthly blood tests; he goes on his own for these as well. The day he goes to hospital, his schedule changes; he gets up, dressed, walks to the hospital, does the test, and has breakfast afterwards—then he goes to the Sunshine Home from there.

He also goes to hospital for a saline drip without my company if he's ill. He can travel to the city alone, take the bus to his maternal grandma's place, or his maternal big auntie's home at Dinghai Bridge Road.

These days, after his weekend training at the district DPF center, it doesn't matter how cold the weather is, he always likes to have a shower. After he changes into clean clothes, he likes surfing online, but he doesn't play online games much, he prefers mahjong, poker, or Fight the Landlords.⁷ Most of the time, he watches programs about history, particularly stories about the emperors. The rest of us only get a chance to

⁷A popular poker game in China, played by three people with one or two sets of cards.

use the computer after he goes to the Sunshine Home, but we have to give it back to him when he comes home.

Mixed Feelings About the Sunshine Home

Yang's mother: He studied quite well; I never needed to worry about him. My worries started when he graduated in 2005. At that time, I was working in the cotton factory. I had to think about what he'd be able to do if I couldn't let him stay at home on his own. When he was at school, he would go out regularly and it was good for his social skills. I didn't know what would happen to him if I kept him at home all the time, it was a huge worry.

Later, I learned about two things that he could do; one was a baking course, the other was that a Sunshine Home had opened in the community. A couple officials from the subdistrict office visited us, asked about him, his condition, experience, and other details. Compared to other students at the home, my son is in a better condition than many of the others who had never been to school. They told me about the Sunshine Home that had just opened, it was in our community, very close, just one bus stop away. After thinking about it, I decided to send him there.

The reason we didn't choose the baking course instead of the Sunshine Home was the distance; the latter was very close, easy and safe for him to walk there. But the Sunshine Home was a new thing, I knew nothing about it, I thought we'd just give it a try. I felt confident because he could find his way there and back; also, finally he had somewhere to go. I was relieved because now he had some independence.

Q: Have you ever thought about sending him to a junior vocational and technical school, to learn some job skills?

Yang's mother: There wasn't such a place when my son graduated. That wasn't available until the second year after he'd left school.

Q: And now, does he always go to the home?

Yang's mother: From Monday to Friday, he's always there.

Q: So, he goes to there every day. What does he usually do there?

Yang's mother: Yes, he goes to the Sunshine Home every working day. There isn't very much going on, they don't teach them a lot. They'd do a special class when you visit, but normally they don't have educational classes. Every morning, they do some physical exercise to start, then back to their seats and sit there.

My son doesn't like one of the teachers. These children are bright, they're smarter than you think, but this teacher always orders them to do this or that, her style annoyed him. So, he never engages with her teaching, just writes in his reading diary, the story he read the night before, or does some origami, making a wastepaper basket for the lunch time rubbish. It's why he asks me to buy paper sometimes.

Q: Don't they have classes? I saw them learning adding up with an abacus last time.

Yang's mother: Yes, they have an Abacus class; he didn't like it at the beginning. The teacher told him it won't work like that, and reported him to me as well. So I

told him, if you study there, I don't care about your results, but you have to engage with the class. Then he started to pay more attention.

Q: Did he start to learn how to use the abacus when he joined the home?

Yang's mother: No, the class started last year. It's probably a special class created by the district DPF office, because all the Sunshine Homes in the area are running the same curriculum.

Q: Do they learn anything else?

Yang's mother: They had drawing classes, that was a very nice teacher who taught drawing and singing, but he left and nobody replaced him.

Sometimes my son plays mahjong during their free time, he likes the game; he likes to invite the other children to play, otherwise, he'd watch TV.

Q: When he first went to the Sunshine Home, was the overall environment the same as it is right now?

Yang's mother: There were more severely disabled students than today; quite a lot had been kept at home and they hadn't been schooled before. When they first came to the Sunshine Home, the teachers did some simple stuff for them, but my son didn't like these courses, because he'd already learned such basic things at school.

Q: What do you mean by "simple"?

Yang's mother: It was about their life skills. For example, how to put on your shoes, how to get dressed. Some children couldn't do these very simple things, they couldn't even feed themselves, and they were spoon fed by their parents at home; but now, all of them are doing much better. My son was very independent, very good, those courses weren't suitable for him. Another example is how they got home; my son walked to school on his own all the time, but some children were totally dependent on their parents: these children had never been school. Their parents cared about neighborhood gossip too much; they didn't dare take their children out, just kept them at home.

Q: Do you think there is anything the Sunshine Homes need to improve?

Yang's mother: I think this Sunshine Home is poor. I heard that some homes do more things, like dancing or something else. So there are a lot of things they need to change and improve, better quality teachers, for example. Some teachers aren't very well trained; they don't have any new things to teach. There's a teacher who is over 70; a two-generation gap with the children. She is always talking about her own experiences, what she did when she worked at a subdistrict office. How can these children understand her old stories? They've never heard of such things before.

Like my son, he is a big fan of history; he read a whole set of books about the 12 emperors of the Qing Dynasty. He's working on modern Chinese leaders' stories now, Zedong Mao and Xiaoping Deng's generation. He's reading a book on Zedong Mao this moment; he knows Chairman Mao's birthday is on the 26th. These days, not many young people like history like my son does, reading books, asking questions, discussing it with his dad. There is no way he could understand the teacher's personal stories from the 1970s. Students don't like it.

Some other homes are already doing the Ninth Edition of the People's Radio Calisthenics, but here they still practice the old version. The teachers are not bothered about guiding them, they just let students do the exercise in their own way, and they

don't care. The students just sit there and watch TV programs afterwards, then they have lunch and sleep at their desks until 2 p.m. Then, it's clearing up time before they go home; some children sweep the floor while others mop it.

Q: So you mean the home needs some new blood?

Y's mother: Today, children are very different from in the old days, much smarter. They are different from the ones who first went to the home; it's why this place needs new teachers with new ideas and knowledge. But here they do bring in more new people, but they should also have some new ideas.

Why does our district DPF drum team have so many children? Because there's always something new going on. Teacher Zhou is good at choreography, teaching different dances from time to time, all the children love it.

But at this home, they have lost some children already because the teachers repeat the same things all the time. At least my son plays mahjong; some children do nothing, they just sit there, waiting for lunch time, waiting to go home. Some parents tell their children: "Just go there anyway, let us have a break at home, at least the home feeds you." For some children, it's the only reason they still go.

I don't have any other choice, even though I know he doesn't like to be there. The home does a roll call every day; low attendance makes you look bad, it tells people the teachers aren't good enough. Here there should be more than 30 children, but usually only 20 come. I don't have a choice, so I have to say to Wei Yang: "You'd better go, you have to go."

Q: Did he participate in any activities?

Yang's mother: Yes, he did. For example, he joined the drum team of the DPF office in Hongkou District, with a dozen classmates. Years ago, they had a choir and went to Heping Park for shows. The teacher in charge of the choir was a very good teacher, he chose Wei Yang as the conductor. But these activities were only kept up over the first several years. They didn't do these things for very long.

Q: I've seen your son's photos on the home's wall, one I think of him with a visiting leader?

Yang's mother: That's a long time ago. He's always had a bit of luck... hard to tell why exactly. People always like him wherever he goes; leaders like to take their photo with him, too. There's also a photo of him at his birthday party at the home. That day he told me he wanted to have his birthday at the home, so I bought him a birthday cake and some drinks to share with his classmates.

He Grew Up with the Special Olympic Games

Yang's mother: I'm a working mom; I didn't know anything about the district drum team before he joined the Sunshine Home. How can I say this... You should know, a family with an intellectually disabled child... We feel that outsiders look down on us, on the child. It's heartbreaking when he's despised by his own cousins, the children of his paternal uncle and auntie.

One day, he told me, a classmate's mom had asked him if he wanted to join the drum team; she was the vice chairman of Zhiqinhui,⁸ an organization for people and families like us. I asked him: "Do you want to play the side drum?" He said yes, so he joined. As parents of an intellectually disabled child, we are a bit... a bit inferior when we meet other people. I stay in our own world; I don't know very much about the outside world. But that time, I thought about it again and again, and I decided to let him have a go.

This drum team has a long history. In the beginning, the founder, an elderly man who worked at the district DPF office, tried to set up a band. There are lots of intellectually disabled children in the association, some are mentally challenged, some are normal but their brain has been damaged by disease, but my son is a Down syndrome child. The vice chairman said to me: "Please let the founder have a look your son." The guy liked him straightaway and said: "Wow, I didn't know there was a child like him in your area, of course, we want him!" He wants Down syndrome children, the more, the better; but he can't use severely disabled children. Finally, my son joined his team.

Playing the side drum has a formula, it's a kind of mathematical formula, he practiced the rhythm and hand movements at home, it was quite hard. He also went to Heping Park to practice every Saturday. One Saturday, I met two teachers there, one was the vice chairman, they said: "Wow, you're Wei Yang's mom, he looks like a smart boy!" I was so happy when I heard this (see Fig. 1).

Later, I joined the class with him, I learned how to play first, and then taught him at home to help him learn more quickly. After some time, he seemed to get the hang of it.

One day, he was called in by the district DPF office, so all three of us went there together. The place is on the Guangzhong Branch Road. Then we found out that he was invited to join two classes: English and dance. He couldn't speak English at the time, but there was a dance class after the English class and he enjoyed this and became a good dancer. Once his dad and I went there and watched their dance, his beautiful performance touched our hearts.

Since then, he trained every Saturday and Sunday. I joined them to learn and volunteer when I was free. He's been with the team for around 5 years now, the teachers spend so much love and attention on all of them.

At an election of the district Association of Persons with Intellectual Disability and their Relatives board, a worker in the district DPF office asked me if I'd like to stand for the vice chairman's seat. The incumbent vice chairman, a physically disabled dad who had an intellectually disabled child, had to leave because of old age.

At the time, I'd been laid off from the old place. My new job was as a community worker for the subdistrict office, coping with public security and hygiene issues and I had more free time than before. So I took this volunteer job in the end.

⁸Here, Zhiqinhui refers to the district branch of the China Association of Persons with Intellectual Disability and their Relatives.



Fig. 1 Mr. Wei Yang practicing side drum

The drum band trained up to three times a week; Tuesday afternoons and Saturday and Sunday mornings. The new day job gave me more time on Tuesdays, so I started going to their afternoon classes, and I got on well with the teachers. It was always a happy time being with them, we had that one thing in common, a special child at home. We had so much to share, children, family, and we could speak our minds to

each other. The kind of things I couldn't talk to my colleagues about, joining in the workplace chatter, especially when they talked about their college children, there's nothing I could say.

Those years were the worst part of my life, imagine, even his own paternal uncle and aunt called him an "idiot," it hurt so much. The pressure made me lose my temper all the time, because I was so hurt; but his dad was a really good-tempered man. So, the teachers invited me: "Why don't you join us as a volunteer?" They had a team of around nine people at that time and I got on well with all of them. So I became one of them, a volunteer, also a district DPF teacher.

Special Olympics came to Shanghai after my son had been at the home for a while; this was the 2007 Special Olympics, Shanghai Special Olympics.⁹ It was his first bocce competition ever. On October 1, well, it was the second actually; I had to visit my mom who lived in the Pudong New District, while my son went to the event alone with a disabled assistant from the subdistrict office.

That morning, he told me: "Mom, I'll bring you back a gold medal." I replied: "Well, I'm just so pleased you can go in for this competition, the Olympic Games, a national¹⁰ game, I'm so glad you can be part of it." I thought I'd be completely thrilled if he won a silver medal, so I told him: "Just concentrate on the game, try your best, and meet me later at Grandma's place." Around noon, he phoned. "How's the competition going," I asked him. He said: "Mom, I won a silver medal." Wow, I was so delighted and crying at the same time, I just cried at my mom's place.

All I could think was, my son entered Special Olympics and won a silver medal; most normal people couldn't compete at this level, right? So I really cried. When he came home that evening, he really was proud of himself, so were his dad and me, too. His paternal aunt smiled but you could tell there was a very different feeling. They just looked down on him, but their attitude did change a little bit after his win.

My big sister was very pleased for him too. She told me: "It's been such a hard job for you to raise this child and now look what he's achieved." At that moment, I couldn't explain my feelings in words, I had a sleepless night, I was awake the whole night.

From then, the Special Olympic Games became a turning point for him. He changed gradually after that; he became a quicker learner. At the DPF center, Teacher Zhou and eight other teachers who cared for him, had been concerned about his studies; from then on, they gave him all kinds of opportunities. And the founder of the drum team let my son join in performances whenever there was a chance. All of those opportunities came from the teachers. Since then, he's grown up bit by bit, going to competitions and games, one after another, winning more and more medals. Once he had a chance go to a competition in Beijing.

He's getting better and better all the time, even though he's a little bit out of line right now. He learned better and faster when he was younger. He was in a

⁹2-11, October 2007, Shanghai hosted the 12th Special Olympics World Summer Games, usually known as the Shanghai Special Olympics.

¹⁰The Game is a global sports festival.

competition¹¹ at the Songjiang District yesterday. It was a unified run,¹² where 12 people have their legs tied and run together. There was heavy rain that day—we were soaking wet. I'd just washed our clothes that morning—but our team had to go. There were a lot of foreign athletes at the competition, everybody had to be there on time, we couldn't let other players down.

Here's some pictures of him at Special Olympics (shows pictures of Wei Yang in competition, and some of his medals), and quite a few gold and silver medals, and certificates of merit. This picture is when he went to *The Global Happy Family*¹³ event. This one is when he played with the drum team at Heping Park, a performance from our community. And, this is one of him at the Sixth National Special Olympics.¹⁴ He has another nice picture (goes through pictures)... I can't find it—he's biting a silver medal—quite nice. But I couldn't find it yesterday (she has a regretful expression on her face), I'll show you when I find it.

Q: He is great!

Yang's mother: Isn't he great (she looks very happy)?

You can tell things are much better these days; there are quite a lot people who care about our son. But years ago, we were... it's hard to describe our situation (sadness appears on her face).

Q: What did you mean earlier when you said he's now "a little bit out of line"? Do you mean he is different from before?

Yang's mother: Since he started playing in the drum team, he's become smarter, but he gets clumsy when he is fat. He was very good 2 years ago, but now, he's getting weaker gradually. At this age, around their thirties to forties, Down syndrome children begin to go backwards. From this point, their condition doesn't improve but starts to decline. These children don't have a long life; their organs are as weak as 70-year-olds at his age. It's why they go downhill from here. My son is different from 2 years ago, he can be awkward and learns slower than before, he can't learn as fast as before any more. This year (she's sobbing)... he's going downhill (she cries).

Q: When was his fastest period of development do you think?

Yang's mother: When he joined the drum team, in 2006, he was improving so well until last year. This year, I realized he has started to age. There are several children with the same condition as him at the home, they are all getting weaker as well.

Q: Are you worrying about his condition?

¹¹Here, the interviewee talks about 'the Special Olympics Sunshine Unified Run' on 22 October 2016, hosted by the Shanghai Special-Care Foundation and other NGO groups and a commercial company. More than 40 Chinese and foreign teams attended the event. Wei Yang was one of the athletes of the Shanghai team.

¹²Unified Run is a popular game of mixed teams of disabled and non-disabled people. As an extended event of Special Olympics, it encourages two groups of people to cooperate together and understand each other.

¹³*The Global Happy Family* is a competition run by a famous show, *Happy Chinese* from CCTV, China Central Television.

¹⁴The 6th National Special Olympics also known as the 9th National Disabled Games, took place on 12–20 September 2015, in Chengdu, Sichuan Province.

Yang's mother: Of course, but there's nothing I can do, even though I understand his situation. All of the teachers and volunteers think the same: while they are here with us, we should make them as happy as possible, try our best to provide whatever they like (she's crying, and the interviewer hands her some tissues).

Q: How did you find out about the competitions and games that he entered?

Yang's mother: From the district DPF office. When we get the details of a competition from the office, the teaching team will choose some suitable children. My son is usually on the list because he's a popular guy.

The teachers make a huge effort; they are very patient with the children, because the children can only remember things after they have been taught several times; they forget faster than they remember.

Q: Did he join in other sports as well as bocce at Special Olympics?

Yang's mother: He took part in several other games, dance, side drum, waist drum.

We're still going to the district DPF center to practice regularly, every Saturday and Sunday; the weekend practice opens to the public if you want to watch. He also did the dragon and lion dance several years ago, but they don't do this activity anymore. Here's a picture of the show—he is playing the dragon ball. Bingbing Li has donated 50,000 yuan for this event.

Q: Dragon ball is a difficult role!

Yang's mother: You're right; people were surprised at how good he was. This is a picture of him playing the side drum (points to a picture). Our teacher and volunteer team train them every weekend. He's a good conductor as well; he conducts the choir if we have a performance. For one performance, his teacher asked me to find a choirmaster's suit for him, so I dressed him up in his grandpa's shirt.

This is Teacher Zhou that I talked about (points to a woman in the picture). Her child has multiple disabilities, he is disabled physically and intellectually. But she brought him up to become a college student and now he's graduated. She's a very good teacher, really, she teaches them to sing and dance, choreographs the team, too. Here's the founder of the drum team (finds another picture), his family name is Ni, so everybody calls him Uncle Ni. This one, the event didn't finish until 10 p.m. that night, it was called "Shanghai Top Ten," but I can't remember the meaning of the ten. This one (moves to another picture) is the "Shanghai Disabled Performance for the 90th Anniversary of the Communist Party."

Q: Do you think he has changed a lot since he joined Special Olympics?

Yang's mother: It's been a very big change. Before, he liked to focus on his own things rather than play with other children; he kept away from them. But he liked watching adults play mahjong a lot. After Special Olympics, he started interacting with his classmates, playing mahjong or chatting, and he became part of the group.

His social ability has improved a lot since he joined the drum team. We always let them do group exercises together, dancing, or doing physical exercise. This helped him get closer to the other children; some of their parents were also teachers and volunteers of the band.

We are all on good terms; we usually hang out with our children together, have a meal or go for a trip. So these children get a chance to play with each other. He's quite close to several children in the drum team but he doesn't get on that well with the

children at the home. Those Sunshine Home students have a more severe condition than my son; they find it hard to interact.

Q: Did it affect your husband and you when he entered Special Olympics? For example, like your feelings or lifestyle?

Yang's mother: Yes, it's affected our family a lot; we are happier and feel better. I used to lose my temper quite easily, but we're delighted now he's grown up, it's very satisfying. We are a more harmonious family.

Q: What is your husband's opinion about your son's involvement in Special Olympics?

Yang's mother: He's very supportive. He was always supportive when our son entered a competition or performance. He's very pleased about the child's achievements as well. In the past, children like him were kept at home by their families and they knew nothing of the outside world. But now...

Yesterday morning we left home at six in the morning for an activity. His dad drove us to the district DPF office on his electric scooter, and then cooked dinner when we came back home at six in the evening.

On the weekends, my son and I have to leave before 8 a.m. and get back in the late afternoon. Sometimes I have to go to the office to prepare for meetings for almost the whole day before the next day's activities; my husband is always fine with this. He says to me: "Please do whatever you need to do."

I used to get angry at home quite often when I was in a bad mood, but now I've changed too, and that makes him happier as well.

He kept working after he retired at 50. But when I retired and tried to find another job, my husband stopped me and told me to look after the child and leave the family finances to him. Now he's stopped working, he does most of the housework, cleaning, cooking, and shopping. I only need to do the washing. As you can see, he even bought me some snacks today. He said he'd be happy if I looked after the child well.

Q: What role do you think a father needs to play in a child's development?

Yang's mother: I have to say, he was a good father when the child was little. He's very fond of children. He took Wei Yang to his factory's social events, like playing mahjong or other games when he was little, sometimes Wei Yang even played charades with other people. Back then, my colleagues liked my son very much, too. My husband would never leave the child at home alone, but took him to his business meetings and dinners with other salesman. He encouraged the child to study hard before exams, used to tell him to work harder all the time. He never complained when I bought things for our son. Neither of us have new phones, both of them are the child's old ones.

He is always patient when the child asks questions, they can talk about everything to each other. Our son likes talking about football with his dad, especially during the World Cup season. But Wei Yang doesn't like to chat with me because I can be quick tempered or because women are always too busy with the housework, we don't have much free time.

Q: I was told by one parent that your son is a real star at the district DPF center—what's special about him?

Yang's mother(smiles): It's all down to his teachers, they are very good teachers. Before the performances, they would teach them one to one, correcting their movements all the time, full of patience. All his development is down to the teacher's excellent hard work.

Q: Last time when I visited them at the district DPF center, I saw they were baking. Do outside volunteers come along to do this kind of activity very often?

Yang's mother: They do a baking class every 2 weeks, probably, they cook different things every time, cookies or cakes, they always do something different.

Enjoying Music and Reading

Q: Did he show a liking for anything in particular before school age?

Yang's mother: He liked music. I got a big radio cassette player, a double-horn,¹⁵ when I got married; he really liked to play with it. I usually left it with him when I was working. He would sit down and play with it the whole morning.

Q: Does he like anything in particular or all kinds of music?

Yang's mother: Now he's older he has his own favorite stars; I guess one is Jay Chou,¹⁶ another is the singer of *Red Dust Rolling*,¹⁷ and several other musicians. Before school, he liked Chinese martial arts TV; he played along, copying their actions on his bed when he watched things like the *Little Dragon Mermaid* and the *Monkey King*.

Q: What did he like after he started school?

Yang's mother: He liked... I'm not quite sure what, but he likes literature, and writing, he writes at home all the time.

His paternal uncle and his family live with us, and when my son was young, his uncle would sometimes fight with my husband about some family business. My son wrote all of these things down, about when his uncle fought with his dad, how his aunt, his uncle's wife, insulted his mom, he recorded everything. Even though he didn't argue with them, he just wrote everything down.

He still writes now, at the home. His teachers say the same thing: your son is writing all the time when he's here. Why does he do this? He likes reading before bedtime every night, he always reads before he goes to sleep. And then he writes in his reading diary the next day at the home. Anyway, he writes about things he reads in his books. He likes reading and writing very much, it's a habit with him. He doesn't read everything, only books about the emperors, they are the only books we have. For example, this kind of book (takes out a book about Emperor Tongzhi) a set

¹⁵'Double-horn' is the local name for a ghetto blaster, a large portable cassette recorder with two speakers, one of the most popular wedding gifts in the 1980s.

¹⁶Jay Chou is a popular pop singer from Taiwan, well known around Chinese speaking areas.

¹⁷There have been several singers who sang this famous song since the 1990s, Da-Yu Lo and Sarah Chen, two very famous Taiwan stars from those days were singers. But another Taiwan singer Sally Yeh, who was also very popular around the 1990s has a similar song. It's not clear which singer or song she is talking about.

of 12 books about 12 emperors. He asked Teacher Zhou to buy the missing volumes in this set for his collection, one by one. He kept telling her which book was missing. Now he has all 12, the whole set. He can talk about those stories after reading. This emperor, emperor Tongzhi, he can tell you about the time of his accession, how long he reined over the country, who his successor was, and so on.

Q: Does he take the book to the home or just write from memory?

Yang's mother: No, he doesn't. He has a very good memory; he can remember stories he read the previous evening.

Q: He has a good memory, then?

Yang's mother: A good memory is one of his virtues. When Doctor Yang met him when he was a teenager, he said: "You'd better give him cosmetic surgery when he grows up. Because he's smart but his face lets him down. Surgery would make him look smarter." He never forgot these words. Once he was told the same thing by a teacher who works at the district DPF office. My son said to him: "We don't have the money; the doctor told me I'd look different after facial surgery. But we don't have this kind of money; otherwise, I would have had the surgery already!"

It Can Be a Lot of Fun Being with Other Parents

Q: Are you working as an associate with the other parents?

Yang's mother: The association is for intellectually disabled people and their families, in our subdistrict, I'm the Chairman.

Q: All of them are parents or families of disabled children, aren't they?

Yang's mother: Yes, it's a social organization; there are five non-government organizations under the district DPF office, associations of intellectually disabled people, those with a physical disability, deaf-mutes, mental problems, and blind.

Q: What's your main duty in the association?

Yang's mother: We're under the management of the district DPF office; they assign tasks to us when the district government produces new documents and orders. Also we get requests and complaints about the government of disabled families from the other side. We arrange meetings with parents and families and record their thoughts and needs and make a report.

Sometimes, we cooperate with the Sunshine Home as well. One time, after a child was absent for several days, they called me to help the child's mother make a report to the local police. They also call me in if any children have been in a fight and need their parents to be there.

Q: Do you plan some of the activities as well?

Yang's mother: We help with the drum band's weekend training at the district DPF center. There are eight subdistrict offices in the district; the children stay in their own subdistrict run Sunshine Home from Monday to Friday, but some of them come to the district DPF center for special practice at the weekend; it's on the Guangzhong Branch Road. We train them with the side drum or teach them dance.

Why do we help the children with practice? One reason is these children are always indoors when they study at the homes. We want them do more exercise and get a chance to socialize with other children. We have the same situation here, parents develop friendships with each other, and the children, too. These children can't make friends with normal children; they can't even get on with their own relatives' children. An ordinary and a disabled child behave in very different ways; they don't have much in common. But all the children in our team are the same; they chat and play with each other very well because they are in the same situation. They are happy in each other's company.

The children come every weekend, it doesn't matter what the weather's like, windy or rainy, cold or hot; there are usually 50–60 children on a Saturday. I'll always be there for them even if I don't feel great, or if I'm sick.

Why do I have to go? There are lots of parents with disabled children from the Sunshine Home; they never talk about their problems to anybody because they don't dare to let other people know that their children are different. After I retired, I spend most of the time at home, and I go to the district DPF office for meetings or other businesses from time to time. So, at the weekend, after 5 days at home, our volunteer/teachers—we have ten teachers volunteering at the same time in the team—want to meet and catch up with the news. Sometimes we just talk about what we've done at home during the week. Outsiders can't understand us, my husband is my only audience at home, but at the center, we get a chance to open our hearts.

There are seven teachers, we are all good friends, sometimes we go on trips together, self-financed journeys, we've been to Japan, South Korea, Yunnan, and the Yangtze Gorges. We visited Zhangjiajie this August.

I can't take my son to my old classmate's party, I just can't take him there. What should I do if I have to leave my son at home while I go out? He would just follow me. I used to keep him company as well. Some of my old classmates are going on a 3-day trip next month, but I won't go. I feel a little bit down when we're together; I don't have much to share with them. I can't join in the gossip. They talk about somebody's child who's getting married, or they've got a newborn grandchild, but my child will never get married. Anyway, I have nothing to share with them and that's the reason I don't like to spend time with them.

Teachers and parents join together with the children for all our trips. It doesn't matter when and where we go, even on a week-long trip. I always feel easier when my child is with me, even though sometimes it's quite exhausting. Because they are different from their ordinary peers. My son can't help me carry stuff, and he's a slow walker, I have to do everything, but I just feel safer and can relax if he's with me.

There Are Some People Who Despise My Son

Yang's mother: Since he was born, I really... I cried all the time. There would always be somebody staring and pointing at him whenever I took him out. Once, when we were on a bus, a man stared at him for a long time, very long, it made me very

angry. So I turned my son to face the guy and thought: if you like to stare at him, I'll just let you do it! This kind of thing really broke my heart. When I worked at the cotton factory, I never talked about my son with my colleagues, I was worried that I'd lose face if they knew my son was different. When they talked about their college children, daughters getting married, it always upset me. It broke my heart; I can't tell you how many times I cried.

When he started school, the tuition fees were quite high, over 600 yuan a semester. So I saved 100 yuan every month. After 6 months, at the beginning of the new semester, I used the money to pay the fee. His paternal auntie said to me: "You shouldn't send him to school, it's just a waste of money!" I was very angry and told her: "Did I borrow the money from you? It's my money, why can't I send him to school? Education is good for him." Both his paternal uncle and auntie looked down on him.

Q: Did people say anything bad about him when he went out with his grandpa?

Yang's mother: His grandpa never told me if they did, he usually only went to a relative's place to play mahjong. These people would never say bad things to his face. His dad would take him to business dinners with colleagues quite often. His paternal grandpa and grandma, maternal grandma, and big auntie don't hold anything against him, only his paternal uncle and auntie. But my son doesn't like to talk to them either.

Q: You just said his paternal uncle and his wife live at the same place with you, right?

Yang's mother: Yes, we still live together.

Q: But you said you don't get on very well with them.

Yang's mother: We've always had a bad relationship, even today. His paternal auntie insulted him only last month.

Q: What's the main problem between the two families? Is it about the child?

Yang's mother: How can I say this, it's just the small things that come from living together; there are always some everyday frictions. But he isn't their problem; they shouldn't insult us when there's a problem. They just take it out on my son when the two families argue, and they despise him at the same time.

Q: You said his paternal auntie had bad opinions about your son; has she changed mind now?

Yang's mother: Yes, their opinion has changed. They said to me: "Only you could raise a child like this. If we were in your situation, he probably wouldn't grow up as well as this. You sacrificed so much for him."

Q: You have made a lot of effort.

Yang's mother: I think about it this way, when those teachers spend so much attention on the children like my son, as his mother, how could I stand by and do nothing? I like to do everything for my child and that's why I became a volunteer. I would never have joined the district DPF volunteer team if it wasn't for him. Someone like you, a college student, and your parents could never know about the Sunshine Home or the disabled children's drum team. Only the parents of these special children know about the institutions for them, where there are special activities for them.

I Want Him to Have a Good Life

Q: Does Wei Yang get any welfare benefits from the government?

Yang's mother: One welfare benefit helps to keep him at the home; the place is free and provides free meals as well. He also gets a salary, a severely disabled and unemployed person's salary, which is in two parts, 1,150 yuan and 330 yuan go into his account separately. He also gets 150 yuan nursing allowance monthly.

Q: Has he been getting these benefits from a young age?

Yang's mother: He started receiving benefits quite early, when he was 18. You need an ID card to prove your identity to get welfare, and you have to be an adult first. But I don't know if there is a new policy for younger children today.

Q: Did you discuss your son's future with your family when he was at school?

Yang's mother: We didn't. Because in our family, his paternal uncle scorns him, and his grandpa and grandma are too old to talk about this issue. His paternal auntie disagreed about my son going to school; we couldn't talk about this with her either. I only discussed it with his dad. We made an agreement to try our best to make him happier, and satisfy his needs while he is living with us.

How can we have any hope for his future, even though we don't wish for very much? Can there a bright future for a child like him? Even though he was able to go to university, there won't be a big difference when he graduates. Can the government provide him with a job? It's impossible! So many college graduates are unemployed today. For a child like him it's even worse. When I think about everything I have done for him, at least I can say I treated him well.

Q: Did you ever think about letting him learn some vocational skills?

Yang's mother: At the moment he doesn't seem to want to learn any kind of job skills. I can't really tell what he wants to do right now. I think, I'd like to pay for his training if that's what he wants to do. I don't mind what he wants to do, I just try my best to support him. I buy everything he wants if I can afford it; it doesn't matter whether it's clothes or shoes, but I also told him we can't afford branded stuff. We won't let him get things that look worse than other children. Wearing clean, tidy and decent clothes is the rule. If he tells me he wants a new phone, I'll definitely buy one if I can afford it. Or, if he wants a new pair of shoes and I have the money he can have them. But, I can't tell what he wants to study at this moment, so I don't want to force him.

Q: What would you wish for him in the future?

Yang's mother: A job, he wants to work. For me, it's impossible because he doesn't have any real practical abilities. We have to take some responsibility for this. As you can see, this place... the stairs are so narrow, I worry about he might fall down when he's walking up and down, so I stopped him doing housework. He just needs to relax and play at home. The one thing we really want is for him to look after himself, to do his own thing. If one day we move to a new place, I'll teach him to do some housework. His dad can teach him to cook, but we can't do this now.

Thinking about his future, I just want him to earn a little bit more money than he gets now. He only earns over 1,000 yuan, but it's not enough for him! He won't be

able to depend on us forever, what will happen to him when we pass away? There's a big income gap in the disabled group, some children with a milder condition can work, or they're affiliated to a company and can earn more money. Then they get the subsistence allowance at 20 years old, over 2,000 yuan monthly. But our son is severely disabled and unemployed; he earns much less than other children.

Also, he has free Medicare, but he has to visit certain hospitals. There is a Medicare-designated department at the district hospitals, but if he needs a transfer to a city hospital, he needs special documents. For example, he needs special medicine for his diabetes; it's an inherited disease, his grandparents and dad have it. In the beginning, he just visited the local hospital when his blood sugar level was high. Then I would take him to Xinhua Hospital and he was treated with a special prescription. His condition is now under control. Transferring him from the local hospital to Xinhua Hospital required a lot of paperwork every 3 months, and we had to repeat the whole procedure every 3 months. At the moment, we can help him, but I'm 60, his dad is 65; we won't be able to do this in 10 years. What will he do then? He can't do this on his own! So the best solution is to allow him to go to choose the higher level hospital and go on his own. That's one of our worries for the future.

Some Stories Are Unforgettable

Q: As well as the stories you've already told us, could you tell us something else that impressed you about his development?

Yang's mother: The happiest thing for me was his first performance after he joined the drum team. I was so glad to see him do this. I'd never seen him on stage before. That was a dragon dance, and he was dancing with the dragon ball on stage at the Shanghai Television Station. He'd also been in a dance show in Beijing.

In another show, a choral performance, he was the conductor of the choir. It was very successful, so many people applauded, but the evening before the performance we were so worried because the rehearsal didn't go well. When I was sitting in the audience, I was thinking, years ago these disabled children never had this opportunity; they were brought up to beg and scavenge for food from rubbish in the streets. But my son is up on stage, giving a wonderful performance, I was... so glad. Since then, my optimism gets stronger and stronger. I feel better for having the other teachers in my life: I was always depressed before. At the end of this month, we're going to do another show, at the annual convention of a well-known company; they've also invited lots of famous stars, as well as us.

Q: What's your son's best characteristic?

Yang's mother: He's totally changed, probably because now he has his own ideas, he isn't as naive and simple as he was when he was younger. And I think he's very different from other children; he's always interested in adult things, even though some aren't his business.

Apart from this, he's a bit of a lazy boy; he doesn't like exercise. He just plays with his computer, it's the only thing he likes to do after dinner.

Q: How about housework like folding his clothes?

Yang's mother: He'll do some housework when I'm not at home. Also, if he thinks I'm in a good mood, he won't do anything, but if I'm in a bad mood, he'll offer to help. He's really good at reading people's moods and thoughts.

Q: Could you talk about his virtues?

Yang's mother: He's a caring person and worries about me if I'm sick; he gets concerned about whether I've taken my pills or not, often asking me if I want to eat or drink. Maybe that's because I'm the person who looks after him every day. He doesn't worry about his dad in the same way. He's also very respectful; for example, he always remembers his maternal grandma's birthday.

Q: What did his development bring to your life?

Yang's mother: A child who was born disabled to grows up like this, I'm very pleased. You see, ordinary children would never stay with their parents every day, but he has to. At his age, an ordinary child would be married and settled down and have his own life. If it was like that for us, we'd already have an empty nest. At this moment, I feel fulfilled and delighted with my son.

Interview with Wei Yang's Teacher

Interviewee: Wei Yang's teacher

Interviewer and Writer: Fengzhi Liu

Interview date: May 2, 2017

Interview place: Sunshine Home in Hongkou District, Shanghai

Q: When did you meet Wei Yang?

Teacher: I met Wei Yang in 2009 when two subdistrict Sunshine Homes merged.

Q: He wasn't a student of this home before the merger?

Teacher: He was with us before, at that time we merged two of the homes, and just kept the home we're in right now but closed the other one.

Q: Are there more students than before?

Teacher: For sure. We don't have many children, probably a dozen, more or less, in this street, but there's another street with over 20 children. But some children moved out of this area because of relocation. If all of them had come here, we would have had more than 30 students.

Q: What was your impression at the very beginning?

Teacher: It was fine. He is a... how to explain, a very obedient child, he tends to listen to the teacher's orders most of the time.

Q: How's his relationship with his classmates?

Teacher: Pretty good, he gets on very well with them, but he's a bit naughty sometimes; anyway, he's a boy!

Q: What do you mean by a bit "naughty"?

Teacher: I mean boy's behavior; you hit me and I hit you back, this kind of thing.

Q: Does he have any good friends in the class?

Teacher: Yes, he's friendly with Lin; normally our children are on friendly terms.

Q: How about his relation with the teachers?

Teacher: Not too bad, he doesn't argue or challenge the teachers. He usually does what they ask him.

Q: What courses do you have?

Teacher: Education and training, rehabilitation training, Special Olympics training, inclusive activities, life skills, and simple housework training.

Q: What do they do in the education and training class?

Teacher: The education and training course includes Chinese, mathematics, and English, just teaching some very basic knowledge.

Q: Are they different to the courses at the Special School?

Teacher: There're some differences. We have an uneven level of student ability; our teaching context is too simple for some students who have very strong learning and studying abilities. But for some other children, they struggle with the pace of teaching. They're unable to learn effectively; they easily forget things, even something they might have been taught the previous day. We have to repeat the same things over and over. We have a higher requirement for quick learners, but for those weaker students we have to go over the lessons again and again.

Q: I attended their abacus class last time. What do they do in other classes, like the Chinese class?

Teacher: In the Chinese class we're teaching Tang Dynasty poetry, but we don't have a textbook. The Sunshine Homes don't have standard textbooks; we just choose some suitable poems. They are good at reciting the *Three Character Classic*,¹⁸ for example.

Q: What are the inclusive activities?

Teacher: Sessions that deal with hand-eye coordination, include finger exercises, basic body exercises, and several sets of radio calisthenics. Bad hand-eye coordination is a common problem with intellectually disabled children.

Q: You mentioned the class for Special Olympics; what's the schedule for this? Do you have training every day, or one session every week?

Teacher: It's part of our weekly schedule, two or three sessions a week. We're short of space, so we just let them play poker, badminton, and ball games.

Q: Do you have a fixed daily timetable?

Teacher: Yes. A very important part of their daily timetable is to help with the cooking. We have four teachers at the home, one is a cook, one of the other three takes turns to help.

Q: Do you cook for the students?

Teacher: We always cook, it's part of our tradition. We don't serve takeaway food; parents think home cooking is better for the children. Also, our budget isn't big enough to buy takeaway food for the whole month, cooking is the only way we can provide a free lunch for the children. Some homes serve takeaway food, 15 yuan

¹⁸The *Three Character Classic* called *San Zi Jing* in Chinese, has been one of most classic texts for the formal education of young children from the Song dynasty to the late 1800s. The text is written in triplets of characters so it can be memorized easily.

each box, 150 yuan for each person's budget, but it's only enough for ten meals. After that, the children have to pay for their own lunch. But we resolved the low budget problem with home cooking. So the children like it here, our free meals are tasty and healthy, some takeaway food's quality isn't guaranteed.

Q: Do the students help the teachers cook?

Teacher: Yes, of course. It's the season for broad beans, so we usually buy a lot and let the children peel them. Sometimes they also do simple house work, domestic training, teaching them to make wonton, dumplings, some basic cooking skills. Sometimes volunteers come here to teach them how to make sweet dumplings and they'll share the food together afterwards.

Q: Do you get volunteers for activities very often?

Teacher: Yes, they always come after Spring Festival, but that tends to drop off after a couple of weeks. Most of them are local residents; one good-hearted man who works for the Children's Art Troupe, visits the children every year.

Q: In your opinion, what do his classmates think about Wei Yang?

Teacher: His behavior is just so-so, sometimes he's naughty, he's a person who will fight with other students. Some students don't like his attitude, but the others like him a lot.

Q: Is he an active boy?

Teacher: Yes, he's quite active.

Q: What's his performance like in the classroom?

Teacher: Pretty good, he likes to answer the questions he knows, but hides away if there's something he doesn't know.

Q: What's his favorite course?

Teacher: He's good at dancing, because his mom is the choreographer of the district DPF dance team; they practice every weekend. He always enjoys it, and he's very active in these sessions.

Q: How about other courses? Is he an active learner, in the abacus class for example?

Teacher: In the beginning, he was very reluctant to get involved with this class. He told me he's not interested and refused to read the textbook. I pushed him to study, even though he tried to give the book back to me. But he's getting better now he understands more.

Q: What do you think about his ability compared to his classmates at the home?

Teacher: He's just about okay, he isn't one of the stronger ones. We have several children with outstanding ability; they usually help the teachers with their duties. We also have some simple life skills training to help them develop their independence. We teach them how to go shopping, but he has no interest in this area.

He doesn't like to help other children, he only cares about himself. But some children, those who are close to him in the class, he'll help them, but not the ones he doesn't really know. I let him lead a student group when we went out for an activity and he really engaged with that role. Children like him really love to be flattered; a little encouragement helps their self-confidence.

Q: Yang is in his thirties. What is the average age of the students?

Teacher: They are between 16 and 35, but we also have several in their forties, even though there is a government policy that those over 35 have to leave. Some parents tell us their children have nowhere to go if they leave the home, so we just keep them here temporarily if they don't want to go. It's a flexible rule, we have more students in their forties in our community than most other places; three or four, but other homes won't let the over-aged students stay.

Q: Are the extra students a burden?

Teacher: Of course. When the children graduate from the Special School at Miyun Road, I always find a space to squeeze them in if their parents ask me. But we won't get any more funding from the government after they are 35. There's nothing we can do but ask our subdistrict office to extend their expenses for the home.

Q: Do they go back home when they leave at 35 years old?

Teacher: They still receive social care services when they go back home, the carers will go to do their washing and cooking every day, but they prefer to be here—the more people, the more fun. They get lonely when their parents have to go out, but if they come here they can always socialize with other children.

Q: I've been told by Wei Yang's mother, that he came here in 2005, so he's one of the old students?

Teacher: He's been here for years, since we opened.

Q: Do you think he's changed since you met him in 2009?

Teacher: He's changed a lot. Now he's a very independent person. We take them to a 3- to 4-day training camp without their parents every year. They have to look after themselves—washing, cleaning, eating—he's on top of all of these duties. This is something he couldn't do before. Now he can even help the others; he's a leader at the Sunshine Camp. Now, he's able to go shopping on his own. Usually we don't encourage them to buy things, but he's so excited to buy his own snacks after he finishes here at three o'clock. Anyway, he has good independent life skills.

Q: Wei Yang's mother said he likes history books very much.

Teacher: Yes, yes. We don't have many books, people don't donate books to us, but the volunteers brought some books when we moved here in 2009. He just kept reading these books all the time. He always reads after lunch, I'm not sure if he borrows books from elsewhere.

Q: So he's a student who enjoys reading very much?

Teacher: He'll read if they aren't allowed to watch TV in their free time in the afternoon. He likes to watch *Running Boys and Girls* from Anhui Satellite Television.

Q: What do students usually do in their free time?

Teacher: Playing poker, chess, or chatting.

Q: Is there much conflict between the students?

Teacher: They are good-hearted people, they always make up again within minutes after they've argued, and they won't hold a grudge for very long.

Q: Does Wei Yang like to chat with the teachers?

Teacher: He'll chat with me if he's been somewhere with his mom. They visited Thailand last week and he showed me his pictures. He also brought some Thai snacks for the other children. His mom takes him on several trips every year, but some parents never do that. His mom cares about him very much.

Q: Does the home arrange trips for students?

Teacher: We've just received approval for doing this by the district DPF office, but we haven't been on a trip yet. It's the old concerns; security reasons stop us from going out. Actually, the students are all very well behaved when they go out. When we took them to Heping Park, they were so excited, they really want to go somewhere together. We used to take them to karaoke for several years, and they were always completely delighted.

Q: I heard that Wei Yang isn't in good health, he has diabetes, right?

Teacher: Yes, but he won't give up sweets. He insists he shouldn't eat sweet congee if we serve it for lunch. But then sometimes he just runs off to a local shop for soft drinks after school. I told him these drinks are high in sugar as well, and he shouldn't have them, but he won't listen to me. We have several children who have hyperglycemia, hyperlipidemia, and hypertension or HTN, and they love meat so much, what can you do except buy meat, they won't touch vegetable dishes? Sometimes we buy some steamed bread for them for a change. But Wei Yang won't stop drinking sugary drinks; there is nothing we can do.

Q: Has he done anything in particular, or does he have a special character that's impressed you?

Teacher: The most impressive thing about him is his stubbornness, if he is in that kind of mood, he will ignore anything you say. Once, it was Labor Day or National Day, the home had to close early, and we told everyone to go home early. I told him to call his parents and let them know this change, but he was determined not to. This thing really impressed me. When one of our teachers, a cook, told Wei Yang he has to listen to the teachers, he said: "Aunt, you only need to care about the cooking and mind your own business."

Q: That's all, I'm sorry for keeping you such a long time today.

Teacher: No problem at all, just give me a ring if you have any more questions.

Q: That's great, thank you again!

Interview with Wei Yang

Interviewee: Wei Yang

Interviewer and writer: Fengzhi Liu

Interview dates: November 27 and December 14, 2016

Interview places: Hongkou District Disabled Persons' Federation, Shanghai, a Sunshine Home in Hongkou District

Q: Are you used to being at the Sunshine Home, now?

Yang: I started coming here in 2005 and started playing the side drum in 2005.

Q: So it's 11 years. A very long time, isn't it?

Yang: Yes, quite a long time.

Q: Teacher Zhou told me that you're a star in the band!

Yang: I went to Beijing in 2009.

Q: What did you do in Beijing?

Yang: A performance with Bingbing Li. Because Tiananmen Square was being refurbished, so we didn't go there.

Q: Do you like to play the side drum?

Yang: I do, Teacher Zhou told me to do it.

Q: Do you do radio calisthenics every day?

Yang: We exercise every day except it's too hot. We'll start again when the weather gets cooler.

Q: What do you usually do here?

Yang: Usually we have rehabilitation training, social interaction, and Special Olympics activities, all of those.

Q: When do you have the Special Olympics activities?

Yang: The Sunshine Home doesn't have it; we have to go to the district DPF center for it.

Q: How long have you been involved in the Special Olympics activities?

Yang: When I left school.

Observation of Wei Yang at the Sunshine Home

Observation date: 9:00–15:00, December 14, 2016

Observation place: Sunshine Home in Hongkou District

Observer and writer: Fengzhi Liu

Time	Content	Observed activities
9:00	Class starts	Wei Yang is late. His mother said he might come later, it's because of the cold weather. Wei Yang left home with his mother, but then he went for breakfast
9:02	Wei Yang arrives	He sits in the front row, with a fluorescent yellow coat
9:03	Wei Yang greets m	He nods his head without talking when he sees the observer
9:05–9:15	Watching TV	Wei Yang is discussing something with a classmate and gives a piece paper to him. Compared with the other students, he's quiet, watches the TV occasionally. During this time, he looks back many times; he might look at his mother or just out of habit

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Time	Content	Observed activities
9:17–9:19	Preparing for an exercise	He has a short talk with a classmate across the class, puts his coat back on and gets ready
9:20–9:24	Practicing the people's radio calisthenics	They practice the ninth edition of the people's radio calisthenics. Wei Yang doesn't move very much, mostly upper body movements, and he hardly moves his legs. He is smiling or looking at classmates during the exercise
9:24–9:26	Practicing another set radio calisthenics	Students exercising and singing a song about the Sunshine Home. But Wei Yang only does simple actions, he doesn't sing
9:26–9:31	Preparing exercises	Most of this part is about finger exercise, Wei Yang doesn't do very much, he smiles occasionally. During the exercise, Wei Yang looks at the room where a student's parent enters
9:31–9:39	Waiting for class	Wei Yang gets some water from the water dispenser after the exercise and asks the observer if she wants to have some water. The observer declines gently. Then he walks back to his seat. Wei Yang is searching in his bag for school things when the teacher asks people to find their exercise book and abacus
9:40–9:48	Teacher switches off the TV, to prepare for a class	It takes a while for the teacher to sort out the whiteboard. Wei Yang doesn't come to help, but he is concerned. He watches the teacher all the time
9:48–9:55	Wei Yang goes to the bathroom	Wei Yang gets some tissue from the drawer to wipe his nose. He takes off his coat. His classmate's mother tells the observer: the class starts at 10; they will have lunch here; take a nap after lunch; and the students will head back home at 3. Some children with more ability will help the teacher with their duties

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Time	Content	Observed activities
9:55–10:00	Teacher and students are chatting	They talk about the content of today's lesson, some students say it's too complicated, but the teacher says they just need to keep working on the simplest addition and subtraction questions. Wei Yang doesn't say anything
10:00	Class starts	They are reading the abacus rhymes and doing finger exercise for a minute
10:01–10:02	The teacher asks the students to work on the first question	The teacher lets a student show the class how to do "plus 7" on the abacus on the blackboard. Wei Yang repeats the action after the classmate's demonstration
10:02–10:04	The teacher asks Wei Yang to come to the front to do a demonstration	This question is about "plus 4." Wei Yang rearranges the abacus, and then finishes the teacher's instruction successfully. The teacher praises his smooth finger movements, and the students applaud him. He smiles before going back to his seat
10:06–10:09	The teacher lets the students practice two questions together continuously and quickly	The exercises are "plus 8 on two abacus bars" and "subtract 8 from two bars." Wei Yang looks at his desk mate's exercise during his own practice. The teacher asks one student to perform the questions at the front later
10:09–10:10	Double figure exercise	The teacher lets them practice "add 16" and "subtract 16," and also reminds them which way they should start. The teacher asks for a volunteer, but the first student has to finish their practice with the teacher's help. Wei Yang is watching this student's practice after he finishes his own work
10:11–10:15	The difficulty of the exercise increases	Wei Yang raises his hand to be a volunteer, but the teacher chooses somebody else. Wei Yang is watching the classmate's performance
10:15	Practice to plus '92467'	Wei Yang raises his hand first when the teacher asks who has finished
10:20	Practice to plus '340971'	The teacher asks Wei Yang to practice at the front, he does the job successfully

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Time	Content	Observed activities
10:22–10:24	Practicing “ $2 + 1 - 2 + 5 - 1 + 4$ ” with fingers to simulate calculation using the abacus	Wei Yang does his exercise correctly and chews his fingers while he practices
10:25	More practice	The teacher asks for a volunteer for the demonstration, but Wei Yang keeps his head down, the teacher can't see what he is doing
10:28	The teacher asks Wei Yang to do the demonstration, but he refused	Wei Yang tells the teacher: “I really can't do it; my hands aren't good enough.” Because of his fingers' poor flexibility, he can't do the exercise. Some other students volunteered
10:29–10:33	Break time	Wei Yang doesn't leave his seat
10:34	Wei Yang leaves his seat to get some water	
10:36–10:40	Wei Yang is walking around and talking with his classmates	They are talking in Shanghai dialect some distance away and the observer can't hear what they are saying
10:41	Reading abacus rhymes	
10:43	Doing practice in the exercise book	Wei Yang is taking the task quite seriously
10:47	The teacher walks around and asks them about their practice	Some students have finished the practice while Wei Yang is still working, so he doesn't raise his hand to answer the teacher's question
10:49–10:57	Classmate demonstration	Wei Yang is bending his head, not sure if he is correct or not. More or less half the students have problems with this part of the abacus exercise
10:57–10:58	The teacher asks if anybody has finished the exercises from another page	Wei Yang raises hand
11:01–11:02	The teacher asks if anybody has finished again	Wei Yang doesn't raise his hand
11:02–11:05	Classmate demonstration.	Wei Yang concentrates on his own exercise, he doesn't raise his head
11:05–11:06	The teacher lets the students pack their exercise book and abacus away	Wei Yang packs his stuff up very quickly
11:06	The class has finished. The students on duty are cleaning up	Wei Yang is packing up his stuff

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Time	Content	Observed activities
11:25	Queuing for lunch	Wei Yang and his classmates go to the canteen. The place is opposite the classroom, and they form a queue to collect their food. The lunch is tomato and egg soup, pork chops and a marinated egg, and a banana for dessert
12:00–12:27	Playing with his phone	Wei Yang is sitting down and playing with his mobile phone after lunch, he doesn't talk to other people
12:27–12:35	He puts the phone away and watches TV	Wei Yang isn't watching the TV news all the time, and looks somewhere else quite often
12:35–13:00	Having a nap at his desk	The classroom is very quiet at this time
13:00–13:26	A cooking program is playing on TV	Wei Yang isn't interested in this program, he leans on his desk and looks around
13:26–13:29	Preparing for the next class	The desk mate wakes Wei Yang up, but he still leans on his desk
13:29	The teacher tells Wei Yang to sit up and prepare for the class	
13:31–13:40	For the afternoon's entertainment, the students need to warm up first	Wei Yang and his classmates stand up from their seats. The teacher tells them to clap their hands 100 times; they hit their palms and tap their fingers 36 times in each session. Wei Yang's actions aren't quite correct, and in a faster rhythm. Wei Yang keeps doing the exercises but doesn't have eye contact with the teacher. The students become very excited, practicing in a lively way
13:40–13:43	The teacher takes a look at Wei Yang	The teacher spends a lot of attention on Wei Yang
13:43–13:46		Wei Yang moves less and less, getting less involved with the exercise than before
13:46	The activities are finished	The teacher tells Wei Yang he doesn't do enough exercise and needs to do more exercise for a healthy body. Wei Yang walks back to his seat when the other classmates go for water

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Time	Content	Observed activities
13:55	Entertainment time starts	The teacher asks the students to sing, Wei Yang is looking forward to the other students' show, applauding very happily
13:55–13:58	One male classmate sings	A classmate sings Emil Chau's ^a <i>Friend</i> , but Wei Yang has his head down during the performance
13:58–14:01	Another male classmate sings	The classmate sings <i>My Happiness is Thinking of You</i> . Wei Yang's humming alone; at the end, the whole class is singing together
14:04–14:06	Wei Yang sings	Wei Yang sings Teresa Teng's ^b <i>If You Asked How Much I love You</i> . He remembers most of the lyrics, and only forgets a few words. He's totally engaged in singing and gives a salute at the end
14:06–14:08	The fourth student sings	The classmate sings <i>Raining in the Heart</i> . Wei Yang is chatting with his back turned to his classmate during the performance
14:08–14:10	The fifth student sings	A male student sings <i>The Lapping Waves of Honghu Lake</i> . Wei Yang doesn't watch the performance but applauds him at the end
14:10–14:12	The sixth student sings	A male student sings <i>Little Apple</i> . Wei Yang is singing along. Wei Yang looks very happy, laughing all the time
14:12–14:15	The seventh student sings	A male student performs <i>A Grateful Heart</i> with sign language. Wei Yang is singing along without sign language
14:15–14:18	The student who sang the second song, sings the same one again	The student sings <i>My Happiness is Thinking of You</i> again. Wei Yang looks very happy throughout the song
14:18–14:23	Three female students sing	Three female students sing <i>My Happiness is Thinking of You</i> together. Wei Yang is singing along. When Wei Yang's mother walks in though the back door, he turns back and looks at her
14:23–14:29	One male student sings on the stage	The student is singing <i>Run</i> to an excited class, but Wei Yang isn't as excited as his classmates. Actually, Wei Yang is always calmer than the other classmates

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Time	Content	Observed activities
14:29–14:32	A female student sings	Wei Yang plays with his phone when the classmate sings <i>Mouse Loves Rice</i>
14:32–14:35	A male student sings	Wei Yang helps the singer hold the phone for the music while the classmate sings <i>The Most Dazzling Folk Style</i> and <i>Little Apple</i>
14:35–14:40	A male student sings the last song of the entertainment session	The last song is <i>Stupid Child</i> . Wei Yang sings along with his classmates
14:40	After school	After school, he goes to the bathroom while the students on duty start cleaning up. His mother doesn't go home with Wei Yang, she left earlier

^aEmil Chau, a well-known Hong Kong–Taiwanese singer during the 1980s and 1990s

^bTeresa Teng was a Taiwanese singer, one of the most famous Chinese-speaking singers in the world. She was popular in the 1970s and 1980s until she died in 1995

*Translated by Huili Meng
 Edited by Russell Murray*

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Becoming a College Student Through Hard Work and Persistence



Yuyun Wen

Interview with Mr. Xiaodong Yu's Mother

Xiaodong Yu, male, born in 1983. Only child. Grade III intellectual disability. Graduated from a regular college (Shanghai TV University), received a Modern Clerical (International Trade) degree. Joined the Jiaxing Subdistrict Sunshine Home in Hongkou District in 2007.

Interviewee: Meizhen Zhou¹ (Yu's mother)

Interviewers: Yuyun Wen, Zhen Wei

Writer: Yuyun Wen

Interview dates: October 22 and December 27, 2016

Interview place: Xiaodong Yu's home

Excited at Birth, but Troubled by His Condition

Q: How did you and your husband get to know each other?

Ms. Zhou: My husband graduated from middle school in 1967, and I was a year later than him. Then, he was an educated urban youth in Jilin Province for 3 years, before he became a "worker-peasant-soldier" student.² After that, he worked as a high school math teacher for a while.

In my family, I'm the youngest of three, I lost my dad when I was four. After both of my brothers went to the countryside, I stayed with my mom after graduating from

¹Ms. Meizhen Zhou, born in 1952, was the Special Olympics World Summer Games East Asia Regional Family Leader of the Shanghai Special Olympics in 2007. She is also the chairman of Zhiqinhui, the Association of Persons with Intellectual Disability and their Relatives of the Jiaxing Subdistrict.

²'Worker-peasant-soldier' student refers in particular to Chinese students who enrolled in colleges during 1970 to 1976. More details about this group are available on the Wikipedia website: https://en.wikipedia.org/wiki/Worker-Peasant-Soldier_student.

Y. Wen (✉)

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school. My mom raised my brothers and me by herself, I was very reluctant to leave her, but I didn't have any choice and I had to join the other urban youths. When I got the chance to be drafted as a literary and art soldier in Heilongjiang Province, I told my mom that I'll only stay away for a year, but actually I spent 2 years there before I had chance to come back home.

When we, the educated youths, returned to Shanghai, some worked for the community offices, and some joined processing factories. I joined the community offices at first, and then I went to a neighborhood clothing factory in the Songjiang District when an opportunity to change jobs came up.

After reform and opening up of the country, quite a lot of foreign companies came in. I was a good learner, and I was able to leave the clothing factory and join a stainless-steel products company, a foreign company. In 1983, when my husband and I got married, he moved to the Wangting Power Station in Suzhou, the following year, we had Xiaodong.

Q: Is Xiaodong the only child in the family?

Ms. Zhou: Yes, that's right.

Q: How about Xiaodong's paternal grandparents' health?

Ms. Zhou: Both of them were healthy people. Grandpa passed away, but Grandma is still alive and in her nineties.

Q: Did you have trouble with a natural birth? Or...

Ms. Zhou: No, I had a caesarean. The surgeon was a friend, and I booked into the surgery on the expected date and told him I couldn't wait any longer. I had a prenatal examination and the result showed that my son was only tiny, he might have problems with a longer pregnancy.

I had very bad morning sickness, but it wasn't the reason for Xiaodong's problems because one of my friends also had very bad morning sickness but she had a healthy baby.

My son was very small when he was born, only 3.3 lb, a tiny "bead." Even though he looks well now, you just can't imagine the size of him when he was born. Have a look at Xiaodong in this picture, do you think he looks like a little puppy? (Shows a picture of her son when he was little.)

Q: He's in the middle?

Ms. Zhou: That's right, that's his grandpa next to him. Compared to other newborn babies, he was so tiny, he looked like a kitty or puppy. It was a hard work raising him. Before he was 2 years old, sometimes I'd worry that he might be a dwarf. But some of my friends told me that they had relatives who had a one kilo baby or just a little bit bigger, but all of these underweight babies grew up properly. They developed well with good nutrition. If you look at my son, he has got quite big bones even though he's very skinny. I fed him very well but he's still just as thin as this.

Q: When did you realize he had a problem?

Ms. Zhou: When he was two. To be honest, when I thought about how tiny he was at birth, I used to worry that he might not grow up properly. There was a neighbor's baby who was born on the same day as my son, and they looked totally the opposite to each other, one was big and tall, another one was short and tiny.

My son was so skinny and he looked quite sad, but he's grown up safely, there was nothing unusual about him except he was a slow walker. But he could walk quicker if you let him hold on to something. That same year we found out that my son's heels couldn't touch the floor when he was walking (uses two hands to make the shape of a bent foot), he was walking like this.

Q: He tiptoed when he was walking?

Ms. Zhou: Yes, that's right. He walked exactly like he was on his toes. I told him: "You've got to walk on your heels," but he said: "Mom, it's too tiring to walk like that." It was a problem, so we tried two kinds of acupuncture treatment. My auntie who was a doctor introduced a very good acupuncture therapist to us. At that time, my husband was working in Wangting District, and I had a full-time job as well, so I had to get up at four in the morning and take him by bus, with three changes, to the doctor's in Wujiaochang Square, and then took him back home with his head full of needles after the treatment. Later I'd take the needles out when I rushed home in my lunch break. But my son didn't get any better after 3 months of treatment, and I had to try something different.

I talked about my son's condition to a friend who was a massage therapist and he said that massage treatment might do some good. The treatment was too painful for a 4-year-old baby. After 6 months of costly treatment I couldn't stand to see my son's suffering anymore, and I decided to learn massage and do it by myself. But his feet didn't get any better; in fact, they were getting worse (she bends her hands again further). It looked like his heels were lifting up more and more.

There was a neighbor's relative who had a son with the same condition; the family thought his problem was caused by the foot ligaments. So, the boy had a ligament operation, but he was paralyzed afterwards. This story scared me, and I stopped thinking about him getting an operation. Later, I was told my son's problem was ischemic optic neuropathy, the left side of his body has a movement disorder through lack of cerebral blood supply and nerve compression. Although he's not paralyzed, it affects his flexibility, and he was then diagnosed with cerebral palsy, a multiple disability. The right side of his body functions normally but the left is affected by the disease. His speech lisp problem is caused by the same thing. Basically, even though he could walk with a limp, it was difficult for me to accept that it couldn't be cured, so I've never stopped massaging his feet.

When Xiaodong was nine, my husband met Doctor Li who worked at the Central Hospital in the Luwan District. He was a professional surgeon in this field. He said as a rule, my son was too old to perform an operation on his heel, because after years of lack of exercise, his ankle muscles might be wasted (points at her ankle). But after checking and testing him, the doctor was surprised by how good the condition of his ankles were; they were flexible and didn't have any dead muscle. The reason for that, of course, was the daily foot massage I'd given him for all those years. Of course, I wasn't conscious of preparing him for any operation, I just thought that massage was good for him and I never gave up believing that one day he'd be able to walk properly again. I lived with this conviction and was determined to massage his feet every day for 9 years.

Sometimes, I wonder if an earlier operation would have had a different effect—before his bones had hardened and developed—when his bones were soft and he had a better ability to recover. If you look, you can see that his left hand looks like this (imitates the posture of Xiaodong’s left hand, the palm is bent outwards and he can’t move it; it can’t be corrected).

When my son was little, he used to cry if somebody touched his left hand. In the Shanghai dialect, this is called *taga*, which means his two hand bones are detached. We took him to see a doctor at the City Central Hospital and found out the two hand bones were twisted (compares Xiaodong’s twisted left hand with a normal hand posture). The normal hand should be this shape, but his hand can’t bend back. I felt very lucky that he had this operation earlier, I can’t imagine what might have happened if it had been delayed or canceled. These days, when he’s walking, his heels touch the floor, but his left leg is still weak (taps her left leg), but the right leg is strong (taps her right leg). However, he is still lame and disabled.

Mother and Son Study Hard Together

Q: Has Xiaodong ever been to a nursery?

Ms. Zhou: No, he hasn’t. Firstly, his maternal grandma lived with us and she could help me to look after him; secondly, my son’s walking problem had started already, also he couldn’t speak properly until he was 4 years old. Because of his condition, it was impossible to let him go to a nursery.

But he started learning very early, I taught him basic arithmetic when he was only one and simple calculation when he was four. I also taught him to read; I read stories to him very often. Today, some people call this “Don’t let your children lose out on the starting line,” but in those days this phrase didn’t exist, it was a kind of “early education” for me. My son has loved reading since he was very young, you could even use a book to calm him down when he was angry.

Q: When did Xiaodong start to speak?

Ms. Zhou: He started to understand the meaning of words when he was four.

Q: Did your family and you worry about his condition before he started speaking?

Ms. Zhou: Of course, we were worried, but our worries were reduced by our friends’ encouragement: “Late speaking is a common thing among children, the later a child speaks, the wiser he/she will be.” We were relieved when he started saying some simple words like “Papa” and “Mama,” we were sure that Xiaodong would be able to speak after this.

Q: Did you give him some speech training?

Ms. Zhou: No, we didn’t, but we would tell him stories, teach him to speak, and read to him.

Q: How did you help him?

Ms. Zhou: I used children’s songs.

Q: Did you let him sing with the music?

Ms. Zhou: With some songs. Then we taught him Mandarin to help him speak as clearly as possible; he also used Mandarin at school, he only learned the Shanghai dialect when he was 20. I also trained him by letting him read a story back to me, he would practice that way. I put a huge amount of effort into his study and education.

Q: I looked at Xiaodong's resume. He studied at Tianshui Road Primary School in Hongkou District before he went to the Hongyan Branch Campus of Shanghai TV University. Am I right?

Ms. Zhou: You're completely right, I can show you his certifications later.

Q: Did Xiaodong's condition affect his studies?

Ms. Zhou (speaks proudly): My son was never left behind at school, he kept up with all of the other students. In the beginning, some of the ordinary schools rejected my son, but I didn't want to send him to a special school because I didn't know anything about them. Anyway, my son needed go to school, so I had to get him in through the "back door." My big brother's classmate was the headmaster of the school, and he helped us. For the first couple of years, my son had very good results in math; he would get the highest score in his math exams, even though his logical thinking was weak at the time. In his second year, when he was nine, he transferred to the Tianshui Road Primary School in Hongkou District, which was just across the road from our place.

When he was two, my son stayed in school for just the first semester and spent the second semester in a hospital ward. He had two operations that time, one for his ankle and another was hernia surgery. During that half year, I decided to teach him in the ward every day. When he returned to school in the second semester, his math exam score was 80%, even though he'd been away from school for the whole semester; both his teacher and I were very pleased for him. In ever expected too much. His exam results stayed above 80% until he was in year four; after that, his math performance got worse year after year. We didn't know about his cerebral palsy condition at that time, we only knew that problem was caused by ischemic lesions. When he was ten, we took him to hospital again, and the X-ray results proved positive for cerebral palsy. There was nothing we could do but accept the fact and we kept him in hospital. Our family life only settled down again when my son came back home from hospital. While he'd been in the ward, my mom would keep him company in daytime and I would go to him at night.

Q: Which courses did Xiaodong prefer?

Ms. Zhou: At first, he didn't like math, physics, or chemistry; passing the exam was his target for those courses. Chinese was his favorite, but I forced him to pay more attention to English. When his next school offered French, we learned this language together.

Q: How about college?

Ms. Zhou: Where could he go after he graduated from the Second Academy? At that time, he couldn't find a job and I didn't like him sitting around at home either. I wanted him to go out into the world, so when I saw the brochures for the undergraduate courses runs by the TV University and a French University, I told him to prepare a CV and apply.

Q: Did he write his own CV?

Ms. Zhou: Yes, on his own.

Q: Can he use Word on the computer?

Ms. Zhou (speaks with a positive attitude, clearly very proud of her son): Of course. He taught me all my computer skills and knowledge.

Q: So, Mom taught Xiaodong using school textbooks first, then Xiaodong taught Mom how to use the computer later. When did you swap roles?

Ms. Zhou: We swapped the teaching and learning roles when he started studying computers at the Secondary Academy. My son received many certificates of merit; every year at school he was the winner of the “Diligent Learning Star.” My son was always diligent in his studies, even though he knew that he had a disabled condition; I encouraged him all the time. Also, I kept telling him, you can’t build a good life without culture and knowledge.

Q: I’ve read a report about you, it says you had to study everything yourself before you taught Xiaodong; is that right?

Ms. Zhou: You’re completely right. He never lagged behind at school as long as I tutored him. Anyway, I used to say to him: “Pass the exam is your long-term ambition; for now, just try to keep up to standard.” In the 12 years before Xiaodong graduated from college, I only slept 4 h every night, and I kept alert and clear-headed with strong coffee and tea. These days, I’ve got stomach problems from too much caffeine. Usually, I started to prepare for his tutorials when he went to bed; later I helped him to prepare for the next day’s new lessons, especially for math, physics, and chemistry. I tried different ways to help him remember the formulas and how to work through the problems step by step. I practiced every math question with him, and told him to remember all of the formulae to solve different problems; that’s how he was able to graduate. Even today, I can still remember all of the formulas. I worked so hard for him. Until he went to college, he used to study the same thing twice, the first time taught by the teacher and the second time was with me.

Q: Did Xiaodong study computer science at the Secondary Academy and the Modern Clerical Course at college?

Ms. Zhou: Yes, that’s right.

Q: In addition to these diplomas, I heard Xiaodong also gained some computer and Internet qualifications, how did he achieve this?

Ms. Zhou: Some people used to say his school wasn’t difficult for students, everybody received his/her degree, but that’s not true. I remember the school practiced very strict rules with the students. Once he passed the computer test at the second attempt; he failed the first test with just 1% less than the standard. It was the National Computer Test, and the places to sit the exams were decided at random, so he had to go another school, a place at Fuxin Road in Hongkou District for this exam. On the day of the examination, he took the bus and got car sick before he arrived, it was so bad he even vomited. Then after the exam, he lost his ID card.

Q: How about his relationship with his classmates?

Ms. Zhou: Xiaodong is an easygoing, enthusiastic, and kind person; he isn’t a troublemaker either. So, he’s always got on with his classmates pretty well since primary school; nobody bullied him and lots of the youngsters helped him.

We also discussed his situation with the teacher, we didn’t want too much but wanted to avoid my son being bullied. I did this because I thought the classmates wouldn’t pick on a teacher’s favorite student. I felt at ease with his school life because the headmasters and class teachers treated him very well right from primary school through to college. He was also a “Study Star” for 2 years at school.

At primary school, the children are too naive to bully somebody, but something happened at middle school. There was a clever boy who lived in the same community as us, he was also Xiaodong's desk mate. The boy was clever and good at math. One day, Xiaodong went to school with a soft drink and this boy tried to take the drink away from my son. That evening, my son told my husband and me what had happened at the school. The next day, my husband went to school and sorted out this drama between the two boys. China has an old saying, "No discord, no concord." After that incident, these two boys became good friends; the boy helped my son with his math and supported him when he found things difficult.

My son likes to help other people and in return his classmates are kind to him as well. For example, we had a printer at home and Xiaodong used to bring his non-Shanghai classmates back to our place to print stuff.

Q: Does he have many friends?

Ms. Zhou (speaks with confidence): He has lots of friends, anyway, all of the people I know are also friends with him.

Q: Does he can make friends with people of any age?

Ms. Zhou: Definitely, everyone treats my son very well. Xiaodong is respected by everybody who's had a chance to get to know him, no matter what age they are. In the Shanghai dialect, we would call a person like him "Lao hao," which means very good; Xiaodong is exactly that kind of child, as good as gold, never made any kind of trouble.

Q: The news said Xiaodong also made some foreign friends at college?

Ms. Zhou: That's right, he has a French friend.

Q: He got to know his foreign friends when he was studying foreign languages?

Ms. Zhou: That's right, they met each other when my son was at college; they've been good friends ever since and still keep in touch.

Q: How do they contact each other?

Ms. Zhou: By phone, Internet later, and email.

Q: Does Xiaodong use QQ?

Ms. Zhou: Yes, he has a QQ account, he likes to try all of these new things. But now this friend is married and they're not in contact as much. But my son is making new friends all the time, some of them come from Taiwan region and other countries. But my son has only two close friends among them; in addition to the French friend, there's also a Canadian boy.

Q: What kind of language does he use with his friends?

Ms. Zhou: Some simple French with the French friend. Most people who visit China have a little bit of Chinese, so they use a mix of languages with Chinese and English to communicate. My son doesn't have any problem with simple English conversation, but I guess he's probably forgotten quite a lot of words now because he hasn't practiced for a long time. But I use English in some of my work meetings from time to time.

Q: When did Xiaodong start taking care of himself, I mean cleaning his teeth and getting dressed by himself?

Ms. Zhou: He started dressing himself when he was at the Secondary Academy.

Q: How old was he?

Ms. Zhou: Sixteen or 17, more or less.

Q: When did he start to clean his own teeth?

Ms. Zhou: When he was around ten, at primary school. It was difficult for him with one of his hands immobile, that's why we looked after him so much. But that was a parents' problem and I realized it was a problem for him later.

Q: So, you started to train him in personal and domestic skills deliberately.

Ms. Zhou: That's right. But it was quite difficult to stop my mom spoiling him when I wasn't at home. As his maternal grandma, she used to think, "Why shouldn't we help him if his disability makes things hard for him?" But now, she understands that to be independent is very important for Xiaodong's future. Xiaodong might be half-paralyzed, but his right side is healthy! When he carried a bowl from the kitchen, as a timid boy, he would worry that the bowl might fall out of his left hand (imitates her son's movement to show that he can't control his left hand). But I told him: "There's nothing to worry about, I'll clean up the floor if you drop the bowl."

Q: He has to be able to make mistakes.

Ms. Zhou: Yes. I just let him do things; I know he'll be okay after he's had enough practice. But I only started thinking this way after he graduated, when he was around 20. Then he had more free time at home and I let him do some housework. When he was a student, he didn't need to do any housework because on the one hand he had a very busy timetable; and on the other, I wanted him to concentrate on his studies and forget about housework altogether, leave all these things, he only needs to come to the table when his food is ready.

Q: He didn't need to do any housework at all when he was a student, but now?

Ms. Zhou: These days he cooks for the family. I had to find him something to do after he graduated. At first, I tried to help him find a job by asking around my contacts, there was nothing.

Q: Can he cook?

Ms. Zhou: Yes, he can. He also has to clean the house. Every morning, he sorts out his personal business and his own room first, air the bedding, for example. Then, he mops the floor, cleans the kitchen after the breakfast, and gets on with his own business afterwards.

In our family, we always share the housework together, Dad buys vegetables, Mom buys meat, and the son cleans the house. Every morning, after we've bought fresh food, Grandma and our son start preparing the vegetables, washing and peeling them. He can cook some simple dishes like steamed eggs, but he's still afraid of the burning oil in a hot pan when he is cooking. He'll step back immediately after pouring in the oil, and I have to push him back to the pan when the oil is getting hot. I grew up in a family that lost the father when I was only four and I had to learn housework when I was very young. I started to light the stove on my own when I was only five.

I taught my son how to do housework step by step. I would keep saying to him: "You just need to learn one thing every month, or even take a whole year to learn something new, and if you keep doing it, one day, you'll be good at all of them." Anyway, I'm making sure he learns housework these days.

Q: You don't ask too much at once, just ask him to keep doing something at his own pace?

Ms. Zhou: Yes, that's right. Also, he has to help me with my work when he's free. I've been very busy since I became involved in Special Olympics. All of my documents are typed by my son; for him, it's also an opportunity to practice his working skills.

Q: Sounds like he's become your secretary.

Ms. Zhou: You're right, his subject was secretarial studies, it's a chance to practice what he has learned.

Since the 1980s, the stock market has been rising, people went mad for it, but my husband and I made a decision that we wouldn't play with stocks. At that time, my husband was working at the power station and he had very good welfare, in fact he was given two small apartments. Later we started earning rent from the properties. This inspired us and we started investing more money in this business and kept buying more properties when we could. Now, Xiaodong is managing our family's tenement properties, it's skilled work of a kind. He has to look after the business, collecting rent, managing the apartments, and repairing broken equipment. But sometimes he disagrees with his dad about some issues; for example, his dad insists on repairing broken equipment himself, but my son likes to let a professional—a plumber—fix the problem. When this happens, I have to talk to both of them. I tell my husband: "You can fix the equipment if you want, but our son definitely can't deal with this by himself." But really, only they can sort out their own argument; both of them have a reasonable argument, to hire a plumber or do it yourself. The children at the Sunshine Home and the drum team call my son "Manager Yu" (laughs loudly). If you ask them why they call him this, they'll tell you it's because my son manages our properties.

Q: What's been the most difficult aspect of Xiaodong's development since he was born in 1984?

Ms. Zhou: He became willing to speak on the initiative. He didn't like talking because of his lisp, he can't pronounce *pinyin* "L" or "N" properly. So, I told him to speak in Mandarin instead of the Shanghai dialect, which is easier for people to understand. My son would practice speaking all the time, now he's much better. But this was a problem for other people, they found him very hard to understand.

Participation Comes First at the Special Olympics

Ms. Zhou: Xiaodong took part in Special Olympics in 2007; he played ricket. At the opening ceremony, the coach asked me: "Did your son join the competition because you are one of the organizers of the competition?" I said: "Yes, he joined your team to show support for my work." I knew, compared to the trained athletes that my son was a showcase, just a participant. But participation is the most important thing in any game, right? Eventually, I started to let him exercise every day, even these days, he still does 10 min warm-up exercise every day. Exercise is something worth persevering with.

Xiaodong Yu has one advantage; he is stubborn and never gives up. Once the class went to the Expo site for a day trip, my son walked for a whole day, he never stopped

or complained like some of his classmates. He only said to me after he came back home in the evening: “Mom, my left foot has cramp.” But he said nothing before finishing the tour. I’m pleased that he’s a real glutton for punishment; I guess he gets this character from both me and my husband. I survived a lot of difficult times in my life.

Q: Does he like any other sports besides cricket?

Ms. Zhou: He’s fine with bouncing a ball, table tennis, and other ball games, but he can’t jump or run. Let me show you some of his pictures (stands up and picks up some pictures). This one is a group picture of the district DPF team; our full name is the Disabled Persons’ Cultural and Artistic Training Group of Hongkou District. My son is known as an excellent student there. Our Hongkou District Drum Team is well known, famous in Shanghai and all over China.

Q: How about his cricket training? Do they have a coach who is in charge with the practice?

Ms. Zhou: He had 2 weeks of intensive training before the competition, but I wasn’t with him.

Q: Did anything special happen during the training? For example, did he ever want to quit or...

Ms. Zhou: My son would never give up, you had to tell him to stop. His stubborn character showed up in this way, it didn’t matter how difficult the training was, he tried his best to the last minute. However, that kind of training was exhausting for him. He had to exercise for the whole day every day; it was something he’d never experienced before. One time he called me and said: “Mom, I’m so tired,” and I could only reply: “Practice is necessary for everybody, even a reserve gymnast as well.” Apart from this, he told me that he was very pleased with the friendly treatment from the coach and his teammates. I was so glad to hear that. You know, I worried about him a lot before he came back home; on the one hand, I worried he might not be able to make it; on the other, it was the first time he’d been away from me.

Q: Was it closed training?

Ms. Zhou: Yes, the training site was in the Fengxian District, and my son went there by himself. Before that time, my son hadn’t left me. He said: “Mom, I’m afraid I can’t stay there without you,” and the only thing I could do was encourage him: “One day, you’ll have to live alone.”

Q: What did Xiaodong’s coach say about him?

Ms. Zhou: I met his coach at the opening ceremony, I said: “Teacher, I’m sorry to have given you so much trouble; my son has never played cricket.” The coach said: “Not at all, he’s very good, obedient, well behaved and caring; he likes to help other people.” He also talked about my son’s attitude; he said Xiaodong had helped his teammates to look for stuff that had gone missing, he also helped his mates to sort out the room if some of them had forgotten to do so. Small things for other people, nothing very important, but it was his way to help the others. But he is always really caring and willing to help other people.

Q: Did he call you from the training site every day?

Ms. Zhou: Not really, because I told him to only call me if he couldn’t sort out any problems by himself. Once he said he couldn’t reach his back when he was having

a shower, and I said to him: “Do you remember what I told you before? Hold the two ends of the towel and rub your back that way. Don’t worry if you can’t clean your back properly, because you can always take a good shower when you get back home.” I also said: “Anyway, just try your best to look after yourself there. I don’t mind if you bring back a suitcase full of dirty clothes, but please try to wash them yourself first.”

Q: For him, to keep trying to do something is more important. He has to try first.

Ms. Zhou: That’s right. There are two important things for him: the first is to try to participate in different events and exercises; the second is to keep trying new things. Even today, I keep telling him: “The result isn’t important, you just have to do your best.”

Q: How about his performance in the competition? Did you go to watch the game?

Ms. Zhou: I didn’t go to the competition that day. I had to attend an international forum of the Special Olympics committee held at the International Cultural Exchange Center at the Shanghai International Studies University. When I asked him about the game, he said: “Mom, I was knocked out in the first round” (smiles). It wasn’t a surprise to me, he didn’t have much of a chance to go further after only 2 weeks of training, and he was playing with athletes who had been training for 2 years. That game was the first and last cricket game of his life, but just participating was the most important thing for him.

After the game I started paying more attention to his exercise routine. We put a lot of effort into his practice; he got involved in Special Olympics related sports, like bocce, basketball, table tennis, and other things. Bocce is rolling a ball along the ground and trying to hit your opponent’s ball.

My son likes basketball and football; he’s the goalkeeper in football. He never misses any TV program about basketball or football. One time, the night before his middle school entrance exam, the World Cup was on; he went to the exam directly after watching a late-night game. What a crazy thing to do! But I couldn’t criticize him, I didn’t want my words to affect his exam. Anyway, he passed the exam.

These days, we join in some sports games every year; one is the unified run, where around a dozen or so people run together with their legs tied together. It’s an international, inter-city competition; some teams come from Spain and Belgium, for example. This competition is attracting more teams than before, because now there are volunteer teams taking part in the games. I’m very proud of our team because we won first place.

Xiaodong also plays badminton, shoots baskets, does shot put, and plays other non-competitive sports. Our center also has some track and field events, but Xiaodong isn’t good at this sort of thing. Recently, our team participated in wiser ball,³ which combines Chinese chess, bocce and snooker—it’s a game that needs strategy for set-up and play.

³Wiser is a combat sport using both spiritual and physical skills. The two teams have seven players in each team. There is a referee, record keeper, and a linesman. The game includes three rounds, ‘first lock’, ‘second lock’ and ‘strike-out’. The game is about improving the ability to make strategic decisions and exercising the body at the same time. It’s a battle to control the whole ground and the ball’s position. It’s also a test of tactics and understanding between players.

Q: Did you notice any obvious change in Xiadong after he'd been involved with Special Olympics?

Ms. Zhou: He became stronger, people said he was good at long distance walking as well. Once, he walked around the Expo site for a whole day. After Special Olympics, I encouraged him to do more exercise every day, like climbing the stairs. Before we moved out of the home on the fourth floor on Tianshui Road, he used to climb the stairs ten times a day. You might think, how could he do this with one foot in such poor condition, but he is really good at walking.

He also became braver than before, really. He had agoraphobia and didn't dare look down from the fourth floor. But after a time, with my encouragement, he climbed the Erlang Mountains when we went out there with the children and parents' group. I even used my son as a model to encourage the other children when some of them felt too tired to carry on. I said if Xiaodong can reach the summit with his disabled foot, how can you say I want to give up when you have a pair of healthy feet. In this way, my son became a role model for the children in our group. In the end, all the children climbed the peak with my encouragement.

In our group, my son is regarded as the big brother of the other children even though he isn't the oldest. He has more knowledge than the others, so the children would invite him to do all kinds of things with them; somehow, my son is like a "wild card" for them. They like to ask him for help when they have something they can't work out or can't understand. They used to say: "Xiaodong, I don't know anything about this thing, could you help?" His knowledge made the difference.

Q: Did the experience of Special Olympics help him to be included better into society?

Ms. Zhou: He certainly got better at socializing with other people. During that 2-week training period, he had to talk and communicate with other people all the time. After that, I started taking him out more often, and encouraged him to talk to people that he doesn't know. After a while, he became more confident when he was faced with a stranger. But before that, he would never talk to a stranger when he went out with me. Today, for example, he talked with you without needing to be encouraged.

Q: Did you and your husband feel any personal change since your son became a part of Special Olympics?

Ms. Zhou: There's a parent in our Association of Persons with Intellectual Disability and their Relatives who never stopped crying when she talked about her son, but I'm different from her. I said I had "sent all of my tears back to my ancestors," after living with my son for 30 years, I don't have any tears left. I'm quite a relaxed person these days. You have to take things as they come and don't pretend that nothing is different when you have a child like mine. If you kept trying to close your eyes, it means you are going against your own heart. But I don't do this anymore, I just let it go and don't worry about anything anymore. I don't care what people think, because I know who I am, and that's the important thing.

The worst moment in my life was when I found out that my son had cerebral palsy, but I didn't want to cry. My generation suffered all kinds of difficulties, we were sent to mountains and the countryside for years, I also had a bad experience

with my first job. To be honest, none of my dreams and ideals came true. I woke up from my dreams when I started to worry about bringing my son up and giving him a fulfilling life.

Then I started teaching my son by myself, it's a good way to save money and I could learn something from this at the same time. I was too busy to cry or complain. The only moment I got really upset was when he had to have the operations, I thought that my son had really suffered enough at his age. But these days, I no longer to obsess over this; it isn't a problem for me anymore. Compared to a family that has an autistic child, our life is easier, right? If you think about your life in this positive way, you'll feel better.

A Journey of Parent Leader with Great Joy in Hardship

Q: When did you hear about Special Olympics for the first time?

Ms. Zhou: In 2005, I'd just retired. At that time, I'd put a lot of effort into my son's study, but hadn't looked after myself enough for 12 years. This tough life had caused some health problems for me and it affected my teeth, they don't look as pretty as they once were.

I was a sales supervisor at a Sino–American joint venture making stainless-steel products. We got to know this American company through a Shanghai investment company, a relative of mine was the manager. The agreement meant that the business could only run for 11 years and would close down in 2005, around my retirement age as well. But the investment companies wanted to carry on, but without me, so I had to sell my part of the business for my retirement.

Two months after I went back home, the district government disabled assistant came to me and asked me for help. I asked him what kind of work I could do for them, and he said that it would be something worthwhile. I said to myself, I'd like to do something good for other people, and I've been working with the ever since.

I started working with the disabled assistant and the subdistrict office; I support their work in any way I can. Later, a parent who came from a family with a disabled child asked me to teach English to the children in the drum team. I asked what kind of English they wanted to learn, and then they said it was for the Beijing Olympics and Special Olympics. It was the first time I'd ever heard of such a thing as Special Olympics. After I joined them, I never left, but I regretted leaving the factory, because I could have given some work to these intellectually disabled children, if I had had this factory for 2 more years! What a shame, I didn't get to know about Special Olympics earlier.

Q: You couldn't have had the foresight when you made that decision.

Ms. Zhou: It's true, I really didn't know anything about this area before that time. The only knowledge I had was about my son, severely disabled and unemployable, and looked after by the government. The idea behind setting up the business was to make some money for my son and his future care, that was all. I was horrified when I saw so many children living a less comfortable life than my family.

Compared to those children, he was in a much better situation, on the one hand, he spent most of his time at school; on the other, his family education always focused on the positive things.

After I became involved with the social work for disabled children, they became the center of my life. I thought about them and how to develop their lives all the time.

Children with intellectual disabilities could develop their minds if you keep teaching, stimulating, and constantly spurring them on. My work has never stopped from that day until now.

Q: What was the opportunity that led to you becoming a Family Leader of Special Olympics?

Ms. Zhou: In 2006, our drum team attended the Special Olympics Shanghai Invitational Games held in the Shanghai Stadium. We gave a large side drum performance and a Chinese martial arts show to welcome the international athletes who came from all around the world. It was the first time our team had received any real public attention.

By the way, our district charity group focuses on Special Olympics, with the slogan “Achieve Your Dream,” training disabled members through sport. Our team won the prize for the “National Advanced Group of People for Disabilities and Rehabilitation Work” in 2008.

Back then, every province could elect one Family Leader as a candidate; Shanghai gave the opportunity to Hongkou District and the drum team. Who would make the ideal candidate in Hongkou District? I was chosen for two reasons; I could speak English, and I worked in the field. That opportunity came after our performance in 2006; I was chosen from five candidates.

Q: So, the drum team brought about that opportunity?

Ms. Zhou: Yes. During 2006 and 2007, our students made rapid progress and performed very well.

Q: Could you tell me more details about your role as the Family Leader?

Ms. Zhou: I'd never been a representative before, so in the beginning I was quite anxious. In 2007, I attended a forum in the Shanghai Foreign Language University Hotel. I was so nervous even though my English wasn't too bad. I used to speak English on some business occasions with Chinese and foreigners, but this forum was different. For the first time, in that kind of international setting, I wasn't sure whether my words were suitable or not, so I worried that I wouldn't be able to explain myself properly. If that happened, it might ruin everything. The first sentence I said in English was: “Good morning, ladies and gentlemen,” but I didn't carry on speaking English and changed to Chinese. I was worried that I couldn't deliver the speech in English, or those people couldn't understand me. After the conference, Li Juan, an official of Special Olympics East Asia said to me: “Your pronunciation is very good but why didn't you speak more?” I replied: “I was too nervous to speak in English.” That was my first experience in the job, after that I became more open and comfortable talking with the other international workers and representatives in English.

Now, taking part in Special Olympics has become standard practice in China. From my point of view, the Special Olympics World Summer Games in 2007 was the most exciting one. After that, I attended the International Special Olympics Games and related events every year, for example, the Fifth Special Olympic Games in the People's Republic of China (Fujian, 2010). I'm also a regular visitor to Shanghai's Special Olympics events. Special Olympics was an event where the public could

really participate, a real soul-stirring event, especially for intellectually disabled people. It's genuinely encouraging for everyone, the only grand sports event for disabled people. Through Special Olympics events, intellectually disabled people have been able to develop themselves intellectually and physically, and also engage with society. Our slogan is: "Achieve Your Dream." The next five years after 2007 was an exciting period for us, the volunteers/teachers and I achieved many things and became successful, the whole business and our volunteers made a big difference in those years.

As time went by, I noticed that lots people were holding Special Olympic events and this made it more of a formality. I never stopped promoting Special Olympics, but in some provincial and city annual Special Olympics events, people don't take them very seriously anymore. I keep telling our people, Special Olympics is an opportunity for us, everybody has to take it seriously, it isn't for the government, it's for ourselves.

Q: The novelty of the event wore off?

Ms. Zhou: The novelty definitely wore off. For some of the volunteers and teachers and me, the bigger the Special Olympics event, the better. We didn't mind paying the expenses. The only thing we wanted was to have some sporting opportunities for our children. Our students are so keen to take part in the competition every time; some of them who didn't win the initial trials were so upset they cried. I used to tell them: "There's nothing I can do for you, because the results depend on your training and how hard you worked." But the annual Special Olympics events are becoming more of a formality. For parents, the events were much more rewarding in 2007 and 2008. Those 2 years were thrilling for our children.

But I never changed my mind; I introduced a new game for our children, wiser ball. It's also supported by the local DPF. These days, the district DPF office has ordered every subdistrict to have a weekly Special Olympics practice and training, or host a competition. I'm the person who introduced the game to our Sunshine Home.

Q: What's your main duty as a Family Leader?

Ms. Zhou: The main duty includes promoting Special Olympics, participating in all kinds of Special Olympics events and attending the conferences and forums of Special Olympics East Asia.

I've presided over two public welfare programs which were funded by the government, from August 2013 to August 2015. The projects aimed to promote Special Olympics and I organized some promotional events in various places with our children, to inform people what Special Olympics is, what an intellectual disabled person is, what a Special Olympics athlete is. Our event went around Shanghai and finished in Gongqing Forest Park. All of the district DPF offices in Shanghai knew about our promotions, because I wanted to use these events to enlighten people who still discriminated against our children.

The drum team performed in Hongkou Park drumming up the public attention to the rhythm of the drums. Lots of visitors stopped to watch our show and we played for an extra hour sometimes. Our Special Olympics promotional events were quite vigorous.

During those 2 years, the project received over 90,000 yuan in the first year and 140,000 yuan in the second year. We spent all of this on training, competitions and promotions, and other events but not on ourselves. According to public welfare project regulations, the manager could have taken 3,000 yuan salary every month, and the workers and volunteers could receive 50 yuan for every event. But none of our volunteer/teachers would take this money and we used every last penny on the children. Our events are open to every intellectually disabled person and are always free. We didn't take any kind of club or membership fee; we just kept admission free and welcomed everyone who wanted to join us.

They were 2 years of really hard work and my health suffered. I was both organizer and accountant and fortunately, my partners told me that because I was the mastermind, I didn't need do any physical work. To be honest, if I had another choice, I wouldn't have done the organization either; it was such tiring work. That was a very busy period for me, we had two events every week and had to prepare some of them up to a month before. Sometimes, I only slept 2 or 3 h a night while preparing the events. Fortunately, my mom was living with us and helped me a lot. It proved the old saying: "Having an older person at home is like having a treasure."

Q: What did you do in those weekly events?

Ms. Zhou: We would take the band for some promotional performances. We went to some busy public places, squares, parks, streets, the stations. We were promoting the "Seven Irregularities"—civic etiquette—while our children performed or played their side drums.

Q: Did you have any kind of difficulties during that period?

Ms. Zhou: I didn't take the third project after I finished the first two years of programs because I was too tired to do any more work. Our projects got "excellent" results from the project appraisal company, and the examiners were very positive and gave us a very high evaluation. If we got another "excellent" result, we would be exempt from further evaluation.

But I was really couldn't carry on with the project any longer, because I have a family to look after and I can't imagine what would have happened if I became unwell. Many of my friends said I shouldn't carry on, but I thought the project was worth continuing with if I could step away from the managerial role. Anyway, if I got sick, it would have been impossible to take over the job.

Our new application funding had a problem, and finally we decided not to set up the new phase of the project. For me, it was the best time to leave. I said to our team: "If we don't have a special advantage at the next stage, we might not get any funding." We decided...even though we closed down the project, it didn't stop our long-term vision.

Q: What was the type of training that you just mentioned?

Ms. Zhou: We had a Special Olympics Family Network; every family who had an intellectually disabled person was supposed to be a member, because intellectually disabled people have a common name "the Special Olympics athlete." As their family, we're also their volunteers. The aim of the network is to let parents cooperate to help these children to improve themselves and engage in society.

After we brought these children together, we provide them with practice, training, and education to create an opportunity to help them reach their full potential, to become heather, stronger, and wiser. Then, they might get a better chance to engage in society. Every child, whether they are disabled or without disability, has their own potential, and it can only be realized if you encourage it.

For over 10 years, many of our children found their full potential in manual ways, using their brains, singing, sport, dance, or opera singing. For example, we have a student who failed all kinds of things—he has really immobile limbs and bad coordination—but one day I noticed he had a special ability with English. At that moment, he turned into a quick learner; he even learned phonetic symbols by himself.

Q: The phonetic symbol of English?

Ms. Zhou: Yes! He was the best English learner in the group; he studied very hard, liked to ask questions and was a proactive learner.

He was very frustrated after he failed at sport and dance, but all of his potential was in his gift for languages and his learning ability was realized through the study of English.

Q: What was this ability?

Ms. Zhou: Firstly, he's an earnest student; secondly, he's highly motivated to learn and even brought an English dictionary to help with the phonetic symbols. Once, we had an English competition at a Spring Festive gala. I asked them some Chinese words and let them answer the corresponding English words. When I said "turtle" in Chinese, most of students were confused even when I repeated the word very slowly; this boy was the only person to raise his hand. When I asked him to confirm his answer, he said: "I'm sure, it's turtle." That was very good. After the party, I asked him how he knew that word, he told me: "I looked up every word that you taught us in the class in the dictionary after the class." I checked this and found he had told me the truth.

There is another boy, he has been in our group for around 2 years, but when I first saw him, he was hiding behind his mother all the time when she came to ask me if I could let him join the group. He changed over time from refusing to do anything consciously to soon becoming very close to us and able to communicate with us. Actually, we help them all to improve their verbal communication through sports and produce language from sports. Whatever they say, whether the word is incomprehensible to others in exercise, to engage in communication is the most important thing, because they can build up their self-confidence through communication and speaking. Now, that same shy, timid boy has become our team leader in oral training, and he has become a confident person.

Special Olympics gives these students a chance to do more physical exercise, explore their potential through exercise, and help develop their intelligence. Sport can help speaking and thinking.

Q: In addition to being the Family Leader for Special Olympics, do you have any other titles?

Ms. Zhou: I'm also the chairman of the subdistrict Zhiqinhui, and a deputy worker of the district drum team. In our group, the teachers do much more than their titles suggest; actually, everybody does as much as they can. We would all teach dancing,

singing, playing the side drum and flat drum, sport, but now we also cover the new courses like baking, English, culture and literature, and training for competitions. There are so many new things for us to learn to teach our students.

All of our classes start with shouting the slogan together: “Who are we? We are the Special Olympics athletes!” I also keep telling them: “Everybody in our group has two names, one is an intellectually disabled person, another one is a Special Olympics athlete, the latter is unique.” I say this to remind them that they’re sportsmen, and everybody is proud of this identity.

Q: We heard from some other interviewers, those parents appreciate what you have been doing, leading the group out of difficulty and guiding the children to engage with society. What’s your motive to keep doing this?

Ms. Zhou: It’s pitiful to see them and they need help. Sometimes, my family’s phone gets jammed with calls from our students and teachers if I don’t attend practice. The students will ask: “Madam, why didn’t you come in today? Are you sick? Shall we come to see you?” I was touched by their words, and they really treat you as a family.

It’s a real joy to be with these children. Some of our parents were living an isolated and sad life before they joined our group, but the experience totally transformed them into different people. It’s the Special Olympics group that lifts up their spirit, and lets them feel: “I’m better, my life has changed.” Now, I think I’d better carry on doing this for as long as I can.

He Has a Better Life by Taking Care of Himself

Q: Let’s talk about how Xiaodong is getting on at the Sunshine Home?

Ms. Zhou: Xiaodong used to go to the Sunshine Home every day in the beginning, but after he’d been there a while, he said to me: “Mom, am I a student or a teacher?” He said that because he felt bored in the classes, and he’d learned everything the teachers had to offer.

I told the officials of the subdistrict office that Xiaodong could become a disabled assistant for them.

Q: Disabled assistant?

Ms. Zhou: These days, the DPF office has a job called disabled assistant, a worker who can help other disabled people in the area and deliver the policies relating to people with disabilities. Also, they receive a salary from the subdistrict office. Now, most of the disabled assistants are physically disabled and hearing-impaired people.

I said to the officials that I’d like to let my son take this job for free; I just wanted them to give him a chance, to get involved in society and use his abilities. But the officials said: “It’s a little bit awkward.” So, I said: “All right, forget about it.”

Now, my son is still a student at the Sunshine Home, but he only attends events and not the classes anymore.

Q: Do you think there is anything the Sunshine Home can do to improve?

Ms. Zhou (speaks with a positive attitude): Of course! Take our Sunshine Home as an example, all of our teachers have to prepare their classes and follow the teaching syllabus. But does every Sunshine Home have a teaching syllabus? The teachers have to learn a lot of things if they want to do their job well. I suggested to the leader

of our Sunshine Home that he should hire some parents of intellectually disabled children as teachers. But he asked: “Do you have a teaching certificate?” I told him: “Do your present teachers have one?” Actually, they’re just disabled assistants acting as temporary teachers and they don’t have a teaching certificate either.

As parents of intellectually disabled children, we know what our children need better than other people and we’re concerned about the quality of their teaching, but the teachers at the Sunshine Home treat our children in the same way as the older people who live in a nursing home. They just try to keep them out of trouble. Compared to some of the other Sunshine Homes, ours is pretty good, and the children are quite happy and have an interesting and colorful life. This is based on those parents and myself who are always trying our best to improve their learning experience. We set up an interesting weekly curriculum with drawing, singing, dancing, and Special Olympics training.

I usually use my contacts to organize some external events for them. Many parents of intellectually disabled children are well educated and have a good public status, they also know how to make school life better for the children. Why doesn’t the DPF office approach these people to become Sunshine Home teachers?

Q: What does Xiaodong do, as a routine, every day? Has he ever worked before?

Ms. Zhou: As you know, these days finding a job is even difficult for an ordinary person, so it’s even worse for my son. I asked around to find a job for him, but there was nothing. I said to my contacts so many times that we don’t need a salary, just a chance for him to work. But the owners of private companies really couldn’t afford to give him any special attention as a new worker. So, the problem isn’t from my son’s side, he wants a job.

These days, he is managing our letting properties; it’s a job of sorts. My husband and I don’t play the stock market, but we like to invest our money in buying and letting properties. All of these things will be left to our son. We didn’t think too much when we started buying properties, but now I realize that looking after the properties is quite a good job for him.

There are some particular problems about these children’s lives; for example, a lot of the Special Olympics parents wrote to me because they were worrying about the custody of their children after they pass away. Xiaodong and I have talked about this problem too. I said: “Xiaodong, you’ll have to look after yourself when we pass away.” My son said: “Mom, I can’t do that, (according to law) we aren’t allowed to be independent, we have to have a custodian.” He also asked me if it would be possible for him to apply for self-custody, but I could only say: “You can try when the time comes. It was the only thing I could tell him, there are laws and legal regulations about this matter.

Q: What is his daily routine now?

Ms. Zhou: Usually, he gets up at 7, makes the beds, has his breakfast, tidies up the house, and then helps his grandma with the housework; like washing the vegetables. At the moment, he’s learning domestic skills, it’s part of his daily duty, so he has to watch Grandma making breakfast. In the afternoon, he likes to surf the Internet, listening to some stories, TV programs; he could listen to stories all day long. He also likes to share the stories with me: “Mom, I heard a good story today.”

Q: Does he use the Archimedes FM app that just he mentioned?

Ms. Zhou: Yes, that's right. He listens to audio books while reading the text at the same time using the application. If he finds something he likes, he'll say: "Mom, this story is interesting, would you buy the book for me," and then orders the book online. He's a slow reader and has to read word by word, but he reads everything from the first page to the last, even though some of the books are as thick as bricks. He takes great pleasure from reading.

Q: Does he buy his own books?

Ms. Zhou: Yes, he buys books from online shops; shopping online isn't a problem for him.

Q: What does he do at the weekend, for leisure or entertainment?

Ms. Zhou: Apart from going out to buy breakfast, he usually goes out with us. He doesn't go out on his own often. In our group, the parents usually take the children with them; there are plenty of things that let parents and children enjoy themselves together. We usually go to a karaoke bar or play chess or poker. The children weren't great singers at first but they're improving; they play Chinese chess, and have even learned western chess, Gobang and Go. The children develop their intelligence through practicing these intellectual games, a sort of self-development. These improvements show us that the children can progress if the parents spend enough time and are patient with them. Now, our group has become a big family.

Q: Have your husband and you had any differences about Xiaodong's education?

Ms. Zhou (speaks with a positive attitude): We definitely had our differences! His dad wants him to learn how to deal with money, but I think learning to be independent is more important for him. His dad is always asking Xiaodong: "Do you think your life is good or not?" And our son replies: "It's a good life, but there's a fly in the ointment."

When my husband is losing an argument with Xiaodong, he likes to say: "You've made a point here, I can't win." But my husband doesn't think his son is intellectually disabled and has high expectations for him. I guess it's because I was the person who brought him up—he didn't make that much effort—he was busy with his work.

But for me, the first thing for our son is making sure he feeds himself properly, so I have to ask my husband to think about this, too.

After working with these children for over 10 years, one thing still confuses me—they don't seem to be grateful enough. I ask them: "Your parents and teachers give you everything with all their hearts, your classmates are so friendly to you, but what can you do for them to let them know you're grateful?" They would say: "I help my dad and mom as well; I make a cup of tea for my mom when she's feeling unwell."

There are always some parents who complain that their children are naughty or disobedient, but the only thing I can say is think about their condition and be patient with them. With my son, I have high and strict demands about being a grateful person.

Q: What does your family usually do together?

Ms. Zhou: We do quite a lot reading together. Xiaodong will remind me: "Mom, it's our reading time," and I'll go upstairs and read with him.

Q: When is your reading time?

Ms. Zhou: I'm busy every weekend morning and hardly get any free time, but my son always asks me to sit in the reading room with him if I have any free time at home. So, whenever I'm home and free, we like to have 1 or 2 h of quiet reading time together. Anyway, Xiaodong reads for 5 or 6 h every day.

His dad is always busy, and he doesn't like traveling so he never comes on our group trips. He says, "I have to work every day and can't find the time to go out."

We have different ideas about life. My husband likes antiques and mahogany furniture, he'd like to spend his money on these kinds of things and provide a quality life for the family. But my philosophy is to take the child out whenever I can. I say to Xiaodong and the members of our group: "Please remember, even though our children are disabled, as their parents, we have to let them try everything that a person without disability could do." And everybody in our group agrees with me (see Fig. 1).

Q: How about Xiaodong's relationship with his relatives?

Ms. Zhou: He isn't very close to his two cousins on his father's side, but he's pretty close to my two nieces. Both of them live in Canada, so they usually chat on WeChat. Most of Xiaodong's clothes were bought by my big niece, the little one likes to buy him snacks from all around the world. He's also close to my nephew, and they chat on WeChat quite often. In general, my son is closer to his maternal relatives.

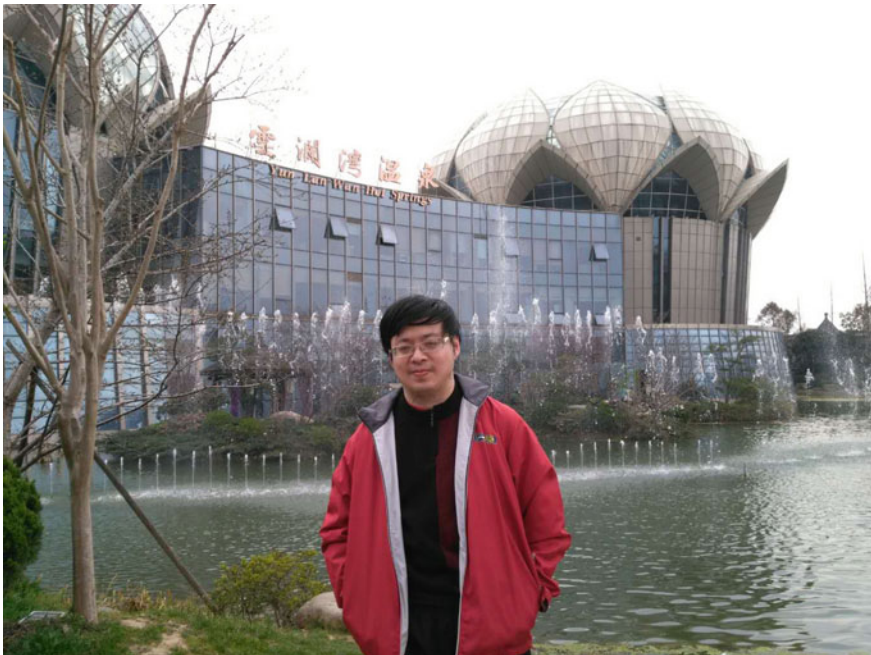


Fig. 1 Mr. Xiadong Yu on vacation

My extended family cares about him very much and Xiaodong never feels any kind of discrimination from them. I'm not quite sure about his experience in the outside world. Basically, he doesn't socialize with other people.

For the people who know Xiaodong, like our old and new neighbors, they all say my son is a good and kind child. He used to give beggars money, but sometimes I tried to stop him and tell him that he shouldn't be giving money to those young people. He'd say to me: "Mom, it doesn't matter, all beggars are poor."

Later, I explained to him that not every beggar is poor; there are some disabled beggars who are genuinely poor and need your help, but there are others who are cheats.

I like to help other people when I can afford to. I supported some Yunnan students, and I travelled to the poor mountain areas as a volunteer/teacher. I've been touched and inspired by the care and love that our children receive from the government and society.

Looking Ahead, One Day at a Time

Q: At Xiaodong's age, have you ever thought about him getting married?

Ms. Zhou: Yes, of course but it's problematic. Xiaodong has his own ideas about a partner; our family friends have introduced lots of girls, and some of them are outsiders, but my son sees through their intentions as soon as they start talking.

Xiaodong said: "Mom, I'd like to have an able girlfriend, I don't even mind if she's not a gentle person, because that might be the right kind of character to look after the family's interests. But she has to be a good person. People say to me if I'm not too choosy, it will be easy to find a girlfriend, but if she's a bad person, one day she might cheat on me." Xiaodong is smart but physically challenged, he insists: "I won't get married if I can't find the right person. Some perfect people are single; I can be like that if I can't find the girl I like."

Q: Have you introduced any girls to him?

Ms. Zhou: Yes, we did. One of my friends has a disabled daughter, they've liked my son for a long time. I agreed to give these two children a chance to get to know each other, but they didn't get on. So, I said to my son, you'd better explain to that family why you don't want to see this girl anymore, I'm not going to do that for you. And then he made the phone call himself. I told him, he only needs to get married when he meets the right person, otherwise, I would rather he stayed single. My attitude towards his marriage is let it happen in its own time.

Q: Do you agree with Xiaodong's ideas about girlfriends?

Ms. Zhou: Yes, we have the same ideas, we don't care if she's wealthy or pretty, but she must have a kind heart. She has to know how to treat her family well. I don't mind if I have to find a job for her either. For my son, he wants a girl he can talk to, if he doesn't see this in a girl he's introduced to, he won't see her anymore.

Q: Does Xiaodong know when he has to say no to a relationship?

Ms. Zhou: Yes, he's able to do that. That's why he said he can look after himself if he can't find the right partner.

Q: Is a disabled partner acceptable for him?

Ms. Zhou: He would be happy with a disabled girlfriend if she's bright, but it would be better if she wasn't disabled. It needs to work well from the start to ensure a good future for them together.

Q: What are your thoughts about him having children in the future?

Ms. Zhou: My son doesn't have a fertility problem, we tested him for this already. His problem isn't innate, but acquired.

Q: You mentioned that some of the volunteers have a more complex idea about their job, could you explain what you mean?

Ms. Zhou: In general, there are three kinds of common relationships in marriage for people with intellectual disabilities. First of all, we have some single male volunteers aged between 30 and 50. Most of them are in their forties or fifties; one of their reasons for joining us is to find a mildly disabled girl with basic abilities.

Secondly, there is marriage between two intellectually disabled people. In this situation, the parents don't only have to think about the two children's IQ, but importantly their feelings for each other. It's about how well the parents understand their children, and also what the relationship between two families is like. If the two sets of parents can't get on with each other, the marriage won't happen.

I know of a case where two disabled people got married, but the boy's parents use the girl as a maid—nobody respects her at all. I told the girl's mother that her situation is her fault and she should have listened to me earlier. They're not divorced yet, but if they can't sort out the problem, the girl's life will get worse.

There's another story about a pharmacist who lives in Fengxian District. She is the mother of an intellectually disabled boy who was married to a Sichuanese girl. This mother opened a pharmacy for her daughter-in-law, but after she gave birth to a son, the wife stopped caring for her husband. The lucky thing was, this powerful mother invested all the family assets in her son's name and excluded his wife; otherwise, the wife would probably have left the family and taken their money with her. Even though, according to the new marriage laws, the wife would receive half of the family fortune in the event of a divorce. So, this marriage had more potential problems.

My son used to listen to me when I discussed these family issues with friends; he also liked to discuss them with me afterwards. So, he doesn't need me to remind him about being careful with a relationship, he knows all about the possible problems.

Then, a lot of girls I know got married with non-disabled people because they wanted to depend on these men in their retirement. But a man who might have a poor background, no property, no car, a bad job, or unemployed—he might choose a disabled girl if she's rich enough. He might not mind being a live-in son-in-law, because for him this marriage is a trade-off; he just wants the family money for his own future. Parents who chose this kind of marriage for their daughter have to be sure that he's going to be loyal to the girl and the marriage. Everything will be fine if he's a good man and loves the girl and one day they can pass down the family wealth to this young couple. Some men won't be a loyal husband to a disabled wife in a dull marriage. Our children are not usually romantic people and live a humble life. Take my son as an example, he has a very simple lifestyle, he goes to the Sunshine Home in the morning, watches a bit of TV after dinner, then goes to bed. If this man wants a trade-off marriage, he won't be a good husband. Some men in this situation

might have an affair and when the wife's family find out about this, most of them are honest. For those wives' parents, an unfaithful marriage isn't acceptable; for some shrewd parents, divorce is their first choice; if dishonest husbands won't leave, some poor families have to seek legal aid from the community. In some cases, non-disabled men will cheat on a girl and her family after they have relocated the family home, added his name to the family Hukou and given him a share of a property; then, that will be the end of the story.

To be honest, from what I know, most of this kind of marriage between an able-bodied man and an intellectually disabled girl are failing or going to fail. Sometimes, some of the dishonest men haven't done anything bad, it's just that the mother-in-law is bitter, or the wife has non-disabled siblings. In this latter situation, the siblings will inherit the family estate. Anyway, bad men won't choose a girl who has siblings, because they won't get the family money which is what they are after.

In one of our training classes, I would tell the disabled children how to look after themselves, how to be conscious of the value of their family assets, and teach them financial management. My son is studying the same thing. For him, his lameness is his disadvantage; he doesn't care if his future wife is pretty or wealthy, he just wants a girl who has a warm and kind heart, and one that he can talk with. My son knows he looks all right and has a pretty good family, and the only thing that matters to him is that his future wife is a kind girl and treats his family well.

Q: Are these stories you just talked about true?

Ms. Zhou: Yes, all of them are true.

Q: Are you worried that something like this might happen to your son?

Ms. Zhou: Of course, it's why I'm very cautious about his future partner. Being too cautious can be a bad thing and questioning a girl's integrity is disrespectful. I come across many cases like this at work, and I'm experienced in judging people. I can read some characteristics of strangers the first time we meet. If a girl who is introduced to my son has a 60% good character that would be acceptable to me, but I'll try to stop them seeing each other as soon as possible if I find out she has ulterior motives. Anyway, the most important issue is Xiaodong's feelings; if he can't find the right person, I don't mind if he stays single.

Xiaodong is a positive person, he doesn't like struggling with something too much, and he can always take it easy. When he was a student, he used to say to me: "Mom, I want to die before you," or "Mom, I wish our family could all die at the same time." I stopped him by saying: "What a strange way to think! You're so young. I've still got a long life ahead of me, just like you." I guess he kept saying that because he understood the nature of his condition, and maybe he's heard something from my husband and me, or the other parents' conversations about the future of their disabled children. When I realized this was so negative, I tried to make him think more positively and to be honest; he's usually a cheerful person. After a while, he stopped thinking in this way. And my husband and I also stopped talking about this at home.

In a lot of family TV moral dramas, some non-disabled people who have a good job and wealthy background also have a complex family life—that's definitely not something I want for us. I've thought it through, if my son can meet the right person

that would be great, and I'll help them set up their life. If he can't find this special person, I'll try my best to give him an interesting and colorful life; equal to the life that every non-disabled person can enjoy, letting him do what he likes, playing what he wants to play.

Q: What kind of social benefits does Xiaodong receive?

Ms. Zhou: His social allowance is pretty good, he is a severely disabled person and unable to work, so the government provides a care benefit for him. With all of his allowances together, he receives slightly less than 2,000 yuan each month. We're very happy with this income, because he doesn't have to do anything to receive this allowance. So, we make sure Xiaodong appreciates the Communist Party and government, because without them, he wouldn't receive a thing. Forget our family income, it's nothing to do with my son, for an average worker, the salary won't be much higher than my son's, about 2,000 yuan, more or less.

I always say to Xiaodong: "Before you ask for anything from your country, think about what you can do for our society first." And my son replies me: "Mom, I'll do whatever I can for other people."

We have this kind of conversation all the time, sometimes we argue about something until he understands. It's a good way of getting him to understand things and improving his language skills at the same time.

Q: What are your plans and expectations for Xiaodong?

Ms. Zhou: I no longer have any hope of finding him a job, it's too difficult. Now, he's 32, we've saved enough for his future, but managing our property portfolio is a problem that we have to worry about. The only thing we can do is teach him to look after these properties as a family business, otherwise he'll become bankrupt.

Q: Do you have any other expectations apart from him finding a job?

Ms. Zhou: It would be wonderful if he could have his own family, but it's not something we're going to force on him. Right now, I'm focusing on him learning some life skills and home management, because they are necessary for his future, especially as he's dead against going to a nursing home in future.

Q: He understands what you say?

Ms. Zhou: He completely understands what I tell him. His main problem is his condition, the left hand and the left leg's lack of mobility caused by cerebral palsy, it limits his physical ability.

Q: Do you have any expectations for yourself or for society?

Ms. Zhou: We can't depend on government care. The main thing for us is to gain the understanding and respect of the whole of society through our social movement.

Some of the things we need would be impossible without the government's support, such as the way society responds to the needs of the disabled. For this we need the government's attention and support so that our voice can be heard by society: we want a decent life, what we need is more respect.

Her Story As the Mother of a Child with a Disability

Q: To summarize our interview, could you talk about how it feels to be Xiaodong's mother?

Ms. Zhou: I was very happy when my son was born, because I was given a son who would continue the family line and enjoy his life. But after that one moment, discovering his condition, I suffered a series of terrible blows: his physical problems, language difficulties, the cerebral palsy. What could we do except worry about his future—studying, career, and everyday life—it was a real burden to bear. It's too hard for most people to understand, from the terrible shock, to trying to live with the situation, and then accepting the facts.

I was worried, depressed, had heartache and fatigue—all of my heart, body, and brain were so tired—I couldn't stop myself thinking about things like getting an early night if my son didn't have an intellectual disability but I had to help him with his homework until the late hours. That was how my son was, there was no escaping this for me, I had to carry on and do my best.

When he grew up, I started comparing my son to the other children. With his peers—the intellectually disabled children his own age—my son was doing pretty well. He was one of the four children in our band who studied in a regular class and school. Most of our children couldn't do that; some of them never went to school, some lived in a welfare home, some studied at a special education school, some quit middle school. But my son stayed in a regular class until college, and got a place at the TV University, a state-owned institution with very strict standards, where the teachers would never help the students if they couldn't pass their exams, no matter how close their score was to the pass mark. But my son passed all the exams and graduated comfortably.

Then I saw that my son had a great talent with computers, he could absorb knowledge through reference books, or learn new things through the Internet. And now he can deal with all kinds of IT problems with the help of instruction manuals and the Internet.

But he has the same kind of inertia as other people and tries to avoid difficulties with excuses, like “Mom, I can't do it,” so I have to push him from time to time. Sometimes, his research takes a long time and he misses dinner, but eventually, he always solves the problems on his own. So, in terms of his intelligence, my son is better off than the other children in our band. I chose secretarial subjects for him based on his ability, and it was a good decision.

Now, children of his age are setting up their own families, it's the ideal expectation for my son as well, but we have to think about more than that, like what he's going to do when my husband and I are older; is it better to be married or single; he may get bullied, and so on. Now, we've figured it out, because we've learned from some of the hard experiences of other non-disabled people, who abused their parents, became boomerang children, or were spoiled by their parents. At least Xiaodong has a social allowance which is enough to cover his basic expenses. Of course, as his parents, we're worrying about him all the time, but worrying about things so far into the future isn't going to do anyone any good. We know we'll cross that bridge when we come to it, we can only do what we can do.

I get along well with these children and their parents in my work, I don't think of myself as a leader, the parents trust me and the students come to me if they have

any questions. I want to provide them with psychological counseling, but I only can help them after I've understood and resolved my own confusion. So far, I've helped at least three depressed parents walk out of their darkness. I don't look for gratitude, because for me, we're the same people.

I still struggle with some issues about my son, but everybody has their own problems, even the parents of children without disabilities. I dream about finding the suitable, perfect girl for Xiaodong, but I know it's just a dream. A dream girl without a kind heart won't stay with my son forever. Who knows what will happen next? I have the greatest dreams, but I'm also firmly rooted to the ground.

Q: Could you talk a little more about your work?

Ms. Zhou: Once a parent said to me: "Our children are easier to deal with than their parents." She was talking about the reality of families with disabled children; more than 85% of families that have an intellectually disabled child are low-income families and the parents have little in the way of education and low social standing. Compared to these children from this type of family, Xiaodong is lucky. I don't mean that my husband and me are well educated or have better social qualities, it's because we have a peaceful and harmonious family.

My husband used to lose his temper easily, but I never had to argue with him about the need for peace and calm at home. In my work, sorting out problems with the children is much easier than with their parents. If a Sunshine Home teacher criticizes a child or his/her parents, even if they are to blame, the parents still have to complain.

Some parents leave everything to the Sunshine Home or use the home as a nursery; they don't take responsibility for their children, especially when a problem occurs. After the children go back to their own home from the Sunshine Home, they won't interact with them, but just leave them playing on the computer and Internet. Some parents don't even show their faces, especially in they are single-parent families where the children only have leftovers to eat.

At the Sunshine Home parent meeting, I made a point of speaking to some of these parents and urged them to give their children more attention. These children want to talk to their parents just like other children. I told them the Sunshine Home isn't a substitute for their parental obligations.

A disorderly family life affects the children when they come to the Sunshine Home, this can lead to criticism from their teachers, if they don't sleep well, they might drop off in class. I asked them to put themselves in their children's shoes; what would they think if their parents were workaholics and never cared about them or talked to them? The parent-child relationship is like the husband-wife relationship; communication comes through talking with each other. I remind them all the time that parents are an important part of the children's education and growth. I don't think these parents have any more common sense than their children when they complain how stupid their children are on the one hand, while on the other, they show no concern for them. In this situation, they are their own worst enemy, not the Sunshine Home's teachers. Even if I criticize some of the parents, nobody gets angry with me, because they know I'm right and it's nothing personal.

Many of our children are quite lazy, they're not interested in exercise, and some of the parents are too lazy to teach their children who lack this ability; that's not right. With enough patience, they can learn domestic skills, for example, if the parents are worried that boiling water for tea might scald their children, they certainly can teach them step by step, make half a kettle to start with, then show them how to fill a kettle from the tap, how to use the cooker; it takes a while, but they will learn eventually if the parents have enough patience. To be frank with you, I don't spoil Xiaodong in this way. I order him to learn and correct himself with one thing each month. I give him a month to learn a new thing and I watch him every day until the day before last day. I will criticize him if he can't do the thing correctly on the last day. A month is plenty of time to improve just one thing if he puts enough effort in it.

I love Xiaodong, but I know letting him learn as much as he can on his own is best for him. People often say to me that my son doesn't have any problems looking after himself, but they don't know about the effort that's been put into this. I never watch TV or play with the computer in my spare time. I use this time to talk and discuss things with my son. If I can help him achieve these skills, then I don't need to worry about his future. The other parents should be able to do the same thing.

I encourage the parents to teach their children how to be grateful; I used to emphasize this point in class, at events, or at the drum team practice sessions. These children are very slow learners. I used to ask them some questions like: "Is your mom tired after her long day at work? Are you tired after 2 weeks of training? Are your parents tired after an 8-h working day?" And if they said yes to any of the questions, I'd say: "Why don't you listen to your mom, help her with the housework? Why do you just play your computer when you go back home? Don't you have any respect for your parents?" To be fair, the children will never have a grateful heart if their parents never show their appreciation for the teachers or government, but just complain about everything all the time.

There's a way to be a good parent and teach children positive principles—our social etiquette and domestic skills classes are based on this idea.

In the domestic skills class, we teach them whatever they want to learn. We started with simple things like frying or boiling an egg. To encourage them to learn new skills we have competitions, like cooking, making the bed, sweeping the floor, using the vacuum cleaner, storytelling... In the storytelling competition, they don't need to repeat tales they've read, but use stories from their everyday lives, like their experience when moving home, how they felt after their grandfather passed away, helping their parents with housework, or stories about their teachers and classmates; everybody has a special story. In the social etiquette class, we teach them how and when to greet their parents, relatives, and teachers, and we practice using good manners. In this way, lots of the students become polite people. We also teach them to respect their parents, be grateful to anyone who helps them. We repeat these things every day and every week.

Q: Could you sum up your feelings about being the Special Olympics Family Leader and the chairman of Zhiqinhui?

Ms. Zhou: After doing this job for over 10 years, I'm very pleased that more and more parents have opened themselves up and gave me a chance to help them

free their mind of problems. It's one good thing I've been able to do. Training intellectually disabled children is very hard work, for a new dance movement, it might take a non-disabled person 10 min or an hour to learn it, but for our children it could be a whole day, and there is still a chance that they might forget it the following week. We never give up, we repeat the same movement again and again, until they learn it. Both children and parents were very pleased when they finally learned the movement and never forgot it again. I'm so pleased, because our hard work has improved their intelligence over these years. In the beginning, learning a dance could take up to 2 years, but now that time has been shortened to 2 weeks. I'm proud of their achievement.

I feel guilty about my family, because I've spent most of my time on my work. I only do a little bit of housework in my free time, sometimes I haven't been there when my family has needed me. Once I was working on an event and missed my mother-in-law's 90th birthday; she was unhappy that I couldn't be there. But I was very pleased that event was successful.

My team of workers and students say I'm a perfectionist, because I'm always strict about the way things are done, but I just want to get the best from everyone for our audience and supporters. I'm always very happy when the dance routines live up to my expectations; but I'm even happier when the children's performance is applauded by the audience. I've been able to help these children while at the same time, along with the other teachers, I can have enjoyed the time we spend together—playing, dancing, sports—it's a win-win relationship.

I don't want to say anything noble, but I like to quote a phrase, "A wide heart embraces all." I see that as broadening my mind and caring about other people at the same time.

Q: I'm inspired by your words, and I especially admire all the effort and hard work you've done over these years. Thank you and your family for the generous support.

Ms. Zhou: You're welcome, and thank you, too.

Interview with Xiaodong Yu's Teacher

Interviewee: Teacher Ni

Interviewer and writer: Yuyun Wen

Interview date: December 8, 2016

Interview place: Jiaxing Subdistrict Sunshine Home in Hongkou District

A Cheerful Boy with a Talent for IT

Q: Do you remember when Xiaodong when came to the Sunshine Home?

Teacher Ni: It was in 2007.

Q: Have you always been his teacher?

Teacher Ni: Yes.

Q: What are his favorite classes and sports?

Teacher Ni: He likes brainstorming and events, like “brain twister” games or guessing riddles. Basically, he likes something interesting and intellectually stimulating.

Q: How about exercise and sports?

Teacher Ni: He doesn’t think he’s any good at sports, but when he goes to competitions to represent the subdistrict office, he always comes first or second.

Q: How does he do this?

Teacher Ni: His parents played a very important role, working with us. His mother is very strict with him.

Q: I can see that. What do you teach here?

Teacher Ni: I’m the teacher of the handcraft class.

Q: How does he get on in your class?

Teacher Ni: Not bad. He has a partially disabled hand that prevents him from doing better, but he really works hard.

Q: What are the main aspects of his hard work?

Teacher Ni: Because his fingers are inflexible, he works harder, always making a conscious effort.

Q: How about his relationship with his classmates?

Teacher Ni: He has a very good relationship with everybody. The students call him “Manger Yu,” because he’s well educated and a good reader.

Q: Xiaodong has been here for almost 10 years, have you noticed his improvement?

Teacher Ni: He was a quiet child and used to stay away from the other students calmly. But now he’s quite an active person.

Q: Is this mainly down to a change of attitude? Is there anything else you noticed?

Teacher Ni: He does much better in sports. He plays table tennis quite often, but when he started, he didn’t even know how to hold the paddle; now he’s a good player.

Q: What do you think of him?

Teacher Ni: Well, he loves literature, reading books, and cartoons, and he’s also very interested in the news.

Q: How do you know he likes reading?

Teacher Ni: You can see something about his character through what he reads and learns. I can tell he likes reading and he reads quite a lot.

Q: But what do you think of him?

Teacher Ni: He was a quiet person, but over time he became a fluent talker and a cheerful person. At first, he never spoke very much even though he knew a lot of things; we encouraged him to speak more by giving him a chance to deliver a lesson to his classmates. They understood his stories pretty well.

Q: Did he ever do anything that impressed you?

Teacher Ni: He impressed me when we went to the Expo site together. Compared to the other students in our group, he’s the one who has the real physical disadvantage, but he never complained during the whole day’s walk, even when most of the other students said they were tired.

Q: Do you have any expectations for his future?

Teacher Ni: I hope he can find a job that he likes and that he's able to engage with society. He has good computer skills and it would be fantastic if he could find a job in this area. He can't walk very far but working with computers and the Internet from home would solve this problem.

Q: Thank you!

Interview with Xiaodong Yu

Interviewee: Xiaodong Yu and Yu's mother

Interviewer and writer: Yuyun Wen

Interview date: December 8, 2016

Interview place: Jiaxing Subdistrict Sunshine Home in Hongkou District

'Manager Yu', Growing up at the Sunshine Home

Q: Do you remember when you first started at the Sunshine Home?

Yu: I've been here a long time. I used to go to the old site to start with, before the Sunshine Home moved here.

Q: What are your favorite events and classes?

Yu: About classes... Basically, I know more about culture and literature better than all of my classmates, but they like to invite me to their events.

Q: What kind of events?

Yu: They invite me to join in some events outdoors, but they won't do that if it's an indoor activity.

Q: How do you get on with your classmates?

Yu: Not bad.

Q: What do you think of them?

Yu: They're very open.

Q: Have any funny things happened to you?

Yu: I'm an easy-going person and I can take a joke.

Q: Anything else?

Mother: What do they call you?

Yu: It's because of you, isn't it? (He points to his mother and feels a little bit shy.)

Q: Don't be shy.

Yu: They call me "Manager."

Q: What do you think of the teachers?

Yu: They're pretty good.

Q: Have you learned anything here?

Yu: Of course, almost all of the things I learned here are about discipline.

Q: You've been here for so long; do you think you've changed much?

Yu: The teaching environment has changed; the old campus wasn't as good as this one. I can see... The outdoor space is bigger. Here there's plenty of space for us to move around, we didn't have this much space in the past.

Q: How about you? Have you changed much?

Yu: I don't think I've changed too much, because I have a higher education background than they do. But my practical ability is a problem, so my main improvement is this.

Q: Did you make a lot of friends here?

Yu: Yes.

Q: Do you feel lucky to know them and have their friendship?

Yu: Yes, I do. We usually go out together; a big group of parents and children.

Q: What do you think of the Sunshine Home? Could you say something?

Yu: My feeling is... What I know from my mom, she worked here, before the Sunshine Home opened, the children had to stay at home all the time, some of them were a little bit autistic, they didn't talk or communicate. But now, they all love to chat and joke together.

Observation of Xiaodong Yu in the Drum Team

Observation date: November 27, 2016

Observation place: Disabled Persons' Federation of Hongkou District

Observer and writer: Yuyun Wen

Xiaodong's left side body is paralyzed, so he doesn't practice with the drum team very often. He usually comes as a team teacher, and as a secretary and assistant to his mother, Ms. Meizhen Zhou, to help the teachers and team members to practice. This time, Xiaodong has a new job from his teacher as a "little journalist."

Time	Content	Observed activities
9:00	Students leave the DPF office and walk to the activity room	Xiaodong chats and makes jokes with his friends while he takes out a notebook and pen ready to take notes
9:15	The teacher stops the practice and corrects some of the students' gestures	He gets into the journalist mood and observes the people and makes some notes. But he yawns occasionally
9:21	The teacher tells the group that Xiaodong will be today's "little journalist."	It's Xiaodong's first time playing the role of journalist. The students know each other too well, so they can't help but laugh together
9:28	Break time. The teacher asks Xiaodong to interview the students. He interviews his friends Z and H first	He asks about their feelings after practice, and he gives them some timely advice
9:35	Dancing time. Xiaodong stares blankly, but his mom reminds him to talk to the observer	Sharing his interview experience with the observer, he says he knows these students too well and is aware of everybody's weakness

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Time	Content	Observed activities
9:47	During the break, Xiaodong interviews his peers S and Y	He asks what the students think about the practice, and comments on their performance
9:56	After the interviews, he shares more stories with the observer. He takes out his phone and shows some pictures of his holiday trips and the cartoon doll which he bought at the Single's Day Sale ^a	Xiaodong wins a vote to administrate the Baidu Post forum for this cartoon character. Xiaodong is a big fan of the character and has lots of models of this character in his room
10:00	The students practice the horse-riding step	A student can't achieve the right position because of his bad joints, Xiaodong patiently assists the teacher in helping him
10:14	The teacher asks Xiaodong to join in the practice, and lets him join in the 30-s horse-riding step competition with his classmates. Everybody gives him warm applause after he wins the game	
10:16	Break time	Xiaodong chats with his friends
10:20	The students dance to a medley of music. The songs are <i>Ten Farewells to Red Army</i> , <i>Horse Pole</i> , <i>Happy Dance</i> , <i>Three Toasts to the Motherland</i> , <i>Deeper in Love</i> , and <i>Moonlight Over the Lotus Pond</i>	Xiaodong takes pictures of the band with his phone
10:32	End	

^aThe Single's Day Sale is held by Taobao, a Chinese online shopping platform, a much larger version of Black Friday or Amazon's Day in China, it takes place on November 11

Observation of Xiaodong Yu at the Sunshine Home

Observation date: December 8, 2016

Observation place: Jiaxing Subdistrict Sunshine Home in Hongkou District

Observer and writer: Yuyun Wen

The Sunshine Home's classes are too simple for Xiaodong Yu, so he only attends his mother's class on a Thursday as well as the activities and events that are held at the Sunshine Home.

Time	Content	Observed activities
9:05	Xiaodong helps the workers to sort out chairs, and then he lines up and prepares for the exercise	While working, he talks to his classmates from time to time

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Time	Content	Observed activities
9:08	Practicing the ninth edition of the people's radio calisthenics	Most of his actions are standard, but some of them are difficult for him
9:12	Mental Rehabilitation Therapy class, the students sit in the circle and wait for the class to begin	The doctor comes to the class every Thursday, this time the subject is Expressive Arts Therapy
9:15	At the beginning of the class, the first exercise is relaxation training. The teacher speaks with music; the students close their eyes and listen	Xiaodong is quite relaxed about this
9:22	The limb exercise, the students move their head, arms, waist, legs and feet in succession	Xiaodong doesn't need the teacher's individual guidance, at the same time he helps the teacher to correct some of the students' movements
9:48	The teacher leads the students in a game, they stand in a circle hand in hand. The students in the outer circle run through the inner circle quickly	Xiaodong enjoys this game very much, he laughs happily (they swap position)
9:53	The teacher asks the students to explain their feelings about this game. Xiaodong says that it feels like a wave	The purpose of the game is to help the students learn how to express themselves
10:00	Xiaodong helps the teacher put the desks and chairs back in their original places	Students can do anything they like from 10 to 11 a.m. as free time
10:08	Free activity time. Xiaodong walks into the table tennis room and plays a game with his friend	Xiaodong is a good player and he wins several points. His mother and teacher stand nearby to guide and encourage him
10:14	Xiaodong has a break, he is really into the game. His eyes follow the ball all the time, and he picks up the ball for the other players	
10:20	He's watching his friends play the poker game "24 points."	Xiao L has been trained to play the game by his parents since he was very young. He calculates the numbers very quickly and beats everyone, including the observer
10:24	He chats with people. His mother asks him what kind of house work he does at home. Xiaodong says he answers the phone, cleans up the floor; he's also the IT person and typist as well, his mother's secretary	
10:50	The class is finished. He prepares for lunch	
11:00	He has his lunch	
12:00	A walk after lunch	

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Time	Content	Observed activities
13:00	He comes back the Sunshine Home and has a rest	
14:03	The Capability Training Class. The teacher supervises the student's playing wiser ball, Xiaodong is the referee. He's following the balls all the time and makes some notes when he needs to. He also applauds the other player's performance	The referee needs good observational and responsiveness skills, the teacher says this role is impossible for most of the students except Xiaodong, so he takes on this role all the time. The main duty of the referee is to mark the balls with cubes. He's also the record keeper
14:36	The second round, Xiaodong is still is the referee	
14:50	The third round, Xiaodong plays the same role. He dodges the ball easily. The game is very intense, Xiaodong is concentrating on the game and always ready to place the mark	
15:05	The game is finished. Xiaodong helps the teacher to sort out the space. The teacher asks the students to line up and gives an appraisal of the game	
15:10	Xiaodong is ready to leave and says goodbye to the observer	

*Translated by Huili Meng
Edited by Russell Murray*

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A Telephone Operator at a Sunshine Workshop



Huiran Li

Interview with Ms. Y's Mother

Ms. Y, female, born in 1986. Only child, mild intellectual disability. Graduated from a special education school in Shanghai in 2002 and started working at a Sunshine Workshop of a subdistrict in Shanghai in 2014.

Interviewee: Ms. Y's mother

Interviewer and writer: Huiran Li

Interview dates: October 29, 2016 and January 12, 2017

Interview place: McDonald's, Bauhinia Square, Yangpu District, Shanghai.

A Newborn Saved by Doctors

Q: How did you get to know your husband?

Y's mother: We got to know each other through a matchmaker. He returned from a farm in Heilongjiang Province and worked in the production unit. It was hard work and poorly paid. I'm a local here and younger than he is. I worked in a textile factory at that time. We got married after about 1 year, but we were not well off. Half a year later, I was pregnant. I was very happy when I found this out (with a happy smile).

Q: Did you have prenatal check-ups in those days?

Y's mother: I did have a monthly prenatal check-up, but it didn't reveal any problems, only that the baby was a bit small.

Q: The baby was smaller than normal, no other problems...

Y's mother: No, no. When I was going into labor, the doctors said my cervix was not open, but they didn't induce labor. She was delivered through C-section on May 3. When she was taken out, she cried a lot and her voice was loud. In the next day, within 24 h after her birth, the doctors found that her face and body were purple, and her cry was strange. They gave her emergency treatment. She was not so well after that.

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Q: After she was saved, did you and your husband take good care of her?

Y's mother: Yes, we took good care of her. It was paramount. After her birth, I quit my job and looked after her every day. When she grew up a bit, I did odd jobs here and there, in addition to taking care of her.

Exhausting Resources for Nutrition

Q: Is your daughter always in poor health?

Y's mother: Unfortunately, yes. She was in poor health when she was little. Before she was about 2 years old, she often had colds or diarrhea, so we frequented hospitals. My mood depended on her health. I felt so worried about her throughout those years.

Our economic condition was not good at that time, but we spent a lot to buy nutritious food to gradually improve her health. We fed her various vegetables, bean products, date juice, milk, eggs, fish, shrimps, beef, and other foods that are good for brain development.

When she grew older, she wasn't allowed to have snacks, only after dinner. We adults kept all the nutritious food just for her, since she had a low birth weight of only 2.6 kg and we hoped she would grow healthier. Gradually, her condition was better when she grew to be 4 or 5 years old and basically okay at the age of 6. She didn't have any serious diseases. It's just that her constitution is a little bit weak.

Q: When did she learn to walk and talk?

Y's mother: She toddled when she was 15 months old. Shortly afterward, she was able to say papa and mama. The first time when she called me mama, I was extremely happy and excited (with a happy smile on her face). I can still recall that feeling now! She wasn't an obedient kid, but there were funny stories. Our conversation might be like this: "Why don't you behave yourself?" "Because you often spank me." "But I spank you because you don't listen to me." "I won't listen to you anyway. Also, why did you give birth to me? I can just go back to your tummy." She was very stubborn. She hated criticism, favored praise, and could bear grudges. In her first grade, she was bullied by her classmates, but didn't dare to fight back. In the end, she simply refused to talk to them. That showed how stubborn she was.

Q: Could she take care of herself as a kid?

Y's mother: She was able to brush her teeth, wash her face and feet when she was about seven, and wash her hair when she was about ten. Before that, I helped her with these things.

Preference for Transformers Over Dolls

Q: Did she have any problems in kindergarten?

Y's mother: She went to an ordinary kindergarten. Sometimes she played with other kids, but for most of the time, she preferred playing alone in a corner. Teachers said that she was an introvert and seldom talked. She didn't like to communicate with others, either. That was typical slight autism. For 3 years in kindergarten, this didn't change. If her teachers assigned any homework, she didn't always tell me.

Both her teachers and I told her to be active and open, but it didn't work. She simply said she didn't like talking. Still, she made some good friends. A kid who lived upstairs was her playmate. The two of them played building blocks and sang

together. As for the older kids, she simply ignored them. That was how she spent her days in kindergarten until the age of five.

At that time, her favorite toy was Transformers, in addition to other toys for boys, like origami, guns, yo-yo, and cards. She liked playing with boys. I asked her why. She said boys were straightforward, while girls were too coy. I joked, “How I wish you were a boy! (laughing heartily)” I also bought her 100- or 200-piece jigsaw puzzles. Sometimes she could fit them together. In a word, I bought her everything she wanted, as long as we could afford it. CDs, a CD player, and a radio were also bought for her. She didn’t like those things which were generally for girls, dolls included. Now she knows better.

Q: What was your typical day like when she was little?

Y’s mother: In the morning, I prepared her breakfast. Then I selected her clothes and taught her to dress, which she learned gradually. After she brushed her teeth and finished her breakfast, I took her to kindergarten. In the afternoon, I picked her up and sometimes we walked around. After getting home, I cooked and we had dinner. Then we watched TV, took another walk outside, went home, washed our face, brushed our teeth, and finally went to bed. That’s typical for my day.

Q: So, you have been taking care of her alone. Do you have any helpers?

Y’s mother: Only me. Her dad had to work. My parents had to take care of several other kids and her grandmother was too old to take care of her. Kids like her tend to be hated. Only parents are patient enough. I took care of her until she graduated at about 18, because I didn’t believe in others.

Transferred to a Special Education School Due to Poor Academic Performance

Q: When did you notice her differences from other kids?

Y’s mother: When she was in the first grade. She couldn’t focus in class, either fidgeting or sleeping. We thought it was natural to be fond of playing at her age. She kind of understood what the teachers taught, as she could remember all the *pinyin*. But she didn’t like writing. I was told by her teachers that she refused to write, so I tried to force her. She could read correctly the 26 letters. Her handwriting was not bad, either.

Once, a teacher told her classmates, “Y’s homework was not written by her, but by her parents. She doesn’t like studying. I suggest that you don’t play with her.” When a teacher keeps saying that, a kid would feel inferior. Since you said I was like that, I would act like that. The situation remained like that until the mid-term exam, when she got a bit over 20 for the Chinese exam and over 50 for the maths exam. The score for other subjects was not so bad, though. Anyway, her teacher insisted that she should be transferred to a special education school.

Q: When her teacher prevented other kids from playing with her, did you talk with the teacher?

Y’s mother: I didn’t know about it until two other parents of her classmates told me, but Y had already been transferred to a special education school by then. Her teacher never told me, but simply stressed that my daughter should take extra lessons after school. However, I couldn’t afford it back then. So, I didn’t employ any tutors, but taught her together with my husband. Sometimes I taught her writing and asked

her to write again until I was satisfied. She knew *pinyin* well and she could spell the characters according to their *pinyin*. I also taught her numbering and arithmetic, counting from 1 to 100. Every evening after dinner, I would teach her for about 1–2 h.

Q: Was she eager to learn?

Y's mother: No. She started playing and playing once I wasn't watching her; and she wouldn't start her homework until I was back. She was always eager to play outside, but hated studying. She got spanked for this many times.

Q: How long did she stay in the ordinary school?

Y's mother: Just 1 year. Actually, she could catch up with her classmates, and we expressed our wish for her to stay, but her teacher insisted that she could only study at a special education school since she fell behind. We knew the truth was that the teacher felt shamed and was prejudiced against my daughter, considering her as a drag on the class. It was the teacher who forced her to leave. Considering the high school workloads at that time, I also tried to suggest that my daughter be transferred to another ordinary school. It was refused, however, by the teacher, arguing that my daughter was a poor learner, who would only be accepted by a special school. He even said he had arranged it for us.

This teacher was mean. Apart from my girl, he also transferred another boy to the special education school. He could do so if the student was considered a bad performer and made no progress after receiving extra lessons from him, but what he did instead was to make the kid leave directly at the critical moment when the kid was about to become a second grader.

Q: Have you ever considered taking her to a doctor and trying to transfer her back to an ordinary school?

Y's mother: Yes. We took her to Longhua Hospital. The doctor tested her IQ twice and her scores were a bit over 50. This score, according to the doctor, was lower than normal, indicating the level of a kid of 5 or 6 years old. Learning this, we were worried (in a sincere tone). We took her to the same hospital again for a head CT scan. The doctor said that her fontanel was not completely closed, and she had mild ADHD and suffered from attention deficit. So, to help with her brain development, we gave her traditional Chinese medicine and nutrient supplements, which indeed had some positive effects. To deal with ADHD, I still gave her traditional Chinese medicine for about 4 or 5 years till she finished elementary school. As she grew older, it was more possible to make her behave sensibly.

People would always hate you when you had a child like this, right? Some meddlers would say how come you had a silly child. Gossip always existed. Even some of my siblings would hide their discrimination in my presence, but criticized her as foolish behind my back. Though she didn't know about these, I felt quite uncomfortable. Knowing this reality, I would try not to talk to them, avoided them, but still warned them not to speak evil of my daughter. Anyway, I was sensitive to their contemptible comments. We do not see each other much now.

Whenever I see kids like my daughter being bullied, I go blame the bully, "What's the point of you hurting the kid? These kids are already wretched," and chase the bully away. In my eyes, these kids are like my own daughter. If my daughter is bullied, I feel upset as well. Sometimes, I even felt uncomfortable when my mother asked my

daughter to do housework. I mean it. I just couldn't understand why they wouldn't treat my daughter the same as everybody else. They are common people. You may not care about her, but at least I do. As for her dad, he didn't tell his colleagues about our daughter due to his concern about reputation. Thus, all his colleagues just thought that my daughter didn't like studying.

Q: How was her health after she went to elementary school?

Y's mother: Very good. She grew to be over 170 cm (laughing heartily). None of the other three children in my extended family outgrew her.

A Helpful Monitor for 5 Years

Q: What was she like in the special education school?

Y's mother: She was originally studying in a school in Pudong District. Later, we moved to Yangpu District, so she was transferred accordingly. She went to the special education school when she was 8 and graduated at the age of 17. Her performance at school was not bad, as the lessons, after all, were easier than in ordinary schools, and she might have matured. Anyway, this is your own child. There's nothing you can do about it. It was just an event of small probability like when you win the lottery, I guess. Nonetheless, I'm still fortunate. She simply doesn't like studying, but still performs better than other kids in other aspects.

Q: How were her studies?

Y's mother: Not bad. Her scores were 90-plus, 80-plus, better than many classmates of her age. In the beginning, I forced her to study hard, and she begged me not to do so, saying that she didn't want to study. I told her she must study, because she couldn't afford to be illiterate. Then she still begged me not to put any more pressure on her. So, in the end, I was like, forget it. From then on, I stopped pressing her and allowed her to study as she wished.

Q: Was she a leader in her class?

Y's mother: She was the teacher's assistant, responsible for collecting students' homework and correcting it. In the fifth grade, she became her class's monitor. She oversaw various duties, like distributing stuff, homework, and test papers, and also making the students line up for dinner and ladling food. This role gave her many opportunities to communicate with her teachers, but she didn't do it very often. She just tried her best to finish the tasks entrusted to her and reported to her teachers. Also, she didn't think much of teachers' praise and didn't like to be in the limelight (laughing). She was the class monitor all the way up to the ninth grade.

Q: How many students were there in her class?

Y's mother: More than 30. Some students had severe intellectual disabilities and some were mild. Some kids suffered from cerebral palsy and Down syndrome. My daughter felt sympathy for them and helped them with many things they could not handle, like pouring water, fetching things, and helping them walk.

Q: What courses did she take in the special education school?

Y's mother: Chinese, maths, cooking, pastry, music, physical education. There were no English lessons. Generally, her performance was good, with the scores of Chinese and maths ranking the first or second, but her painting was not. She liked to work with her hands. She could make excellent paper birds, just like a boy.

I always accompanied her to school and back home. She could walk home alone, but I simply didn't feel at ease. She was audacious, and often went out whenever possible. She could stay outside for hours without feeling scared. But I was worried. I asked her, "Aren't you scared? What if you meet bad guys?" She said, "I will not talk to them. I'll just ignore them if they say something. I'll keep walking and never look back."

Q: Did her school organize any activities?

Y's mother: Yes. They went on outings every year. They went to the Forest Park, the Safari Park, the Xijiao Park, and the Oriental Pearl Tower. They also had sports games and gymnastics competitions. She didn't like ball games.

Q: Did she have any good friends?

Y's mother: Yes. A couple of friends. Boys and girls. They played fighting. She also liked to listen to music, or read novels.

Q: Do you know what novels she was reading?

Y's mother: I had no idea (laughing). Her things are kept neat and her books are kept from us. I never tamper with her stuff. I'm wise.

She hated homework so much that she would not even raise her head if I told her to do her homework. She just liked playing and reading. She might read novels for 1 or 2 h without moving a bit, and she would cry if I tore her novels when she played too hard. Once, she refused to follow my instruction and it was impossible to talk sense into her, so I told her, "If you cannot get rid of your bad habit, I will tear your books. I mean it." She didn't believe it, but changed her mind once she saw I wasn't bluffing. I said, "As long as you finish your homework, I will not meddle in any of your affairs. Studying is the top priority." She finally understood. She would show me the finished homework when I got home, and if I was satisfied, I would allow her to play as she wished.

Q: Did she have pocket money to buy books?

Y's mother: Sometimes she asked me to buy books for her and sometimes she used her own money. She also had pocket money from her dad. Most books were bought by me. I bought her everything she wanted. Nowadays she reads novels on her mobile phone. I don't care what she is reading as she's already married. I don't want to interfere with her affairs. I just teach her how to respect her mother-in-law.

Q: What else did she do when she didn't have classes?

Y's mother: She helped me wash the dishes. Since she was about 15, I taught her how to cook. I gave her instructions and she cooked the dishes one by one. Now she can cook various vegetable dishes and soups.

Q: Have you ever taken her traveling?

Y's mother: Yes. We have been to Nanjing and some other places. We also took her to parks when we were not well off in her early childhood. We visited the Jinjiang Amusement Park, where she took various rides. Being brave, she preferred exciting rides that rotated 360 degrees a lot. Normal ones were not her thing. We also went to Changfeng Park, Xijiao Park, Heping Park, and Zhongshan Park, etc. She would try all the amusement facilities in the parks. Sometimes she went to parks with her friends, but less nowadays. Sometimes if she expresses her wish to go there again, I just said, "Let's go have fun. I'll take you there."

A Telephone Operator at the Sunshine Workshop

Y's mother: After she graduated from the special education school, upon recommendation by the Disabled Persons' Federation (hereinafter referred to as the Federation) of Yangpu District, her dossier was affiliated to a company in Shanghai. I didn't know what the company was engaged in. She could receive a minimum monthly salary, increasing from about 1,000 yuan initially to more than 2,000 yuan later. It was like this for 7 to 8 years. And she didn't do any work during those years. She just stayed at home.

Later, upon recommendation by the Federation of Yangpu District, she worked for about 1 month at a bakery, where she was asked to do all the dirty and hard work. This made her so tired that she wanted a rest, so she took 2 days of leave. On the third day, she sprained her ankle on her way to work, but the bakery claimed that she had canceled her contract with them since she was absent from work without permission. This way, the Federation removed her affiliation¹ and only provided her with a minimum subsistence allowance. She rested for about a year to recover and went to the Jiangwan Sunshine Workshop afterward. Her job was to classify threads based on their colors as per the samples, wind the threads onto a board and pack them for sale. She worked there for more than a year.

Q: Why did she transfer to this current Sunshine Workshop?

Y's mother: Because it's the center of our own subdistrict. But she herself actually preferred the Jiangwan Center, where she enjoyed herself a lot with more good friends. There was an old man working at the District Federation who "forcibly" invited her back to the newly established Sunshine Workshop of her own subdistrict. This way, when she needed to participate in any performances, she could ask our subdistrict for leave, without the need to go to other places.

My daughter came to this Sunshine Workshop in 2014. A thorough cleaning was the first task soon as everyone arrived in this new center. After that, for about 5 to 6 months, she folded towels and put them into boxes. Then she folded paper boxes and then strung beads. Stringing beads and folding towels were contracted from other organizations. After stringing beads for several months, my daughter was assigned a new task. She needed to call the households which did not pay their telephone bills in time and remind them to settle their bills. This is what she does every day since then (see Fig. 1).

There are more than 20 people at the Sunshine Workshop. Seven or eight people do the same job as my daughter. Y goes to work every morning at 8:30 and makes phone calls for over an hour. She has lunch there and starts making phone calls from 1:00 in the afternoon, until 2 o'clock. Then she rests and goes home at 3 o'clock. If there is no incoming call, she always fiddles with her mobile phone, watches movies or reads novels on her mobile phone. At home, she plays video games and watches TV series. She likes costume dramas like the *Romance of the Three Kingdoms*.

¹Since one person cannot be employed by more than one organization simultaneously, the editor presumes that the Disabled Persons' Federation of Yangpu District removed Y's affiliation to the company when she was actually employed by the bakery. Then she became unemployed after leaving the bakery, thus claiming the subsistence grant distributed to the unemployed disabled people by the government, which is equal to the "minimum subsistence allowance" mentioned by her mother.

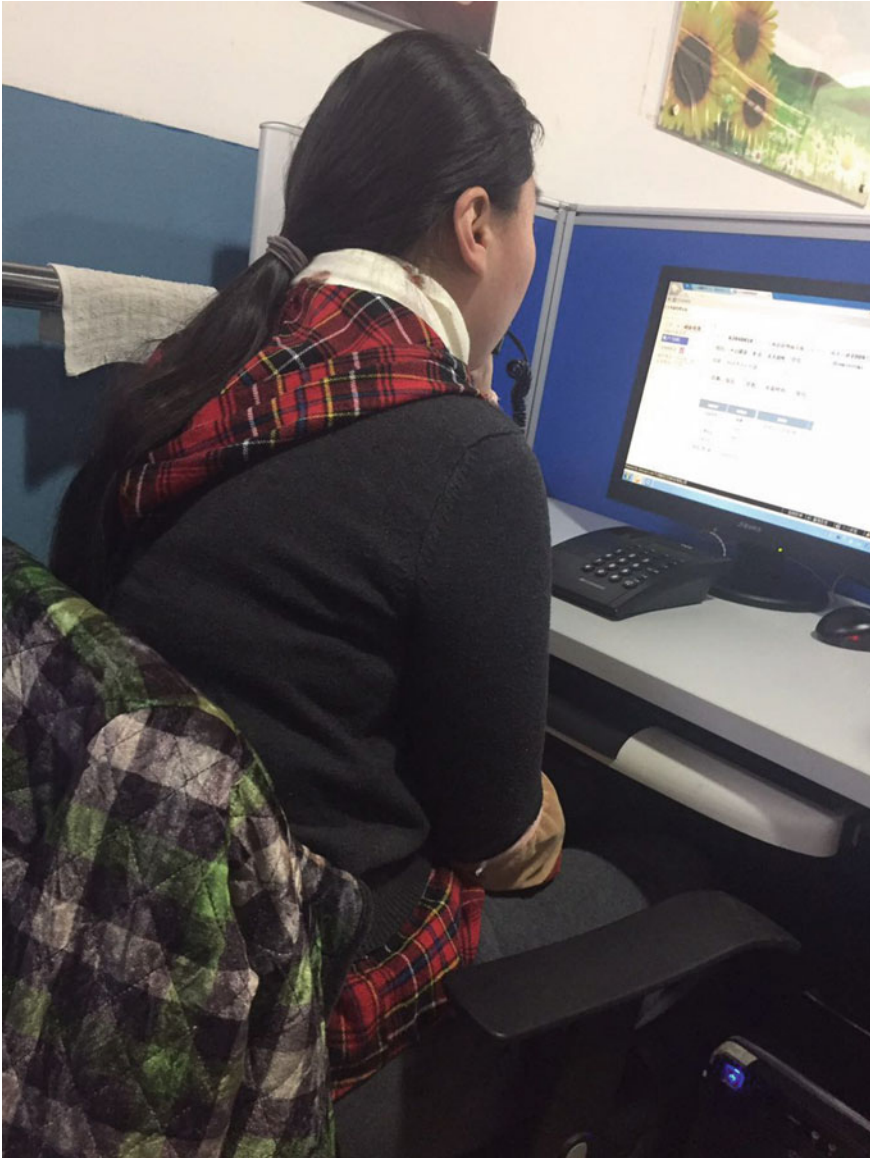


Fig. 1 Ms. Y at work

Q: Did she have any difficulties in adjusting to her new job as a telephone operator?

Y's mother: Yes. She was reluctant. In the beginning, she didn't want to answer the calls as some callers were polite, while some others were ill-tempered people who kept cursing. She felt she was unlucky, saying that, "I was often cursed at, and

it makes me so sad”. After about half a month of hesitation, she still didn’t want to take the job, saying it was frustrating and annoying.

I said, “There’s no point in feeling frustrated. Just ignore them. People have different personalities and ill-tempered ones do exist. Don’t take it personally. You have no choice. This is your job. Let them curse. Forget it as soon as you hear it. Any job can be frustrating at the beginning, but you just need to adjust to it until you ultimately feel at ease. If you don’t take the job, will you just stay at home? It’s not that bad. You don’t like talking, right? But this job makes you talk. You can practice your speaking skills through this.”

Her teacher also said this job was very good and that she would adjust to it over time. Her teacher said, “Y, you are smart, but you don’t talk much.” I told her teacher, “You have to press her. Be strict with her. You can spank her if she doesn’t behave herself.” Of course, she wouldn’t spank her. Ha, Ha! Her teacher likes her. Her mother-in-law also tried to persuade her. Gradually, she got used to it. With 2 years of experience now, she talks much more and expresses herself much better, from simply a few sentences to a paragraph. She also talks politely.

Q: How does she get along with her colleagues?

Y’s mother: Not bad. They help each other. If any of her colleagues is depressed, she will try to comfort them. Compared to other kids, she is well behaved. She is also very kind. Once, a young girl of the District Federation with diabetes got worse after having desserts banned by her mom. My daughter would visit her in the hospital with gifts. In another case, a kid needed hemodialysis due to a complication. Most people donated 2 or 3 yuan at the teacher’s request, but she donated 50 yuan, all earned by her at work. She was already more than 20 by then. She also normally saves several hundred yuan given by the Federation each quarter for those in need.

Q: Does she receive a monthly salary?

Y’s mother: My daughter earns a little more than 2,000 yuan each quarter. Her husband is affiliated with a company, earning a little more than 2,000 yuan each month.

Q: Now that she earns a salary, has she bought you any gifts?

Y’s mother: Yes. After she got married, she bought a mobile phone for me as a birthday present and a short-sleeve shirt for her dad. She generally spends more money on me than on her dad. We asked her not to buy things for us when she didn’t earn a lot before getting married, but now I’ll happily accept her invitation to a dinner if we go out on the weekend. I’m happy to receive gifts from her. She has become more mature since getting married. I tell her not to act like a kid now that she’s married, while she replies she will always be a kid in my eyes.

Favorite Entertainment at the District Federation

Y’s mother: She went to the District Federation half a year after her graduation. The Federation had a waist drum team and she joined in the second batch over a decade ago. She is a quick learner and plays quite well.

Other activities also include singing and dancing. She can sing many old revolutionary songs like *The East is Red*, *The Red Army Song*, *Red Star Shines*, and *Three Rules of Discipline and Eight Points for Attention*. I can’t remember the titles

(laughing). They don't often sing pop songs. As for dancing, it's mainly about Chinese martial arts, Chin Woo gymnastics, Xinjiang dance, Korean dance, and A Grateful Heart dance. I can only remember these.

She also bakes cakes, pastries, and cookies, not Chinese pastries. She once learned how to cook *mantou* (Chinese steamed bun) at school. They had cooking competitions every 1 or 2 years to select the best chef. Teachers would take several eggs for all the participants, namely every student, to boil or fry, to see how well they can cook. Parents would then have a taste. My daughter acted like a good cook, but she was a bit rushed. The final result tasted not bad actually. She can cook scrambled eggs with tomatoes, stir-fried vegetables, and boiled eggs. She was neither the top, nor the bottom, but slightly better than the average. She has also learned some basic English for 3 to 4 years, like hello, snow, or numbers, etc. Her English is not very good, as she didn't know the alphabet and never learned it before like those studied in ordinary schools. She is learning from them bit by bit.

Q: Does the Federation arrange for her to participate in performances? Does any TV station come to record their performance?

Y's mother: Yes. There were also pop singers. The TV stations made programs showing their performance, like *Chinese Kung Fu* and dragon dance, my daughter included. They went to the Shanghai Television Station to perform and the show could be watched from both the Shanghai local channel and the CCTV. I missed it, but my daughter saw a segment. The final performance normally looked much better than rehearsal. The moment they started beating their drums, the scattered crowd became silent.

Q: Do they have teachers teaching them singing and dancing?

Y's mother: Yes. The teachers are also parents. They take great pains to help the kids learn the waist drum and have the kids practice over and over again. The teachers are all nice and patient people. My daughter likes them very much and respects them. One of the teachers, Ms. Zhou, treated the children there as her own kids, teaching them again and again. This arduous effort won her great respect from among the children. My daughter may keep some secret from me, but not at all from her teachers. She considers them like me with much affection. The kids are under strict regulation, while my daughter believes it is for their own good, so she always follows the teachers' instructions. Every year, she also goes on outings with the teachers. This year, they went on a 3-day trip to Zhangjiagang. She enjoyed it a lot. The scenery there was beautiful, she said, but I haven't seen the pictures.

Q: Does she receive a subsidy for participating in activities of the Federation?

Y's mother: Not necessarily. Some kids who live in poor conditions and travel a long distance may receive a meagre travel allowance of about 2 or 3 yuan each time. One year, every kid received allowances, but that was only once. When they participated in contests or performances, the organizers would pay them a little money, about 20 yuan. In most cases, there is no allowance.

Q: Does your husband go with your daughter when she goes to the Federation on weekends?

Y's mother: No, she goes there alone. Her dad is physically disabled, so he can't carry out activities like that. Now she leaves from her mother-in-law to the Federation,

while I go there from my house. Rain or shine, you can count on her to be there, even when she is ill (laughing). She refuses to ask for leave as she feels happy at the Federation with the teachers. She always sends her holiday wishes through text messages to them one by one during festivals, including on New Year's Day.

Participation in Special Olympics Recommended by a Teacher

Q: Did your daughter participate in the 2007 Special Olympics?

Y's mother: Yes, she did. She took part in racing and badminton, ranking first and third, respectively.

Q: How did she train?

Y's mother: She had work to do it at the Sunshine Workshop, so she had to take leave to train. It was a hard time for her. Actually, she didn't take interest in sports, but her teacher insisted that she should take part in the competition. I told her, "You're asked to go, because the teacher hold high opinions of you. You must do your best and win honors for your teacher." So, she took the training seriously. At the training center, coaches from sports clubs trained them to run and serve badminton for over a month. During that period, she trained from 1:30 to 4:30 in the afternoon every day after lunch. She felt tired, because she didn't do much exercise before.

Q: Did many people from the Sunshine Workshop participate in Special Olympics?

Y's mother: Not many. Around a dozen. They gathered at the District Federation and went to the training center together.

Q: Did she compete with Chinese or foreign athletes?

Y's mother: Chinese athletes. I was at work during her competition, so I didn't go to the venue, but watched the live broadcast instead. I started working after she went to work at the Sunshine Workshop, which left me more time to myself. I did sanitation work for around 10 years before I retired.

Q: How long did the competition last?

Y's mother: About a week. She participated in two events, each had four or five rounds, including the preliminaries and finals. I still keep the gold and bronze medals.

Q: The 2007 Special Olympics was a sensation. Did journalists interview her after it?

Y's mother: No. They interviewed the District Federation. She wasn't interviewed. She is a bit slow after all.

A Helper to Her Mother-in-Law in Business

Q: Ms. Y is married, right?

Y's mother: Yes, ha ha (smiling, feeling shy). They were married in 2012. Her husband is only physically disabled with walking problems. He also works at the Sunshine Workshop, but not as capable as my girl. After getting married, my daughter lives with her in-laws. She gets along well with them. She can go to the Sunshine Workshop from her home in 5 min, while my home is only four stops away from her mother-in-law's. Normally, she helps her mother-in-law with the small business after getting off work at 3 p.m.

Q: What kind of business is her mother-in-law engaged in?

Y's mother: She sells snacks like fried chicken and milk tea, and liquor. Her mother-in-law was a natural businesswoman, who adapted one of her rooms as a store. Y helps her every day. They are very busy, but they close the store before 6 o'clock. Then her mother-in-law cooks dinner and washes the dishes. After cleaning, she goes walking for a while till 7 or 8 and goes to bed after taking a shower.

Q: How did your daughter and her husband meet and fall in love?

Y's mother: There is an episode. Once, she sprained her ankle on her way to work, and her foot was fractured. At that time, they were dating. Since I was busy fitting up my house, he immediately called his mother, who sent my daughter to the hospital for an X-ray right away. The doctor found that my daughter had a dislocation, which required surgery. His mother was really considerate and tried her best to ask for help from her contacts, so that my daughter had the surgery the very next day. His mother took good care of my daughter for a month, for which my daughter was extremely grateful. Then the two youngsters got married about 1.5 years after they started dating.

Q: How do you feel, now that your daughter is married?

Y's mother: I am happy, of course. But I'm also anxious. I need to take care of her regardless. She's inexperienced; I constantly worry about her. I need to tell her how to deal with daily life. When such a child becomes independent, you can never relax. I'm always afraid that her husband's family might take advantage of her. I feel concerned even now.

Q: Have they considered having a baby?

Y's mother: My daughter doesn't want one. She said, "Both of us are disabled. What if our child is also like this? I am unable to take care of a child like me. It is unfair to the child." What can I say? She doesn't want a child.

Q: Does your son-in-law have any other problems apart from physical disability?

Y's mother: He only has a problem with his legs. His legs were disabled when he was very young due to high fever. Two operations couldn't even save the legs. He's lazy, incredibly lazy. He needs help with everything. If you don't pour water for him, he would never go for it. He is just like that. Neither does he want to do any exercise, nor can he bear any hardships (sighing). I told my daughter, "How can you bear to be treated like that? His legs are disabled, not his hands. His mother doesn't want him to suffer, but you should have scolded him since you were a couple. Who is he going to rely on when his mom is old? Does he want his old mama to take care of him?" He is not only lazy at home. He also asks my daughter to pour water for him when they are at work. She has no choice.

Mother and Daughter Doing Exercise to Lose Weight

Q: When does she come to visit you after getting married?

Y's mother: She is busy working during the day. When she gets off work from the Sunshine Workshop, after having dinner and washing the dishes, she'll call me while walking for exercise at around 7. We usually talk for about a minute, just a few sentences. I tell her to keep her home clean and tidy. All the housework is done by her at her home, but she is not perseverant and lacks initiative. I need to remind her. She doesn't wash her duvets until I tell her to do so. We often meet on weekends.

Q: Does she stay at the District Federation for the whole weekend?

Y's mother: Yes, both mornings from 8:30 to 11:00, but not in the afternoon.

Q: What does she do in the afternoon then?

Y's mother: We often take her out to have fun. We just wander here and there, seeing different parts of the city. We want to relieve her boredom by taking a walk. In recent years, she also sends me holiday wishes. She's able to understand my hardship in raising her up.

The cause of the fracture I mentioned before was because she fell, because of an oil stain on the ground. After the incident, she was in bed for over a month before the steel bars were taken out. Obviously, she didn't do much exercise during the period, but just sleep after eating. That was how she gained weight. She didn't have regular meals. She skipped breakfast and supper from time to time, but she didn't care. I told her, "You can't skip meals like that. How can you keep healthy without regular meals? It matters the most. You must have a bowl of rice every day, plus some vegetables and meat. Otherwise, I'm afraid that you'll suffer like your classmate at the District Federation. You can keep skipping meals if you want to repeat the failure of that classmate." I just scared her like that.

After she gained some weight, her blood sugar increased accordingly, which may lead to diabetes. So I took her to see doctors. After treatment for about 2 months, the doctor said that her blood sugar was not too high, only a bit high after dinner, which was normal. Doctors told her to do exercise, otherwise, ...

So, I started to do exercise with her every day. We walked for more than an hour each time. She was reluctant to walk for exercise in the beginning, then I asked her to walk with me. After walking together for about 2 months, I told her, "From now on, you need to walk by yourself and rely on your own effort. You must persist if you want to lose weight. Perseverance leads to victory." She followed my advice. Once, she was gaining some weight. I told her, "You need to exercise harder. You are fat again." She replied that she'll try harder. I call her like this everyday to remind her to walk for exercise.

Now she walks all by herself. In the morning, she goes walking for about 40 min after breakfast. In the evening, about half an hour after cleaning the dishes. I tell her the evening exercise matters the most, as fat won't accumulate if she keeps walking. I also say that, "You can count on no one else, but yourself to lose weight. You can walk without other's companionship. Have confidence in yourself." Now she is much thinner. She said she wanted to keep walking until she weighed 62.5 kg. I said, "Go ahead." You must have confidence in yourself no matter what you are engaged in. Otherwise, you'll achieve nothing.

She kept walking, without controlling her diet. She ate both vegetables and fruit. In about 6 months, her weight was reduced to 65 kg from 75–80 kg. God, she was really fat previously. Now she weighs about 65 kg and her blood sugar level is back to normal. She is happy about this. She still walks alone for exercise every day, both in the morning and evening. I also do the same. I told her, "I'm urging you for your own good. You should be thankful." And she said she really was. She sent me holiday wishes by text message and said I was pushing her for her own good. She is now slimmer than before.

Interview with Ms. Y's Teacher

Interviewee: A teacher from the Sunshine Workshop of a subdistrict in Shanghai

Interviewer and writer: Huiran Li

Interview date: December 7, 2016

Interview place: A Sunshine Workshop of a subdistrict in Shanghai

Q: Would you please briefly introduce to me the students of the Sunshine Workshop?

Teacher: There are two groups. One group refers to those who can make phone calls, while the other group stays in the classroom.

Students who can make phone calls can handle simple jobs, but they are only auxiliaries. It is often known as informal employment. They enjoy the minimum standard of five social insurances from the government, amounting to 1,300 to 1,400 yuan each month. They also have an allowance of over 800 yuan. Altogether, that is 2,190 yuan. But ultimately, they can receive only over 800 yuan. The minimum living standard is adjusted annually, so is the amount of living allowance. It is much better than before, when there was no such allowance at all. The government has invested a lot in this field.

As for the second group of students, they do not undertake simple jobs, so they don't enjoy social insurances. They only have the living allowance.

Q: Can you tell us some basic information about Y?

Teacher: Y has mild intellectual disability. She previously worked at the Jiangwan Workshop, and came to this workshop since its establishment, making her a senior staff member here. She just lives across the street. She can handle simple jobs like making phone calls. She receives the five social insurances and the living allowance of over 800 yuan. She also participates in the activities at the District Federation every Saturday and Sunday morning and has been with the waist drum team for a long period. Overall, she's good with a high attendance rate. She always comes unless she's ill or has other difficulties.

Q: Y is married, right?

Teacher: Yes, her husband also works here. He is probably ill these days. Otherwise, you should be able to see him. His condition seems worse than hers. Or to be precise, his condition is the worst among the physically disabled students here. When we had activities, he often fell. We are very concerned, because we bear a lot of responsibility when we take them on an outing. We have two couples in the workshop. This is quite a small number. Strictly speaking, a couple is not allowed to work at the same workshop due to inconvenience in management. Both of Y and her husband were single when they joined the workshop. Later, they dated and got married before I came here. I learned about their story from other teachers of the Federation of the subdistrict.

Q: Is Ms. Y an introvert?

Teacher: Yes. She is intimate with me. As a teacher of special education students, we need to understand their characteristics. When I first came here, she didn't get along well with her previous teacher. There had been tension and even quarrels

between them. Afterward I had deep conversations with her and found that she was not bad. These students are a special group of people. You must use a different way to communicate with them. Ms. Y is willing to share all her secrets with me. We also talk a lot. I like the girl.

We have two types of students here. Students handling phone calls rarely communicate with those in the classroom, because the former have contempt for the latter, who are considered to be foolish and unable to start a dialogue. In fact, students handling phone calls just don't like to hang around with those in the classroom. So, the students in the classroom mostly play with each other.

Students handling phone calls are mostly kind guys, actually. Several of them are especially close. Unlike the past, when she seldom talked to others, Ms. Y is more open now. I told her, "You have to change. We are a group. This place is different from your home. If you keep everything to yourself at this place, it does you no good except for a different environment. You must learn to be included into our big family. All the students here are more or less the same. Otherwise, you won't be here. It doesn't make sense to despise others. You may not talk to them if you don't want to, but you still need to communicate."

She is a handy person. She can do her job very well when she is on duty or required to do some cleaning. The dishes are neat and tidy, and everything is in order. I think she can live an independent life. She washes her own clothes as well. At least she's already a married woman.

Sometimes, I talked to her while walking after dinner. She seemed to bear slight grudges against her husband as both of them are young people and only children, but her husband cannot do any job. I told her, "Now that you chose to marry him, that's your life. You need to take care of him, but he cannot do anything in return. You have to make a sacrifice." Actually, her husband is from a well-off family, it's just that he himself is seriously disabled. Sometimes, she said she regretted it. I said, "It is improper to say that. It's understandable if he became disabled after your marriage, but the reality is that he was like this when you first knew him. Now that you married him, it meant you had accepted him as he was. You must face your future life together. It's lucky that all your parents are still able to support you, otherwise you'd need to count on yourself. You should be prepared." I can tell that sometimes she feels unhappy about her mother-in-law. When she complains to me, I'll try to help her. Now she is much better. I told her, "As you grow older, you should be mature in all aspects." At least, she's already a married adult over 30. But deep down, she is still like a simple and naive child. When she encounters setbacks in life, she doesn't know how to handle it.

Q: I think she is overall very happy now.

Teacher: Yes. She had some friends at the Jiangwan Workshop, but fewer friends here. The situation is much better now. Previously, she didn't even communicate with people. I told her, "That way, you will feel lonelier and more bored. Don't always compare this place with Jiangwan." Now, she has got used to this place. She's basically meticulous, careful, and introverted. This might have something to do with her personality, family background, and her marriage. It is different to live together with your own parents than your in-laws.

Q: Is she always handling phone calls these years?

Teacher: She officially started handling phone calls in May 2014. From 2010 to 2014, we undertook some simple tasks, like folding towels, processing disposable chopsticks and stringing beads. Now that we have undertaken this phone call project, we are unable to do those previous tasks, as there are not enough students in the classroom to finish everything in time. Originally, it was also the students now handling phone calls who did most of the work. Without them, the students in the classroom plus us teachers were still not enough as we had deadlines to meet. We didn't earn much through these kinds of tasks. It was about 0.01 or 0.02 yuan per pack of napkins. The quantity mattered more than the unit price.

The current task is much better. Other people envy us. The room is like an office, nothing short of that for people without disability. We all use new equipment installed by China Telecom. The computers are bought by us. Each of us has a passcode and our own seat. We work through a platform. Sometimes when the phone fails to get through, we have to move to another place. So, we have mobile positions.

Since they are disabled, they may find it inconvenient to press the buttons on the phone. So, we ask them to click the phone numbers on the computer screen instead. We also designed a headphone initially, but they didn't like it. They prefer a landline phone and consider it easier to use. If everything goes smoothly, they can finish a call within 30 s.

They attended a training course by teachers from China Telecom and were required to pass an exam before taking the job. This way, they may feel certain pressure and be more careful on the job. Otherwise, they would not take it seriously. I also attended a training course. Later, when the original teacher left, I took over the responsibilities. I know about the business.

Now, they don't have much difference from ordinary people while making phone calls. Most of them didn't go to high school after graduating from junior high. So, due to limited education, they don't know a lot of characters, especially in the beginning. When talking over the phone, they might not be able to answer some of the client's questions. Now they have dealt with various cases, and they will report to me every week if they have any problems. Sometimes, I instruct them in relevant skills during weekdays. Now they can deal with all the clients' questions. It is very easy for them now.

Q: I don't think she has any problems answering the phone calls just now.

Teacher: In fact, she has encountered questions, but she can answer them all now. In the past, when they first took the job, they didn't know what to reply and just froze there. It took some time. After all, it has been 2.5 years. They are much better and familiar with the job now.

Q: Where is their lunch from?

Teacher: From outside. It's ordered by our superior.² They all have lunch here, rest, start working again at 1:30 and get off at 3 p.m. We have been working together for some time, and they spend more time with us than with their parents. So, in a

²The top-down hierarchical structure is District Federation, subdistrict Federation and subdistrict Sunshine Center.

sense, we know everyone very well, no less than their parents. Overall, I think these students are not bad. They are willing to open their hearts to me and accept my advice. After all, they are all grown-ups. They are not children anymore.

Sometimes, we go out to have fun, like watching films. We go to a nearby movie theatre within walking distance once or twice a month. Last November, we took them to visit the film center in Songjiang. We also have many outdoor activities. The subdistrict Federation determines the schedule, while we will then take them to the destination.

Q: Okay. That's all for today. Thank you.

Interview with Ms. Y

Interviewee: Ms. Y

Interviewer and writer: Huiran Li

Interview date: December 7, 2016

Interview place: A Sunshine Workshop of a subdistrict in Shanghai

Q: How long did you stay at the previous Sunshine Workshop?

Y: A year and a half. I didn't want to come back, but they insisted. I had no choice.

Q: Do you like your present job?

Y: I prefer my previous job of folding napkins at the Jiangwan Workshop. My present job is not bad, but I don't like talking. My previous job involved hands only, so we could chat while working, as long as it didn't affect our work. It was fun. People there were nicer. It was more fun at Jiangwan.

Q: You have been here for about 4 to 5 years. Are you always making phone calls?

Y: No. In the beginning, I packed napkins. You know, if a restaurant does not offer towels, they offer packed napkins. I also folded towels.

Q: You like puppies and kittens a lot, right?

Y: Yes. I like Pomeranian, Chihuahuas, and Yorkshire terriers. And the dogs with very short legs and no tail. They are fun. I like various dogs. I also like cats. I like puppies and kittens (playing with a kitten while talking).

Q: Besides cats and dogs, what else do you like?

Y: Nothing special. I like *Scarlet Heart* and *Scarlet Heart 2*. I also like old dramas and films, like *Righteous Guards*. Now you cannot find them on the Internet. I like various swordsman dramas. They are very interesting.

Q: Out of *Scarlet Heart* and *Scarlet Heart 2*, which one do you prefer?

Y: I like *Scarlet Heart* more than its sequel. I also like the heroine Shishi Liu. I don't know why, but I am somehow attracted to her. I just like her.

Q: Which hero do you like?

Y: One is Qilong Wu. I also like the actors of the eighth and the thirteenth princes. They are also good.

(A nearby student said the weather was good and it was like spring.)

Y: I think it is not spring yet. What about winter?

Q: Do you like the teachers in this workshop?

Y: Yes, they are not bad, but I prefer the teachers of the District Federation.

Observation of Ms. Y at the Sunshine Workshop

Observation date: 9:00–15:00, December 7, 2016

Observation place: A Sunshine Workshop of a subdistrict in Shanghai

Observer and writer: Huiran Li

Time		Activity	Remarks
9:00–10:00	9:00	Seated Tai Chi	Ms. Y practiced Tai Chi following the instructions of a tutor. She was very skillful. When the tutor asked questions about the names of each posture, Ms. Y listened quietly while others answered. She didn't say anything. Sometimes, she mouthed the posture name silently
	9:20	The tutor taught some new postures and asked the people to practice	Ms. Y was learning carefully
	9:50	She practiced Tai Chi to music	Ms. Y's postures were standard, and she could practice the whole set of postures in a skillful manner
10:05–10:50		She went to work and made phone calls	Ms. Y worked at the Disabled Persons' Sunshine Call Center of Hongkou District, Shanghai, under the Department of Debt Collection of China Telecom. Her job was to inquire with subscribers, whether they have received the telephone bill for last month. Ms. Y worked with concentrated attention
10:50–11:00		Ms. Y took a rest and waited for lunch	Ms. Y fiddled with her mobile phone, checked WeChat public accounts featuring kittens and puppies and talked to her colleagues
11:00–11:10		Lunch	Ms. Y enjoyed her lunch silently. She shared some of her food with her colleagues
11:10–13:30		Lunch break	After lunch, Ms. Y cleaned her desk and phone. Then, she went to a path outside the Sunshine Workshop, basked in the sunshine, took a walk, patted the kittens and chatted with her colleagues and teachers. She took out her iPad to read novels and check her WeChat. She ate several walnuts

(continued)

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Time	Activity	Remarks
13:30–14:45	She went back to work and made phone calls	She inquired with subscribers whether they had received the telephone bill for last month
14:45–15:00	Rest. Get ready to go home	Ms. Y packed her stuff and said goodbye to her colleagues and teachers before she left the Sunshine Workshop to go home

Translated by Min Cui

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Completes the Course but Fails the Degree from Regular Schools



Yujia Feng

Interview with Mr. C's Father

C, male, born in 1986. Only child. Grade IV intellectual disability. Completed courses in regular primary school, middle school, and technical school. He entered the Sunshine Home in Hongkou District, Shanghai, in 2007.

Interviewee: C's father

Interviewer and writer: Yujia Feng

Interview dates: October 28, 2016 and May 9, 2017

Interview place: Star Sky Cafe

He Wasn't Clever Enough to Study

Q: May I ask how you and C's mother first met?

C's father: My wife and I met each other through a mutual friend in 1984; both of us worked on the Qianwei Farm on Changxing Island.¹ Our jobs were pretty good, she was an accountant, I was chief of the sales section. We got married in 1985, a year after we met. We had a permanent contract with the Qianwei Farm, which meant that we'd promised to settle down on the farm for life. It was a popular way to settle down for the future for youth workers at that time.

¹The Qianwei Farm is a state-owned farm on Changxing Island, Chongming County in Shanghai. The farm was established in 1958 and had been combined with several other farms or companies. Now it has over 30 farms, orchards, and companies.

Y. Feng (✉)
Fudan University, 220 Handan Road, Shanghai 200433, China

Q: When was the child born?

C's father: We got married in 1985 and had our son the following year. My wife had health problems during the pregnancy, high blood pressure, so she went to the hospital quite often, she even spent 2 or 3 months in hospital.

The doctor told us she had high blood pressure and the fetus was under average size. Because of these problems, she was kept in the hospital for a month before the due date. The doctor said she needed to eat more, but she didn't have any appetite at all; she ate pigeon soup for three or four meals over 2 days. In August, the baby became overdue and the doctor suggested having a caesarean. My son was only a little more than 4 lb when he was born, a full-term baby with a premature baby's problem, birth defects. According to the medical knowledge about his situation, he would be more difficult to bring up than other premature babies. Later, while he was in an incubator, he caught a cold, the doctor found out he had congenital heart disease and pulmonary insufficiency. We had to keep one eye on his condition.

When he was a month old he got pneumonia, so I took him to the People's Hospital. The doctor told me he had to be hospitalized, but I just thought at his age, he shouldn't be kept in hospital and the doctor let me decide what to do. It was just the beginning of pneumonia, he didn't even need an injection, so we fed him some Jiemycin pills. The pills cured him, his cough stopped, and his fever went away.

After that, I went back to Changxing Island to work, my wife was still on maternity leave, but they came with me. From that time, my son went to hospital every few days. I remember one evening when I came back home from work, it was almost 8 o'clock, he was crying badly, my hugs wouldn't stop him either, so my mother-in-law and I took him to see the doctor again. The doctor told us he had a hernia; at such a young age, an infant can have a hernia. So the doctor gave him a slow massage and he was healed.

From 1973, I worked on the farm for over 10 years, so I knew the farm's doctor very well. The doctor suggested that we have another child, but I didn't want to do that because bringing up one child was difficult enough. At that time, we didn't realize he would have learning difficulties. The doctors were only concerned about his physical condition, but they didn't mention any possible mental problems. When he was 2 or 3 years old, he was a very active child, friendly with everybody. One time our department organized a tour to Huangshan, and I took him with us. He walked down the mountain on his own, saying hello to everyone all the time, he was a such a bouncy and active boy.

Q: Who looked after him between the age of two and three until nursery age?

C's father: My mother-in-law, his maternal grandma, brought him up when he was little. Nobody could tell that he was intellectually disabled from his childhood pictures.

Q: Did he stay at the nursery?

C's father: He attended nursery, a good nursery in Qianwei New Village. He started there at the right age, but my son didn't get on with the other children. He always focused on his own things, never took a noon nap like the other children, he was very naughty. Basically, he could do some things very quickly, but wasn't good

at other things. For example, the nursery served a light meal every day, and he used to be the first one to finish the snacks.

He was very funny when he was a little boy. We were new parents, very keen about the way he was dressed, we tried to make him look adorable. He was also a very active child and his teachers liked him very much, too.

Q: When did you find out he had a learning difficulty?

C's father: Only when he went to school, we just realized there was something wrong. He spent 1 year in a school on Changxing Island, but didn't do very well. The teacher said he always thought that there was something not quite right about my son. Then, I took my son for an intelligence test at the Women and Children's Hospital in Hongkou District and the result wasn't too bad, so I decided to let him stay at school. But there were more problems with his behavior and we found out he was hyperactive. A prescription from the doctor improved his condition and the teacher later remarked on this improvement.

Actually, he passed the school entrance test; the teacher asked him some questions about his everyday behavior and some math questions as well, but he couldn't keep up with the pace at school.

Q: Did he have other problems except for hyperactivity?

C's father: Nothing typically, just hyperactivity, some people said his problem might come from a birth defect. We never believed that he could be intellectually disabled.

Q: Do you remember how you felt when you had to take your son to see the doctor because of his learning difficulties?

C's father: It was a very bad time. He was our only child and we always wanted him to be a healthy boy, but... We found out that he had learning difficulties in his first year at school. There wasn't a hint of a problem before that moment; he was an ordinary child until he was 4 or 5 years old. My bosses liked him very much, he was small and cute, very funny, a sweet talker, but he was a slow learner.

Our farm had flexible working hours, so I could take and bring him back to school every day and I even made lunch for him. My office was near his school and I spent quite a lot of time looking after him. Later, I moved to Shanghai for some new business for the farm, also, as an accountant, my wife had to travel to Shanghai quite often. When we were away, my wife's apprentice, a colleague, or his maternal grandma would look after the boy together. The apprentice was very strict with his homework, he seemed well behaved when he was with her, but his class performance was bad. He couldn't engage with the class at all, but there was nothing we could do about that.

Q: When did you find out that he couldn't keep up with the pace at school?

C's father: That was later. I moved to Shanghai for work, so I also moved my son's Hukou around 1992 when he was 6 years old and sent him to a new school where he started the first year again. On school days, I used to drive him to school on my electric scooter and later my sister would take him back to her place and make dinner for him. I would drive him back home afterwards. Sometimes, my wife helped me if I didn't have the time. Both of us were very busy, we worked all the time, especially me.

After he'd been in school for a year, the teacher asked: "Why did he leave the farm school?" I told him because I'd changed job and moved our Hukou, the household registration address. Then, the teacher asked me to get an intelligence test for my son, but the result from the Shanghai General Hospital revealed he wasn't too bad, and he was able to stay at the normal school. So we let him to carry on there. In the first year, his grades were not so good, usually around 70%, but they dropped in the second year. He just about passed the exams at 60%. In the third year, he failed completely. This time I took him to the Longhua Hospital for another test. The doctor said his IQ was below average, but not too bad. The teacher would only allow him to stay if his exam score didn't affect the class average score for the school.

Q: Did the doctor tell you why he had this intellectual problem?

C's father: The doctor said an inherited defect was the only reason that could cause his problem.

Q: Did you try to help him catch up with his studies after you found out about his learning difficulties?

C's father: At that time, my wife and I were very busy with our work and at the same time, because of his condition, private tutorials didn't work well for him. As parents, we could only teach him some simple things.

Another thing that concerned us was he was getting bullied at school. His class mentor was a very nice person and contacted us from time to time. She said she could only keep an eye on him during class time, but there wasn't very much she could do if he was bullied by somebody outside the classroom. So she kept asking us to tell my son not to stay out for too long.

He Has Three Pass Certificates but Never Finished His Education

Q: Did your son study in a special school?

C's father: No, he didn't. He studied in the Hailun Road School from his first to fifth year. Once his mom and I visited the Special School at Miyun Road; we saw some of the students were sleeping outside during class time, but the teachers didn't stop them.

I thought my son isn't a very smart student and he's just going to get worse if we send him to that school. Even though there were some students with a better mental condition than my son, the campus was quite messy and busy. So, I thought, our son isn't too bad, it would be better to send him to an ordinary school and at least give him a chance. Otherwise, he'll waste his time at the special school.

At the end of primary school, he only got a pass certificate. Then he studied at the Jian'an Middle School, and, to be honest, he was just mudding along there and we knew he couldn't make it.

The middle school teachers looked down on our son as well, they thought he brought down the average scores for the class. They told us: "Your son has affected the quality of our class." We had to ask the schoolmaster: "Would you let our son stay if he doesn't bring down the GPA for the class?" With his permission, the boy

got a chance to study there. He spent 3 years there until he finished with another pass certificate.

The school is the same as everywhere else, it has its bullies as well. He's been bullied since he went to primary school. I went to his school many times to ask the teachers to protect him, at least give him a little bit more attention on campus. For example, I asked them to stop my son going outside during the break and to go back home directly after he finished.

The years he spent in middle school were very tough, even worse than when he was at the Vocational School; the discrimination got worse as he grew up. People can be aggressive, like racism, it's the same kind of discrimination between non-disabled and disabled people. There's nothing we can do about it.

Q: Did he have some close friends at school age? Did he meet some good teachers who cared about him?

C's father: None. Even though the Jian'an Middle School was the lowest ranking school in Hongkou District, they still had their own teaching quality targets to meet. It was for this reason that he was told to leave by the teachers.

Q: How about other people's attitude towards the child, other than the teachers and the classmates?

C's father: Discrimination is common in our society. Nobody insults our son to our face, but sometimes some neighbors who are close to us told us: "Somebody talked about your son behind his back." Anyway, it's not a surprise to us, we have a special child, people won't accept that easily.

Q: Did you help with his homework when he studied at school?

C's father: We helped him with his studies when he was in primary school. When he studied at middle school, it was beyond my ability, because I'm only a middle school graduate.

Q: Did he get annoyed with your preaching and teaching?

C's father: Sometimes he said it was terribly annoying. It's a very difficult situation. He can be frightened by strangers, but then he won't take someone who he knows seriously.

Q: What did he study at the Primary Vocational School after he graduated from the middle school?

C's father: Later, when he went to the Shanghai Qiuzhi Vocational and Technical School on Quyang Road in Hongkou District where he majored in Electrical Engineering. He couldn't engage with his studies, he was there to make up numbers. The grade was the last thing we needed to worry about. My son's weakness is that he has no desire to succeed and has very poor practical abilities. He's very fast and good at the things he wants to do, but he won't make any effort with anything he doesn't like. For example, he likes watching TV and football, and he knows all the singers of popular songs, but he has terribly poor practical ability. His middle school teachers told me the same thing.

He started vocational school in 2004. The teacher was very nice, he kept in touch with us frequently. One time he suggested that we do another intelligence test and apply for an intellectual disability allowance; I guess because at that time the school had a special policy for disabled students. So, this time, we went to the Mental Health

Prevention Center at Longhua Hospital and the test result revealed that the degree of his disability was not considered to be serious.

In the meantime, I was working in Shanghai, so my wife spent more time on our son's case. She consulted with the Shanghai and district Disabled Persons' Federation (DPF). She was told she had to get a document and medical certificate from Longhua Hospital first and then take them to the subdistrict office for a certificate of disability.

Finally, my son got the third pass certificate from the Primary Vocational School. He never spent any time doing his electrical engineering course homework, I was always the person to finish his homework for him. He completely failed in his studies, he never engaged with the class, and he even damaged some equipment. But what could we do? The school was close to our home, so we just let him spend his time there. He walked between home and school by himself.

Q: What did he do after he graduated?

C's father: His paternal auntie retired in 2001, so after he graduated from school, his auntie looked after him until he joined the Sunshine Home in 2004. People like us are really proud, we hardly socialize with the outside world; my wife is very introverted, a very private person, she doesn't like to take our son out or let him go out on his own.

I remember once, it was a very hot summer day, I hadn't been home for a whole day. I found out that my son, stuck at home with my wife, got angry and vented his anger by poking an electric fan with a ball-point pen; the fan was a mess. He thought we'd locked him up at home even though he begged us to go out, but we were worried he might get bullied by somebody if he went out alone. I don't mean we look down on ourselves, but his condition is bad enough, if he's being talked about or bullied... We can't explain ourselves to other people, it's not worth trying to discuss it, anyway, he's just not a clever boy. In our society, discrimination against a child like him is common.

When he was born, our careers were going through an unsettled period. We had lots of unusual experiences and didn't look after him properly. A child like him might get bullied by some people if he doesn't get plenty of love and attention from his parents.

Q: What's do you mean by unusual experiences?

C's father: Back then, as new workers on the farm, we were disliked by some people. The only way to overcome this situation was to work harder, to volunteer for heavy work. The only way to learn new skills was by watching experienced workers all the time, like a thief. People might talk about you if you were a slow learner. I tried all kinds of jobs before I joined the supply and marketing section, plasterer, tiler, painter, carpenter, and the dean of the carpentry shop. I came to Shanghai to start a new career and tasted the thrills and spills of life. Once I didn't rest for over 2 days and a night.

Q: What do you mean when you say you didn't look after the child properly?

C's father: These days, children with at least one parent spend all their time raising them, but in our family, both of us focused on building a new business and we didn't give the child enough attention.

The Sunshine Home Is Great

Q: When did he go to the Sunshine Home?

C's father: We didn't want to keep the child at home all the time, so again my wife went to the subdistrict office for advice. The office suggested that we send our son to the Sunshine Home, so he started there in 2007. He joined in some sports and activities there; he also joined the district DPF center's drum team. Later, he participated in the district DPF Sports Meeting, which took place on the Fuxing Middle School's campus. He played badminton, sprinting, and sit-up games and he wasn't bad.

Q: Why did he enter the competition, because he likes sports or you wanted him to develop special skills in the field?

C's father: Neither, just because the teachers of the Sunshine Home asked him to, then he joined in some games. I remember years ago, around 2007 or 2008, he went to the Intellectually Disabled Persons' Talent Show in the area a couple times. Another show he has involved with was a performance of *A Grateful Heart*, a singing show with sign language. The teacher invited my son to do that performance as well. He worked very hard and practiced at the Sunshine Home every day, and I helped with his practice at home too. I found online sign language videos and kept him company while he studied them. Their performance nearly won the Shanghai competition prize.

I usually say my son is a total "dud." If you let him do something, he'll have a go, but he won't spend much effort on it. I think boys don't have the same self-motivation as girls. For the first few years at the Sunshine Home, he was a pretty good student. He was the class monitor for a half year, but after that, he just let himself go, he lost his appetite for hard work. However, some of his classmates' parents said he was a kind person.

These days at the Sunshine Home, he isn't very practical; for example, he can't bake cakes or do this kind of job. Several times, the teacher told me to let him practice eat home, but he just doesn't want to do that. Sometimes, we make wonton together, but he just messes around, it takes me much longer to clean up. The only thing we can let him do is wash up after dinner.

Q: What does he usually do at the Sunshine Home?

C's father: They do all kinds of things there, they have singing classes, the teacher is a special-grade teacher, sometimes he would talk about it and sing to me after they learned new songs. Recently, they learned the Spanish song, *Carmen March*, he likes to listen to it online and enjoys it very much. Actually, he likes music, but he can't sing. They have a drawing class every Wednesday and some other classes like reading and calligraphy, but now the calligraphy class has been replaced by a drawing class. He's pretty good at drawing, he likes water color painting very much.

Sometimes parents talk about the Sunshine Home, and compare them with other homes in Hongkou District. We feel that our Jiaying Subdistrict Sunshine Home is the best of them. The teachers are very nice too.

Q: What was C's favorite course from primary school to vocational school?

C's father: He liked to watch TV and play with the computer. Children's programs are his favorite, for example he likes Hade Strong,² *Ultraman*.³ He also likes to watch *Amazing Detective Di Renjie*⁴ and some foreign war programs.

Q: What was his favorite course?

C's father: He doesn't like studying or learning any kind of skills, but he'll be very happy if you allow him to listen to music, watch TV, or play on the computer. He isn't interested in other things, he can't even sew the holes in his socks or put a button on his clothes.

Q: Does he like to go out with his classmates?

C's father: My son has to travel from the Baoshang District to the Jiaxing Sub-district Sunshine Home by bus, because we don't live in the place of our Hukou registered address. So we're a long way from his classmates who live around the Sunshine Home, but they play together at the home. These children are very naïve, more like 7- or 8-year-olds, they like singing, playing, and bouncing around together.

Q: Did he make some close friends after he joined the home? Did he mention them when you were together?

C's father: Yes, of course. He likes to talk to me about his classmates and teachers. He likes to tell me the result of their Thursday badminton game and he says if the class monitor is his partner they always win. Actually, he always enjoys the game, it doesn't matter if he wins or loses.

Q: Does he like to chat with his teachers?

C's father: The teacher said my son talks too much. Sometimes he likes to interrupt the teacher when the teacher is speaking, and he likes meaningless chatter. My son used to take part in almost all of the activities, but he stopped a couple years ago.

Q: Why did he stop recently, did he want to?

C's father: Not really. Anyway, he isn't a practical kind of child; he joins in games if the teacher needs to make up numbers. The teachers always like the active ones who have the potential to win.

Q: How does he usually get to the home?

C's father: He goes to the home by himself. I probably went there with him once or twice after we moved; he always travels between home and school by himself. If he wants to visit my sister, I only need to take him to the bus stop, and then he can change bus himself to get her place.

Q: How long has he been going to the Sunshine Home?

C's father: Since 2007.

Q: Do you think the Sunshine Home could be improved in some ways?

C's father: I'm quite satisfied with the home, because it's the best in the area. I've visited some other homes and the Jiaxing Subdistrict Sunshine Home is the

²Translator's note: Hade Strong is a character from the popular children's animation *Boonie Bears*.

³Translator's note: *Ultraman* is a famous and classic Japanese animation.

⁴Translator's note: *Amazing Detective Di Renjie* is a very popular historical detective program based on the story of the famous detective Di Renjie, who lived in the Tang Dynasty and served Queen Wu Zetian. The program is in its fifth season with over 200 episodes from 2004 until now.

best. They run so many different classes for the students every week, like math, singing, drawing, and all sorts of things. The Leshanhui Foundation and other NGO groups visit to organize parties with the students. The chairman and vice-chairman of the Association of Persons with Intellectual Disability and their Relatives come on Thursday afternoons for a lecture on national and international politics.

Q: What does your son think about politics and math?

C's father: He's good at math, he has a very good memory and his mental arithmetic is pretty good. He listens to the international news, the Shanghai news, and he listens to the morning news at 6 a.m. every morning. If the teacher asks about the news of the day, he would be the first person to raise his hand in the classroom and he always puts his hand up in the chairman's international politics lectures.

Sport Helps a Child Become More Sociable

Q: When did he participate in Special Olympics and related events?

C's father: Two years ago. The teacher recommended him for a subdistrict sports event and he was chosen for the district competition on behalf of the subdistrict office, but he lost the game. In 2007 and 2008, he won a second and third place medal for the sprint events in the District Disabled Persons' Sports Meeting, which took place at Fuxing Middle School. He has so many certificates of merit we ran out of places to put them at home. Some of them came from the district or subdistrict events, but most of them are subdistrict event awards.

Q: What's his favorite sport?

C's father: He likes badminton and plays with me sometimes and he plays table tennis sometimes. He likes the games in the beginning but soon loses interest in them. He always plays a part in the subdistrict annual sports games and won several second and third place medals, but he never became a champion.

Q: Does he practice often?

C's father: I practiced badminton with him once, but it didn't go well because I was a member of the farm badminton team and he gave up soon. We're not a good match. And there were two teachers at the home who taught him table tennis.

Q: Did he practice with the teachers before the competition?

C's father: No, they don't practice together, they prepare on their own. He won a third-place medal in the darts competition; he did the all exercises by himself because the teachers didn't know how to coach him. It's the same thing for the sit-up game, he prepared by himself with a bar, that's all. Anyway, they're not athletes; improving their coordination is the main benefit.

Q: How did he become involved with sports?

C's father: I suggested that he try speed walking every day, because when we went out together, I realised he got exhausted quite easily. So he did speed walking every evening until recently and then he lost the appetite for it. I scared him by saying if he stopped exercising he might have a blood sugar problem when he had his health

check in June. Actually, his blood sugar was normal, but he was really scared by what I said and took it seriously.

Q: How long has he practiced the side drum t the district DPF center?

C's father: Since 2008, and he enjoys it very much, because he can be creative. He was very good for the first few years and took part in all kinds of performances. For example, the band has a traditional comedy show called *Three and a Half Sentences*; he's the "half sentence" singer who makes jokes.

When my wife got cirrhosis in 2009, he stopped practicing for a while. She was frightened by this disease and stopped going to the side drum practice with him. Also, he used to get sweaty after exercise and all his clothes had to be washed afterwards. It was a lot of fuss, so we told him not to go there anymore.

My son's weakness is he won't focus on anything once he thinks he's learned it. I told him to rejoin the band in 2015, I took him there for the first 2 months, then after that he went by himself. Since then, he goes to practice every weekend except for the very hot summer holidays. I think going outside and doing some exercise, singing or studying English, is better than sitting at home and playing with the computer or watching TV. Recently, the district DPF center started baking classes, but my son isn't a big fan of this. For those students who like baking it's a very interesting and enjoyable thing to do.

He goes to the Sunshine Home by himself every morning, and if we ask him to buy some stuff for us, he can take the bus by himself to go shopping.

Q: Do you like to coach him when he plays the side drum? What do you think about his skill?

C's father: No, I don't do that. And his skill is average.

Q: Did he change in any way after he became involved in these activities and competitions?

C's father: He became more sociable and happier. He always tells me how wonderful his team is, how proud he is and that they're better than the others. He's such a proud person.

And his abilities have also improved; at least he's better skilled at communicating with other people. As a parent, I'm so pleased by his improvements, anyway it's a great thing to let him get involved in activities and win some awards. Children like him need to be praised, it's impossible for them to take criticism in the same way as children without disability. They're happy when they feel they can do something well and their hard work has been recognized (see Fig. 1).

Q: As a parent, you like him to take part in these activities?

C's father: Absolutely, I'm completely positive; because I really don't like him staying at home and watching TV or playing with the computer, I worry about his eyesight. The district DPF is so friendly with these intellectually disabled children. They arrange afternoon classes including drum practice, English, and dance every weekend. Some of the teachers and volunteers are also parents of disabled students in the group; I feel we're so close to each other, like a big family. We often chat with the teachers and others, now we're good friends.

Last Saturday, the district DPF office arranged a family trip to Disney Town. My son and another four or five children and two parents from the Jiaying Subdistrict



Fig. 1 Mr. C exercising on stakes

Sunshine Home went together. This group life at the home encourages the children to be more sociable and friendly.

Q: Do you think it's useful to let him meet different people?

C's father: It's a good thing to let them keep in touch with society and also being close to other disabled children is good for him, but I don't like him getting involved with bad people. It's nice to talk with good people when you meet them. With my son's condition, we usually tell him: "Don't get involved in other people's business." One time, he told me he met a man who asked him: "Do you want a mobile phone?" So, I told him: "Don't talk to a person like this man again." But the good thing is he's aware.

A Loving Family

Q: Do your ideas about the child's education differ from your wife?

C's father: We don't disagree with each other most of the time, especially about the child. We've got on very well since we were married; we don't argue with each other at all, we don't mind losing as long as it's good for our son. We don't care what other people think about my son; we won't argue back if somebody says bad things about him to our face and we're always calm with our son and explain any situation to him carefully.

Q: What does your son do in his spare time at the weekend if he doesn't need to go to the Sunshine Home?

C's father: He likes to watch TV at the weekend. Sometimes I like to tell him to practice calligraphy to improve his handwriting. I always tell him: "You might not be able to change yourself, but you can have beautiful handwriting." But he doesn't like this idea because he isn't a patient person, and he gets frustrated when he can't do things right.

Q: Do you take him out at the weekend?

C's father: Of course, we started taking him out when he was very young, and he's visited a lot of places, such as Hainan Island, Huang Mountain, Zhangjiajie, Suzhou, Hangzhou, and many other places. We went to Huang Mountain when he was five, before he was school age, he was really an ordinary child, sociable and cheerful.

Q: What do you usually do when the family are together?

C's father: After dinner we like to talk about his day, about the Sunshine Home, the classes, some news—somebody went somewhere or somebody's family bought a new apartment... These students talk about quite a lot of things together.

Q: How about his life skills and independence?

C's father: He can look after himself; at the subdistrict office's summer campus, he could wash himself and his clothes, but cleanliness is not guaranteed. He washes his underwear occasionally by hand if you tell him to do so.

Q: Does he do the housework often?

C's father: If you say to him: "Pick some vegetables or peel some beans for your dad," he'll come and help. Sometimes, he washes rice and cooks it in the rice maker.

The teacher always tells them: “You’re not smart people, but at least make sure you can use a rice cooker and a washing machine. Then, you’ll be fine when your parents get old.” At the parent’s meeting, the teacher also emphasizes the same things to make sure we’re as keen as he is to help our children develop these skills.

But I haven’t taught my son to use the washing machine yet, so he has to hand wash his underwear and socks.

Q: Do your colleagues and relatives know about your child’s condition?

C’s father: Most relatives and some very close friends know about him; I won’t tell my acquaintances. I don’t think his condition is a thing worth talking about with other people. Some people pity us, because a normal couple have a sick child. Some people say we should let him start his own family, but I don’t think so, he isn’t a healthy person and couldn’t look after a family.

Q: Do you talk with the neighbors or your relatives very often?

C’s father: My big sister cares for him a lot. She looked after him for a while when we moved to Shanghai; my wife and I were very busy with our work and hardly spent any time at home. My sister would take him to her place after school, my wife was only able to drop him off in the morning.

Q: Could you tell me more about how he gets on with his auntie?

C’s father: His auntie doesn’t have her own children and has lots of love for her nephew. She usually says: “I don’t care what people think about him, nothing can stop me loving my own nephew.” Actually, my son is very close to her and they like to play and joke together. During festivals and holidays, he usually asks us: “When will auntie come around? We should have a nice meal in a restaurant when she comes.”

Q: When do you think your son began to change from when he was little?

C’s father: In my eyes, he never grew up, but when my wife went for surgery in October, my son was there comforting her and giving her a massage; this made my wife so happy. She said to me: “Our son has changed and become a sensible boy now.” Actually, we can see that he’s growing up little by little and we think he’s an understanding person now.

What Will Happen to Him After We Pass Away?

Q: Did you ever think about him getting married?

C’s father: For sure, my son wants to get married, because he’s 30 already. You can’t say he doesn’t want a family; of course, he has the desire. I told him that he can’t start a family even though some of his classmates are married and have children. As the only child in the family, if he wants to get married, he has to find a person with the same condition. If by any chance they have a child like them, the whole family will suffer with the same problem.

Anyway, for the child’s health, intellectually disabled people aren’t encouraged to start their own family. Some good friends told me, if you want you could find him an ordinary wife outside of Shanghai, but I don’t agree with this idea, looking after our family is enough for me. My wife and I are looking for social care for him.

Q: What did he say when you told him your ideas of him getting married?

C's father: He just said, I see. I have to explain things very carefully: "What can we do for you if you find an intellectually disabled wife? What will happen to the whole family if you have a child who has a 70–80% chance of having the same problem? We trust the science, it's a consequence of medical science that tells us this, so what can we do?"

Q: Did he have a job before?

C's father: Never. He wasn't a successful student, if he went for a job, what should I say... My niece, who works at a juice bar in Longhua area, was bullied in the workplace even though she's a normal person. My son might be treated even worse if he isn't good at the work. Besides, he isn't a practical person.

Q: Has he thought about finding a job?

C's father: Not really, and I don't want him to work either. My wife and I both have pensions that will be enough to support him. Our worry is what will happen to him when we pass away? What will he be able to do as an unemployable person when we are very old? Does society have any good policy and rules to support intellectually disabled people and their families?

Q: So you want better social care policy?

C's father: For sure, we do want more social care. My son is a small person, only slightly over 5 feet 2 in. tall, he isn't able to do a lot of things. For example, the district DPF office arranged around 20 lessons in a baking class for children like my son in the hot summer this year, but he couldn't do this work properly even if he tried, so I had to help him. In the end, it became my job. The class was from May to August, twice a month.

Q: Do you talk about your worries with your wife?

C's father: Yes, we do. Now we live on our pensions, but one day we'll get old, what can the government do for a family like us? We have to try our best to save some money for the future, to prepare for the day we get weak and old, but if we can't save any money, there's nothing we can do.

Anyway, "parasite singles," the ones who live off their parents, is a common social problem; children without disability are doing the same thing as my son. To be honest, at least my son is better than those troublemakers, he doesn't throw money away or upset us in that way. Compared to those young gamblers who come back home only for more money, my son is quite easy to look after.

Q: What kind of welfare does your son have at the moment?

C's father: His salary consists of two parts, the first part is 40% of the minimum wage in Shanghai, 2300 yuan—he gets 920 yuan for this; the second part includes three main subsidies: medical, unemployment insurance, and a pension. It's too low.

Q: What do you think about his welfare?

C's father: It's lower than those foreign countries. Compared to disabled people in foreign countries, especially intellectually disabled people, the social benefit gap is from the sky to the earth. My son only receives 920 yuan every month. Can you tell me that this is enough for his living expenses? No way.

We have to say, in China, their benefits are getting better every year, even though they are still much lower than some foreign countries. For example, this year they started to receive a new subsidy of 45 yuan as a transportation allowance.

My son isn't considered to be moderately disabled, but you could say that his problem is more serious than mildly disabled. Years ago, I tried to get him to do another IQ test to find out the grade of his disability, because for different grades of disability you receive different benefits. But eventually I just let it go. Anyway, his salary is less than those severely disabled people, but at least he'll have a pension when he retires. The more serious people are severely disabled and unemployed, they have a higher salary but without those three additional benefits.

Q: What do you want for him for his future?

C's father: We only wish he has a good life in his old age and gets more disability benefit. Right now, we don't think about ourselves, but only our son. His salary is only 40% of the minimum wage, so it's not very much. And recently they have to pay 80 yuan a month for lunch at the Sunshine Home; they didn't have to do that before.

Q: What's your son's plan for the future?

C's father: He hasn't talked about a plan, he just takes one step at a time I guess. He only thinks about going somewhere to play. I keep telling him to learn some skills and knowledge, but he always says, "It's very annoying to hear this."

Q: Will he stay at the Sunshine Home in the future?

C's father: Yes, I hope he can stay there as long as he can, but the Sunshine Home has an age limit; anyone over 35 years old has to leave. I'm worried about where he would go if one day he's told to leave. Maybe there is a similar institute for older people, or the district council might set up one in the future.

At least let him go somewhere every other day to keep him busy and communicate with the outside world. Staying at home only makes him feel worse.

Interview with Mr. C's Teacher

Interviewee: Teacher Ms. Meizhen Zhou

Interviewer and writer: Yujia Feng

Interview date: December 8, 2016

Interview place: The Sunshine Home in Hongkou District

Q: How's Mr. C getting along here?

Teacher: Mr. C is ignorant when he peaks, sometimes his words can be very tough. So I told him: "Your mom is ill, your dad is exhausted, what'll happen if your dad gets sick? You've got to be your dad's assistant to help him look after your mom." After the conversation, his behavior improved, but he went back to his normal behavior after a while. When I talked to him again, Mr. C told me: "I promise I'll do what you told me this time!" Children like him, they certainly can keep their promises, but forget just as easily, so you have to repeat yourself several times to help them remember.

Q: Do you have any regular activities at Sunshine Home?

Teacher: We have quite a lots activities going on, because we have six NGO groups volunteering here to help us. Actually, we prefer to let the students do more exercises rather than sit around in the classroom all the time.

Q: Did you notice any changes after these intellectually disabled people came here?

Teacher: Some students become more open and happier and their intelligence develops as well. Their parents are relieved with this change, because they can be very naughty: throwing stuff, fighting with the others, and so on. These students also reach a better level of communication with their parents.

Some children who missed out on family attention and socialization, might have developed mental problems; for example, some children can be affected by their parents' divorce or family indifference.

Q: How about Mr. C's performance in the drum team?

Teacher: Mr. C joined the band in 2010 for the first time, but left for a while before he came back to us last year. Compared to other students, he's new and needs to do more practice with the new dances, especially his coordination. Even though Mr. C is just mildly disabled, his reflex ability is worse than some of the moderately disabled students.

Q: What kind of Special Olympics events is Mr. C involved in?

Teacher: He joined the District's Special Olympic Sport Events in 2007 or 2008, the year he came to the Sunshine Home. He was an athlete from the Jiaying Subdistrict team; the competition was on the campus of Fuxing Middle School. He didn't participate in the Shanghai Special Olympics World Summer Games in 2007, because for this event we only chose experienced athletes.

There are municipal and district-level Special Sports Meetings in Shanghai every year, and international games every 2 years, for these students. In our area, we have many disabled people, the Sunshine Home has around 80 students, some children over 35 years old stop coming to the Sunshine Home, but they certainly are part of our district Special Sports Meeting. Participation is the first aim of our event. Every athlete gets a small prize, even the people who aren't in the top three.

Actually, our Sunshine Home's students are just a small part of our disabled group, most of them stay at home. About 70% of the parents tend to hide their children away, they don't talk about them with anybody and they never take them out. Only 30% of children get a chance to go outside.

Interview with Mr. C

Interviewee: Mr. C

Interviewer and writer: Yujia Feng

Interview date: November 27, 2016, during the break of the drum team practice

Interview place: Hongkou District Disabled Persons' Federation, Shanghai

Q: Did you feel any different after you joined the drum team?

C: I wasn't very healthy, because I didn't exercise, I got a cold quite often, but now I'm much stronger.

Q: Why did you join the drum team?

C: Because my classmate, who joined the band earlier, told me to join them, so I did.

Q: How do you feel about the band's practice and performance?

C: I look forward to the band's performances, I'm happy to be a part of it.

Q: Did you make any new friends?

C: I met Lu Yi. All of us are good friends here.

Q: Do you practice drumming at home?

C: No, I don't.

Q: Did you join in sports and games before?

C: For the Sports Meeting of the Special Olympics, I did badminton, table tennis, basketball, and the 50-m sprint.

Q: What was the level of the games? Did you win any prizes?

C: It was a Sunshine Home Sports Meeting; I got a silver medal.

Q: You just told me that you didn't like to exercise before—when did you change your mind?

C: I changed my mind when I joined the 50-m sprint.

Q: What classes do you study at the Sunshine Home?

C: We have English on Tuesdays, drawing and dancing on Wednesdays, and we have PE on Thursdays, also Teacher Zhou teaches us to play wisier ball.

Q: Which class is your favorite?

C: I don't like any of these classes. But my dad told me that I had to go.

Q: What do you like to do in your leisure time?

C: I like music, Jay Chou⁵ is my favorite singer.

Observation of Mr. C in the Drum Team

Observation date: November 27, 2016

Observation place: Hongkou District Disabled Persons' Federation, Shanghai

Observer and writer: Yujia Feng

Time	Content	Observed activities
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(continued)

⁵Jay Chou is a famous Taiwanese singer and songwriter.

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Time	Content	Observed activities
9:00–12:00	Practicing the side drum	He watches other people before he starts to dance. He's not very familiar with the movements, so he is usually a little bit later than the others. His movement isn't stretched enough, and his hands are lower than the teacher wants. During the second practice, the teacher lets Mr. C move to the end of the stage, because this place is easier for him to watch the others. He tries his best to follow the rhythm, but in the complex parts, he still looks awkward
	Dance time	Mr. C's movements are a little bit loose and he has to follow other people when they practice some difficult movements
	Break time	Chats and laughs with his classmates
12:00–13:00	The volunteer teaches several small groups to make chocolate cakes	Mr. C watches his teammates make the cake. The volunteer encourages him to join in the cooking. So Mr. C helps to put mixture in the cake tin. At the end, he helps his classmates to pack up the equipment and materials

Observation of Mr. C at the Sunshine Home

Observation date: December 8, 2016

Observation place: Jiaxing Subdistrict Sunshine Home in Hongkou District, Shanghai

Observer and writer: Yujia Feng

Time	Content	Observed activities
9:04	Practicing the People's Radio Calisthenics	

(continued)

(continued)

Time	Content		Observed activities
9:10–9:57	Mental rehabilitation instruction	The students stand in a circle, relaxing their body for exercise	The teacher is a doctor who comes from the Subdistrict Center for Mental Control. In the workshop, the teacher explains to the students what “Expressive Arts Therapy” is, it includes several parts: a. Relaxing; b. Warming; c. Venting their emotions through actions; d. To satisfy an impossible desire by catching objects in their imagination
		Following the teacher’s directions, from turning heads to waving hands and turning shoulders and body actions	Mr. C’s movements aren’t quite right, so the teacher corrects his turning shoulder movement
		A forward bending trunk exercise	Mr. C can’t do the exercise. The teacher helps him to stretch his legs properly and bend his head down at the same time. His movement improves, and he can bend his body down better. During the exercise, he talks and laughs with his classmates
		Body swinging exercise, feet kicking exercise	He keeps his sense of balance and pace most of the time
		“Catching up stuff” exercise	He isn’t a very strong person and he can’t push through the circle. But finally he joins the group with his parents’ encouragement
10:10–10:40	Break time	He draws a mask on paper	
		He plays table tennis with the teachers, classmates, and parents	He isn’t a skilled player, but his coordination and reflex ability are pretty good

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Time	Content		Observed activities
		Sitting and chatting with classmates and Teacher Zhou	He's quiet and only speaks when the teacher asks him something
10:40	Lunch time		
12:40–14:00	Break time		In the rest room, students lie down in their own extendable chairs
14:00–15:00	Ability training: wiser ball		It's a strategic and competitive game. The teacher explains the rules and gives a demonstration
	Mr. C comes on to the ground for the second turn with his teammates		He's trying to score a goal guided by the captain. He fails the first time, but scores the second time and the team win
15:00	At the end, the teacher calls all of students together		Mr. C packs his stuff and says goodbye to his teacher and classmates

*Translated by Huili Meng
Edited by Russell Murray*

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Enjoying Seven Days a Week



Puyu Zhang

Interview with Miss Yijie Sun's Mother and Yijie Sun

Yijie Sun, female, born in 1987. Only child. Grade IV intellectual disability. Graduated from the special school—Miyun School in Hongkou District, Shanghai.

Interviewee: Huifang Zhu (Yijie Sun's mother) and Yijie Sun

Presenter: The mother of Yijie Sun's classmate from the Sunshine Home

Interviewer and writer: Puyu Zhang

Interview dates: October 23 and December 10, 2016

Interview place: Hongkou District Disabled Persons' Federation, Shanghai.

Poor Health, but Rich in Love

Q: May I ask how you and Yijie's father first met?

Sun's mother: We met in 1984 through his younger brother who was my colleague. So, I had an opportunity to get to know my future husband when I visited my colleague's family. At that time, he lived in Anhui Province—this was probably Fuyang City or somewhere close—he had gone to live in the countryside and settled in the commune. At that time, I worked on a state-owned farm. Later on, through the government's policy for educated young people, both of us returned to Shanghai and worked in a factory.

Q: When was Yijie born?

Sun's mother: She was born in September 1987. A normal pregnancy is 9 months, but mine was longer than that because the doctor said the fetus was very small and the best way to reduce risk was to let her spend a longer time in my body. So, I stayed in hospital and had extra nutrition through a drip every day. She was just above 4 lb when she was born, but didn't have any other problems at that time. For a long time,

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being undersized was the main problem for her, even now, she is still the smallest in her group.

I gave birth when I was 32, quite old. At this age, the child was so precious to me and her condition worried me desperately. The only thing I could do was take her to see the doctors and she was given all kinds of tests. People were always surprised by her size when she was a baby; all of her body indexes were lower than average, she was always very weak physically. Anyway, children like her always have one kind of problem or another. Some children might develop well physically, but their IQ is another thing. My girl's main problem is her physical ability.

The doctor said she might be very difficult to bring up and there was a strong possibility that she might not develop into an independent person. The doctor's final diagnosis was the child wouldn't be easy to raise and might not live for very long.

I kept asking myself: "What could I do for her?" I thought, I gave her life, she must be my responsibility, so I just totally ignored what the doctor said. Sometimes, when I think about my daughter, it was really very hard to bring her up.

In her class, Yijie is always the first person to catch something; if anybody gets sick, it doesn't matter whether it's a cough or headache, she usually gets worse much quicker than the student who was sick in the first place. She also has problems with her teeth, which stop her from eating hard food: her front teeth are false. Actually, she has two fewer teeth than normal people, because those teeth didn't develop well, they never came out properly. When she was young, the dentist suggested reshaping her poor canine teeth, and taking one tooth out, but I just thought it's not necessary for a young girl, so I didn't take the dentist's advice.

In the beginning, I couldn't work out why she had such bad teeth, because she didn't eat snacks or do things that might damage her teeth. Actually, the problem stems from her poor physical quality. Finally, she had orthodontic surgery, it was self-financed medical treatment and the false teeth cost us over 10,000 yuan—that's 1,500 yuan for each tooth, and she needed five. At the same time, dental cavity treatment is very expensive as well, 5,000 yuan for one course. Maybe it's a genetic thing, because I have bad teeth too. I've been to the dentist's clinic for periodontitis this Wednesday, it's so painful. I worry about her because her teeth are bad enough at this age, what will they be like when she grows up? It's a real hopeless thing, now, at my age, I can't eat food properly anymore.

Q: What do you do about eating, then?

Sun's mother: The best thing I can have is congee, anything harder makes things worse; my teeth even hurt after eating the rice noodles I had at lunch time.

Q: Did Yijie go to a nursery when she was little?

Sun's mother: Yes, she went to a nursery. She did the right things at the right age like other children, nursery and primary school. Her nursery was an ordinary one in our area.

Q: Did everything go well when she was at school?

Sun's mother: When she was at the nursery, at a very young age, the teacher taught the children to be independent with some domestic things like eating, sleeping, getting up, getting dressed, and using the toilet, but my daughter couldn't do that; she was much slower than the other children. The teacher was very patient with her and gave

her plenty of time to learn new things at her own pace, slowly but surely; from eating to dressing herself, to making her bed after a nap.

She didn't enjoy eating and we had to force her to eat. She was very picky with food and only ate things she liked and wouldn't try other things even if they were delicious. For example, lots of children really like soft drinks, but she wasn't interested in them at all. Anyway, eating was a difficult thing for her and sometimes she wouldn't eat for 3 days if I didn't force her. So, I tried my best to feed her until she was 18, then, and we were so pleased, she started to get a better appetite and became stronger.

After she graduated from the nursery, she passed the entrance exam for primary school without any problems. Then she fell behind in her studies, it got worse and worse for the first couple of years. She didn't have a real sense of time, she was very slow with her homework and never worried about deadlines. I'd monitor her home work each day and we always finished very late. In the beginning, she was left-handed (raises her left hand), it took her paternal grandma quite a lot of work to correct her. She couldn't write her own name properly either and I used to think why didn't I give her a less complicated name like "Yi" or "Ding?"¹

The teacher was always concerned about the class's average score, so my daughter became a problem. The teacher kept contacting me to explain my daughter's situation. Before that I just thought she wasn't very good at her studies and was a slow learner, I never considered it might be an IQ problem. The Dean told me to take her for an intelligence test at the Maternity and Infant Hospital to see if her condition was more suited to a special school; if that was the case, she'd be better off at the district Special School, a non-competitive school where all students are treated equally. Then we did the test.

Q: Do you remember her intelligence test score?

Sun's mother: We did it twice and the scores were 63 and 65. I asked what the results meant, and the doctors told us that the average score is 70. My daughter was slightly under the average, so her problem wasn't severe. But if she tried harder, she might reach the average score. At that time, she was around 10 and in the second or third year of school and she was only little.

While she took the test, the parents had to wait outside, but when she came out, she told me she knew most of the answers and the questions were very basic, just about her address, parents' names, recognizing some animals.

The thing we didn't know was, if she had been diagnosed as a severely intellectually disabled child, she might have been eligible for a disabled allowance from the government when she became an adult; but mildly disabled children—like my daughter—don't receive any money. I'd heard that some parents who wanted their children to get this allowance prepared their children before the test and told them not to answer the doctor's questions. Their disability grade was decided by the hospital and doctor and not the special school, but we didn't know that. We thought her intellectual condition was determined by her behavior at the special school. That's how her disability grade was decided at that time.

¹The Chinese character 'Yi' is written as '一', which means it has only one stroke; 'Ding' is written as '丁', with two strokes. Both of them are among the simplest of Chinese characters.

Q: How did your husband and you feel when you found out about Yijie's condition?

Sun's mother: My feeling was... the truth was, I could have another child and I thought about this, but I was worried that I wouldn't be able to keep the right balance between the two children. If I had two children, Yijie, and a child without disability, I would be worried that the young one might become my favorite and Yijie's situation could become worse. For example, for my generation, almost all people come from a big family with several siblings, like my own family, where the parents usually have a favorite child. I was worried that I might become that kind of parent... Actually, compared to children without disability, my daughter certainly needs more attention. Finally, I made the difficult decision that we wouldn't have another child and I decided to give all my love to my daughter.

Some families in our situation chose to have a second child, but we decided if we did this it might not be fair to her. From time to time, I think about the future, but right now, we're focused on her happiness and her daily wellbeing; we've put the future to one side. That's how I feel.

Q: Did you start keeping her company all the time when you discovered her intellectual difficulties?

Sun's mother: Sure, we looked after her all the time from school age until now. On the one hand, she's a little girl; on the other, she still can't find her way around when she goes out alone. She's very different to Xiao Y who you met yesterday; his mother never worries about letting him go out by himself. My daughter always has to be under my supervision, because she can't find her way.

All her teachers and officials at the district Disabled Persons' Federation office said I spoil my daughter too much. I can't help it, as a parent I must love her as much as I can while we're still together. When we pass away, she might have to depend on her cousins—my sister and brother's children—but one day they'll have their own families as well. It won't be possible for her to depend on them.

Loving Teachers Are Always with Her

Q: When did Yijie go to the Special School?

Sun's mother: When she got the result of her intelligence test, she went to the Miyun Special School and joined the third-year class. There, they used different textbooks to the ordinary school and she had more time to learn. Basically, she was able to read and she was good at reading *pinyin*, but the problem was she couldn't do mental arithmetic without using a pen and paper.

The Special School has a 9-year program, so there isn't a middle school. During her school years, she grew up little by little and started doing things better and quicker until she graduated. It was so difficult for her growing up.

Q: Did you try anything to develop her intelligence?

Sun's mother: Even though it was a Special School, the teachers were very concerned about the students' studies. As parents, we always wanted her to learn as much as possible, at least to be able to read, understand *pinyin*, and have some basic math skills. We tried to help her with her studies, but it was very hard. She was a very slow learner. I tutored her at home until her sixth year and by that time she could

already read. She had a very poor memory and was only able to remember words she used every day. Now, she only has very basic skills.

These days, I understand that parents have to make sure their children learn the right things at the right time, otherwise they might fall behind and never catch up. Even though my daughter can use a mobile for messaging and We Chat, but she wouldn't dare go shopping by herself, because she has never been told how to buy things and she doesn't have a sense of money. Money has no meaning for her and I worry she might not be able to go shopping on her own in the future. Some of her classmates are really good at shopping, but she's totally the opposite, we even have to buy her snacks.

Q: How many students were in her class when she was at Miyun School?

Sun's mother: Around 15 classmates, but they lost contact after they graduated; my daughter lost touch with her best friend when the girl moved somewhere else. There is one boy, years after they graduated, who now studies at the same Sunshine Home. Actually, at this Sunshine home, some of the students like my daughter came from the same school, they are very happy in each other's company.

Q: Were Chinese and math their main subjects at the Miyun Road School?

Sun's mother: Yes, they also had singing, PE, and dance classes, but they didn't have any complex subjects. Basically, their subjects were similar to an ordinary school, but they didn't have to worry about grades. These students have very different intellectual disabilities and they have to go in different ways after they graduate.

Q: What was Yijie's favorite subject?

Yijie Sun: I liked PE and singing...

Q: Did they have any school or class activities, for example, like spring or autumn picnics?

Sun's mother: They rarely had activities because the security of the students is the first concern of the school; but they arranged some activities taking this into account.

It was a heavy responsibility for the teacher when the students went out. I guess for those teachers, it's less trouble and easier when they don't have to take risks while the students are taking part in activities. Here, at the Sunshine Home they have spring and autumn picnics and from time to time, the volunteer companies invite them to do some events together, there is always something going on.

Sun: We have sports events as well.

Q: How about the relationship between Yijie and her teachers?

Sun's mother: She's a very lucky person, all her teachers at nursery and primary school were very nice. For the first 2 years at primary school, the teacher was concerned about her and complained to me quite often before she knew about my daughter's condition. The only thing I could do at that time was to tell the teacher the truth and buy her some gifts, because she looked after my daughter. The teacher never took those gifts, and still gave my daughter lots of attention. What else can we do?! Later she went to the Special School and she was taught by the same teacher until she graduated. She was lucky, because these kind teachers treated her as if they were their own children.

The Sunshine Home has some very nice teachers too; there are two of them who are particularly kind with the children. Actually, some parents think that they look

after these children too well. I think the same and say to the teachers sometimes: “I understand you like these children very much, but they need stricter rules.”

Q: Did she make some friends at the school?

Sun’s mother: She had one very close friend. I met this girl several times and realized she was a very smart girl, always at the top of all kinds of things, except for her studies. The girl had a twin sister who was a very fast learner. This girl got a job with a teacher’s reference after she graduated as a dish cleaner at the Xinya Restaurant—a western restaurant under the bridge of North Sichuan Road. She’s really great and skillful.

Sun: She’s very big, very fat.

Sun’s mother: She’s the same age as my daughter.

Sun: She was “the squadron leader” at school.

Sun’s mother: She sounds like a really mature child. Once she said to me: “This work is too hard for Yijie, she wouldn’t last a week if she was here. Even I had to try my best to keep the job.” Every child has his/her own characteristics, even though all of them are intellectually disabled.

My daughter certainly couldn’t do this job, on the one hand I wouldn’t let her do it; on the other, she doesn’t have the ability, she isn’t suited. That girl has very strong motivation, the same as people without disability: “I have to work, I have to make money, I have to be determined and I don’t care about gossips.” In the work place, there are some good people for sure, but that doesn’t mean everybody has enough patience with a new worker who has a disability. This girl is wonderful, but my Yijie couldn’t do a job like that.

Q: What did you like to play with when you were a child?

Sun’s mother: (She asks her daughter with a smile) can you tell us what you liked?

Sun: Playing with the computer.

Heavy Work Isn’t for a Weak Person

Q: Where did Yijie go when she graduated?

Sun’s mother: She took a 2-year vocational course afterwards. She learnt computer skills, hotel servicing, and flower arranging and something else there. My daughter is very small, she can’t deal with heavy work at the hotel and even her teacher said hotel work is too much to her. After that, she spent 2 years, more or else, at home.

Q: What did she usually do when she was at home?

Sun’s mother: She liked to play on the computer. I was working, so I didn’t have enough time and attention for her. I just let her do things she liked to do; this was the only thing I could do. By the way, could you tell my daughter’s age? She’s 30!

Q: No, I couldn’t tell that at all, because she looks so young.

Sun’s mother: That’s right; she’s a very small girl as well. Employers never want to hire her if she goes for job interviews against people without disability. We stopped looking for a job for her after she had been rejected by employers several times; people always say “no” to my daughter. The real world can be very cruel. After she was rejected several times, I lost my confidence and gave up trying to find her a job. Anyway, I just let her stay at home.

There are several children like her who are working, you can tell they're different from other people by their faces, but they have been very good workers at the supermarket for years. They've been working in the old supermarket for over 7 or 8 years. They're well behaved, conscientious workers and always follow their supervisors' orders.

They're very obedient children, but don't know how to deal with criticism from supervisors or colleagues, they just bottle up their feelings. When they come back home, their unknowing parents might not understand the reason for their children's miserable behavior and this could make things worse.

There's a strong boy, a neighbor's son, who's a shelf stocker at a small Xinhua bookstore nearby. That's a heavy job only for strong people like him; the books are small but very heavy. I can't image Yijie doing this job! Now I don't want her to find a job anymore, I'm just going to let her stay with me.

People tell me my daughter is able to work, but I'm not convinced that she'd be successful. I would never feel at ease if she went to work, I really can't let her do that. She stays with me all the time, everywhere. I know this isn't great, it might be a bit selfish, because I should let her get a job and become independent. It's a just commonsense. My mind won't be at rest if she goes out to work. If she could talk about herself better, for example about what has happened during her day, what the supervisor said, then I'd be more confident about letting her work. The truth is, I can never know what she does in the workplace every day, because she can't answer my questions properly. Anyway, she can't look after herself outside.

I don't feel bad anymore; I just try my best to look after her until one day I can't do it anymore. I guess the government might need to look after them then. Compared to the past, I don't have anything to complain about, even though some people ask for more help from the authorities, but I don't (she's laughing).

Be Happy Every Day

Q: Why did you send her to the district DPF's activities, especially the Sunshine Home?

Sun's mother: I found out about the DPF office and the Sunshine Home very late, because I was always moving between work and home before I retired, I didn't know about the subdistrict office either. Until one day, Teacher Feng, a disabled persons' assistant, came to me and told me about the institute and its weekly activities. He said I should let my daughter try it and I thought it might be a very good thing for her. Actually, by then, I had completely accepted having a disabled daughter. I didn't want to hide her away, so I asked around to find something for her to do. These days, I've got a much better knowledge about the related institutes and their activities and make sure my daughter can join as many as she wants. Since then, some parents and I have become good friends during the children's practice and events.

Teacher Feng said he has a very deep sense of how my daughter has changed since he visited for the first time. Yijie didn't have any social skills and didn't want to talk to him at all. Now she is a totally different person.

The home has a very busy schedule for the children, the volunteers teach them very difficult Bel-Canto every Monday morning, on the same afternoon, another teacher comes to teach them piano and read music.

Sun: At the Sunshine Home, Teacher Zhou teaches us Bel-Canto Monday morning, and in the afternoon is music class. Last time the teacher taught us “Country,” sign language “Country.”

Q: What kind of songs do you like?

Sun: Pop songs. I love A-du,² Yase Chen’s *My Happiness Is Thinking of You*. I liked Wenjun Man’s *Understanding You* a long time ago, but I don’t like him anymore.

Q: What’s your favorite new song?

Sun: I listen to pop music all the time, songs about Tibet and Inner Mongolia. I like *To Wander* and *The Love Story of Western Sea* by Jamyang Dolma,³ she sings both of them.

Sun’s mother: She likes to go to the karaoke hall with her teacher.

Sun: We sing all kinds of songs, including English songs and Yue Opera. I like to sing *The Angel Arrives in the World*⁴ from Yue Opera, Shanghai Opera’s *Open a Window for You*,⁵ *Returning from the Target Shooting Exercise, Songs and Smiles, My Motherland, Today Is Your Birthday, We Are Good Friends, and Joy Division*.

Sun’s mother: What do you do on Tuesdays?

Sun: English.

Sun’s mother: They have a volunteer teacher, a foreign boy, to teach them English. They only study some very basic things, but he gives everybody an English name. There’s another volunteer who comes on Wednesdays to teach them to dance.

Q: Do you dance at home?

Sun: I rarely do, I only dance at the Sunshine Home.

Sun’s mother: She plays with her mobile all the time, she can’t survive without that phone.

Q: How long does it take you to learn a new dance?

Sun: We have to practice it for a long, long time.

Sun’s mother: The dance *Sparkling Red Star* which you saw last time. This teacher comes once every week, but after 2 months of study they haven’t finished yet.

Q: The teacher choreographs the dance as well?

Sun’s mother: The dance teacher, a mother of one of the students, choreographs a part of it and learns the rest from an online video. She’s a member of our subdistrict dance team and has a perfect figure even though she’s 56. She’s very busy with

²A-do, also known as Chengyi Du, is a famous Singaporean singer.

³Jamyang Dolma is a young Tibetan singer who was famous for *To Wander, The Lover Story of Western Sea*, and such typical songs about Tibetan culture and landscape.

⁴*The Angel Has Arrived in the World* is a classic song of Yue Opera *A Dream of Red Mansions*, which is adapted from a famous Chinese classical novel of the same name, also known as *The Story of the Stone*. The duet song is by Daiyu Lin and Baoyu Jia, the heroine and hero of the novel, explaining their subtle first impression and excitement about each other.

⁵The song came from the famous film, modern Shanghai Opera *Last Night Love* made in 1986, which talks about the regret and hope of a remorseful husband who became a criminal.

performances, competitions, and looking after a paralyzed parent. It's very hard for her to arrange a time to teach these children.

Q: The last performance of the side drum band had some quite different kinds of dance.

Sun's mother: There was a fan dance, Xinjiang dance, actually they learned all kinds of dances. They keep practicing new dances; they probably have a dozen dances all together.

They enjoy dancing so much; the parents even make some costumes for their New Year's show and parties. For New Year's show, all of the subdistrict teams in Hongkou District perform their own shows together. They've already started to prepare this year's performance for the show. My daughter is a part of the side drum and flat drum shows; some of them will sing, but she's not good at singing.

Q: Does Yijie have a partner in the side drum band?

Sun: Yes, I have two partners, Xiao L and Xiao D.

Sun's mother: Dancing is Xiao L's main interest; he practices square dance in the park every evening. He enjoys dancing so much; he has a very good facial expression for dance.

There is a square dance team nearby our other home, an apartment in the Anting District, near Yijie's dad's workplace. Every evening, some grandpas and grandmas dance some pretty complex and delicate dances in the community square. I like these dances a lot, but she doesn't want to join them even when I ask her to dance at the back of the team.

Q: Young girls are always a little bit shy.

Sun's mother: My daughter likes to play with her phone, but Xiao L doesn't like to do that; he dances every evening.

Sun: He only likes dancing.

Sun's mother: Our subdistrict team's dance, *Dancing China*, won the silver medal at the Shanghai Disabled Persons' Talent Show recently, it's a singing and dancing show for disabled people.

Sun: *Dancing China* and *Little Apple*.

Sun's mother: I was there as their make-up artist (shows a picture of the performance).

Sun: We found our costumes on the Internet.

Q: They're pretty clothes.

Sun's mother: They danced pretty well, but lost in the second round.

These are her most recent artistic photos. They're expensive but I like to spend money on these for her. She took some artistic photos when she was 20; now she's 30 and I decided to let her to take another set (shows her daughter's artistic photos while talking).

She's been to quite a lot of cultural events in Shanghai and TV shows as well. I'm always there with her, so I've been to many different places.

Sometimes we don't know a child's true potential, but she really likes recreational and sports activities and enjoys dancing and singing. There are 40 to 50 children in our team, she is one of the active ones, but before this I had no idea she could dance and sing.

Q: What did you do at the television station?

Sun's mother: It was an event for Special Olympics in 2007.

Sun: Zhiying Lin⁶ came and took a picture with us; he also gave me a signed CD. We had a drawing class on Wednesday afternoon as well.

Sun's mother: This teacher is well known and has a lot of students, she's one of our volunteers, too. She used to come with her husband before he went abroad, and they even paid for the painting materials for the children.

As part of the "Improving Shanghai People's Physical Fitness Project," the children practice one of the "All Games of Shanghai" sports—wiser ball—a kind of ground-based ball game, every Thursday.

Sun: We have to hit the numbers.

Sun's mother: It's like snooker but on the ground. The sport is still new to us and the students felt awkward at the beginning, but we all grew to like it later, because this game is also good intellectual practice for them. (She asks Yijie) how about Friday's plan?

Sun: Sometimes some people come to us for activities.

Sun's mother: These children are getting smarter and more engaged with the world as they grow up. Generally speaking, they're much better than they were. Teacher Zhou thinks about the children's condition a lot. She suggested if they can communicate and become interested in different things, this will give them an opportunity to cooperate with different volunteers and volunteer companies. They come every other Friday, not every Friday. The volunteers from Bright Dairy and the Communist Youth League of Shanghai taught them to sing and took them to a farm. All of them have creative and different ideas, but recently, most of the volunteers come from the Leshanhui Foundation and Mary Kay, a big company. Mary Kay's volunteers come monthly and arrange all kinds of different events for the students.

Q: What's the Leshanhui Foundation?

Sun's mother: It's a social organization, a public welfare foundation.

Sun: All of them wear yellow vests.

Sun's mother: One activity they do is teaching students to draw on straw hats.

Sun: Face painting.

Sun's mother: They draw all kinds of things. Another time, the volunteers brought material and taught them to do paintings with green, yellow, and red beans. It's why the children are always so excited to see the Leshanhui Foundation's volunteers, because they come with different and interesting things every time. The students like to take pictures after they've finished their handicrafts. Here are some pictures of their handicrafts (takes out some photos), this is a mushroom made with colored beans and some cakes, but my daughter doesn't like baking. If she's made some in the district DPF center's class, she takes them to the Sunshine Home and shares them with her classmates.

There are so many good-hearted people who are concerned about these children. For the DIY classes, the children need money to buy equipment and materials. So, we contacted a life care crowdfunding organization, a very good organization, which

⁶Zhiying Lin, also known as Jimmy Lin, is a Taiwanese singer, actor and racing car driver.

helped us sell the children's handicrafts online. It's why we had money to buy an oven, baking equipment, and material for baking biscuits and bread.

We have another baking class on the 30th, where some volunteers will teach them to bake individually. It's very good for the children. At least it's a thing they can do by themselves even though they can't learn complex skills.

Q: Do you make cakes after you learned to bake?

Sun's mother: No, she only plays the online baking game. They also have a Women's Salon here; sometimes they make nougat together and invite me to join them. Well, I enjoy it very much. It's their hand made nougat (takes out a bag of nougat).

Sun: Only the female students make nougat, the boys don't do it.

Sun's mother: Another time, supported by an NGO foundation, they made hand-made soap. The teachers contacted the foundation and raised the money for the girls to arrange activities in the Women's Salon.

It's so hard to teach them new things but these volunteers insist on coming here to help them. We appreciate this volunteer work and their precious time. It's not easy for them to find the time to come when they have a busy work schedule. We also had some undergraduate volunteers who came from East China Normal University and Shanghai Jiaotong University, but we lost touch with them when they graduated, such a shame. These young people are so smart and would leave us, the older generation, way behind.

Q: Did Yijie make any new friends from the volunteers?

Sun's mother: (asks Yijie) Did you? Her involvement with the volunteers was just taking pictures or playing together, but she isn't in touch with them on We Chat yet. (talks to Yijie) It's not something you're very good at, you don't like to keep in touch with them, but some other students like to exchange WeChat addresses with those volunteers.

Sometimes she brings back handmade wonton or moon cake that she's made with the help of the Sunshine Home teachers. It's pretty good.

Once my daughter said she learned how to make a fried egg and tomato dish with the teachers. It surprised me, so I went to the teacher to check this, because I'd never seen her cook before. One day, the Sunshine Home arranged a cooking competition for the students, they had to tell us what food they needed for their dishes for that day and they cooked in groups in the big hall. The parents were the judges.

As a person of 60, I enjoy spending time with these children even though they always speak without thinking about other people's feelings, but they're so pure.

The Sunshine Home's teachers are loving, but at the same time, practicing a quite strict discipline. They're different to other people who might think "What's the point of teaching them? It's just useless, nobody will learn anything."

There's a female teacher, a short woman with clever hands, she can make all kinds of different things, she is very patient with the children.

Sun: She's good at knitting, origami, and sign language.

Sun's mother: The district DPF office arranges a summer camp every year, most of the independent students—who can wash and dress themselves—from the Sunshine

Homes in the area have the chance to go. Usually there are two teachers who go to the camp in the Songjiang District for 4 days.

Sun: We have classes there.

Q: What kind of classes?

Sun: About personal skills, to be a “little journalist” or a volunteer...

Sun’s mother: They arrange some activities for the students; they let some of them act out a volunteer role and others play the editor of a newspaper.

Sun: Yes, we have to write articles, the “little journalists” have to write something.

Q: How many students altogether?

Sun: Two.

Sun’s mother: Every subdistrict can send two children to this district event.

Sun: We sang karaoke and watched movies there. One time, several students and I went out of the camp for a sports event.

Sun’s mother: She was so happy during the Summer Camp, even happier than she is at the Sunshine Home.

Sun: We have a medal presentation, too.

Q: I saw Yijie’s varnished nails for the first time when I met her, did she do them by herself?

Sun’s mother: No, that was her auntie who did that for her before our holiday. Her auntie tried very hard to take her to the nail salon and get her nails done.

Q: Yijie is the recreation and sports secretary in the class, isn’t she? What are her duties?

Sun: I teach them something about literature and art or read the newspaper.

Sun’s mother: For example, if they start learning a new dance, she’ll be one of the first to learn it and then she will teach the other students.

Sun: We also have to attend regular activities of the Communist Youth League to discuss about striving for the great cause of communism.

Q: When did you join the Communist Youth League?

Sun’s mother: (finds Yijie’s CYL certificate) In 2009.

Q: Is Yijie’s native place Zhejiang Province?

Sun: Ningbo in Zhejiang Province.

Q: Yijie’s really talented at sports, dance, and handicraft?

Sun’s mother: That’s right. This time Teacher Zhou said we are definitely going to make a special gift for everybody in your team. She (points to Yijie) and little Y’s mother is in charge of gift making.

Sun: I start making the gifts when I come back home until 9 p.m. I start working immediately after my dinner.

Q: Yijie is very popular among the Sunshine Home classmates?

Sun’s mother: That’s right. My Yijie is good at the “monkey king” performance, too. If you spend more time with these children, you’ll realize they are very genuine and cute and don’t have any bad thoughts. We really appreciate the government’s Sunshine Home project, it’s such a great thing for these children; at least it provides a place for them, otherwise I can’t think what we would do with them.

Sun’s mother: Some children from the other Sunshine Homes envy Yijie as well, because our Sunshine Home has more activities and the children are happier. Children

like them can be reluctant to study; it would be impossible to let them take serious classes at the Sunshine Home. It wouldn't work because they get bored with the normal way of studying and they only like to engage in recreational activities. These children like to do things which make them feel fulfilled.

People always say that God never shuts one door without opening another. Our Yijie has a talent for recreational and sports activities; all of these children have their own strengths in different fields. But it's hard to say if she will engage with society, I think she will never be a part of the society. You can't tell that she has a problem by looking at her face or appearance until you've talked to her for a while. Then you find out she is very difficult to communicate with and long conversations are just too much for her. Right now, she's part of this big family of the district DPF center. (She looks at Yijie) Can you tell us what you like apart from the computer and mobile phone?

Sun: I like handicrafts, making beads, that kind of thing...

Sun's mother: I don't have any of the things she made from beads with me, but I'll show you later.

Sun: I made them myself.

Sun's mother: She learned to make beads at the Sunshine Home and then started to do this herself.

Sun: I like to sing and draw as well.

Q: What's your favorite game?

Sun: Some QQ games, "Pair-up" for example, or mahjong, Puzzle Bobble.

Q: You play quite a lot of games. Do you watch movies?

Sun: Of course, I watch movies on my phone.

Q: What kind of films do you like?

Sun: Some TV programs like *Journey to the West*, *Romance in the Rain*, and *My Fair Princess*.

Sun's mother: She's obsessed with these programs.

Sun: I'm following *Magical Dog Seven* at the moment.

Q: What does Yijie do at the weekend apart from her everyday activities?

Sun's mother: She comes here to the district DPF center at the weekend.

Sun: I come here for the activities.

Sun's mother: She goes to the Sunshine Home from Monday to Friday and comes to the district DPF center for the weekend activities. She has a very busy timetable and I've to go everywhere she needs to go.

I'm 60 this year. I took early retirement when I was 45; after that, I didn't take any other jobs, but decided to look after her.

Q: Do you think there's something the Sunshine Home could do better?

Sun's mother: I think it's pretty good, this Sunshine Home runs more activities than the others. Sometimes, for me, I feel their busy schedule is too much. I don't think they get enough practical work; they can be quite lazy children. I wish we could arrange more practical activities for them. It doesn't matter what; housework practice or washing clothes, all of these practical activities would be good for the children.

Involvement in Sports, Being Healthy and Cheerful

Q: When did Yijie participate in Special Olympics for the first time?

Sun's mother: In 2007. Special Olympics and related sports are special events for the intellectually disabled and all district and subdistrict DPF offices arranged their own Special Olympics Game events at that time. Firstly, these children can enter some games at district level as an individual athlete; then secondly, the municipal sports committee will select athletes from these events. My daughter won several medals at our district sports and games, (she takes out some medals) these are her medals for first, second, and third places, this one is our subdistrict's group medal.

Sun: I won first place for the bicycle race as well, the Tandem Race.

Sun's mother: This is the latest sports medal she won, just last Friday.

Sun: It's the Unified Run event.

Sun's mother: It's a biennial competition, Yijie always takes part. One team has 12 people, half the children and half the volunteers. I was a regular participant in the games, I joined four games with my daughter. Actually, she's always popular with her teammates, because she is light and much easier for other people to carry around. One time we won a gold medal for the Unified Run, here... (She shows the interviewer the medal). I couldn't take part in this year's competition because of my back problem. This time they won second place in the team event, it's a very hard game for everybody.

Sun: These are my gold medals.

Sun's mother: They are also a record of her growing up day by day. I remembered these medals last night and decided to bring them with me today. There are so many of them, 12 altogether. Yijie likes sports and wanted to join all kinds of sports events, so I just let her enter these games.

Q: It's brilliant.

Sun's mother: This is a medal for sixth position in a table tennis competition in Shanghai, and here are some medals from basketball shooting hoops, 100-meter sprint and other competitions.

Sun: I won the Rhythmic Gymnastics Competition as well.

Sun's mother: The sports games for these children are not really about winning medals, but when we became involved we started to think that we should do our best and try to win. We treated the games seriously, following a very busy training timetable and putting a lot of effort into them.

Q: What else can you tell me about Yijie's training?

Sun's mother: The cycling race includes Singles and Doubles Races. They use a tandem bike in the doubles race like the one you can see in the park, one bicycle with two seats and two sets pedals for two people. In the beginning Yijie was a Single Race cyclist, but she was too weak for this sport, so she had to change to the double race and started training with a stronger girl. We paid a lot of attention to practice and borrowed the sports ground from Miyun Road School for them. They trained with the school coach once a week, which was a very formal schedule for them: the coach put a lot of effort into their training and he was quite strict about it.

My daughter isn't a strong person, she tried her best to get through the training. I was there with her on the day of the competition and I was genuinely impressed with her performance, she finally won a gold medal.

Although Yijie is a small person, she's better than lots of people without disability at (basketball) shooting hoops, it's quite interesting. (She asks Yijie) What was your final position in shooting hoops?

Sun: I don't remember now.

Sun's mother: She forgets the results of the competition, too! A bad memory is one of her biggest disadvantages, I have to remember things for her. I keep telling her: "You have to remember things yourself, because my memory gets worse as I get older." I remember when she came back from the competition and told me the result, I was totally amazed. I never expected her to win anything at this game.

Q: How long do they train before a competition?

Sun's mother: They're having regular exercises guided by the teacher all the time, they only do special training for a competition when they have been told by the district DPF office to prepare for an event.

Q: I watched Yijie's table tennis competition last time, she was fantastic, she's good at "smashing." (see Fig. 1).

Sun: I won sixth place in the table tennis competition.

Sun's mother: Yijie has been involved in lots of events; she likes to go to all the games.

Q: That's pretty good.

Sun's mother: Exercise is always better than sitting down and doing nothing.

Q: Yijie, is there anything that impressed you most about these events?



Fig. 1 Yijie Sun taking part in a table tennis competition

Sun: I don't think so, I just enjoy the games. But I'm even happier if I win a medal.

Sun's mother: Yijie only enjoys competitions that she likes, but she doesn't understand very much about other things yet. For example, once Yaping Deng⁷ visited them, lots of children wanted to take her photo, but Yijie wasn't interested at all. Another time, Zhiying Lin came along and took a picture with her, but she didn't look like she was thrilled by this at all. The events make her happy, medals make her even happier. (She asks Yijie) Are you hoping to achieve anything else? Think about it.

Sun: The best thing is getting a good place or winning a medal (raises her thumb). I like to buy my mates a meal if I win. It's very me.

Sun's mother: As she grew up, she began to understand numbers and money better. Before she had any real sense of money, she would always buy her classmates meals when she received her monthly allowance, and everybody said what a very generous person she was. For her, 600 yuan is quite a lot of money, but she couldn't understand that it was for a whole season, it was supposed to be a 3-month allowance.

There are some other children in the team who have no sense of money; it's impossible for them to save anything. The only thing they understand is that the money belongs to them. Sometimes these children can also get a special subsidy for a competition or performance. Yijie doesn't like to keep the money herself and always gives it to me, but some of her classmates insist on keeping the money themselves.

I've told my daughter, as an adult, you might have to pay some unexpected bills, so you'd better carry some cash with you. After that conversation, she started keeping 100 yuan in her pocket all the time, but she hardly uses it. Lacking the ability to handle money makes me worry about her a lot; sometimes I can't even sleep when I think about her future. So, I have to let it go.

Sun: Once we practiced the Dragon Dance at the sports ground in the hottest of summers. It was a very hard job playing the tail, my face became red, and then I went a very dark color, but I didn't give up.

Sun's mother: It was very difficult practice, indeed.

Sun: It was a really tough job. We were at a military barracks.

Q: Why did you need to go to a military barracks?

Sun's mother: They went there to practice, because their coach was from the Armed Police troop, they have a Dragon Dance team there. We had two teams, a Dragon Dance team for the girls and a Lion Dance team for the boys.

Sun: It was a very hot summer, sweat was rolling down my face all the time.

Classmate's mother: We went to the military barracks once a week in 40 degree temperatures.

Q: The teacher told me that Yijie could handle the temperature and insisted on practicing during the hottest weather. I heard that she had to do two events at the same time?

Sun's mother: Yes, that time, after the dancing event, she ran to the Sports School for Children for a welcome ceremony for returning disabled athletes.

⁷A famous Chinese female table tennis player and Olympic champion, regarded as one of the greatest players in the history of the sport.

Q: Did Yijie change in any way after her involvement with Special Olympics and other sports events?

Sun's mother: Actually, she changed quite a lot. The teachers at the Sunshine Home realized she'd changed as well.

Q: I was told by the teachers that Yijie had changed beyond recognition after the sports competitions.

Sun's mother: You're right. She was an introverted child, she hardly engaged in conversation when people talked to her, she would be totally focused on her phone or computer and ignored other people. Some teachers said she was a little bit autistic. Now she's the opposite, she can engage in conversation and likes to discuss things she knows with people. Now she's an active, cheerful, and open girl.

Yijie used to be only close to me, she liked to share all her stories with me, but now she likes to share things with her friends. For example, if she won a medal in a competition, she'll take it to show her teachers at the Sunshine Home. If they're not there, she will take some pictures and share them with the teachers through WeChat. She keeps in touch with her teachers all the time, and some of them "liked" her pictures on WeChat and praised her, "You achieved this win through hard work." The other children like my daughter, they really respond to praise, and will always try harder to do better if you praise them.

Frequent exercise makes her fitter and stronger, and common diseases don't affect her as badly as before. Lack of exercise is the most common problem for intellectually disabled children, there are so many who are overweight because they just sit around after meals. Some children are different, they work very hard to deal with weight problems, they only become chubby if they don't get enough exercise. My daughter is totally the opposite of those children, she does exercises regularly and is full of energy. When we go on trips with other families, she is always the last to get tired.

So, the biggest changes to my daughter were that she became fitter, happier, and smarter.

Q: Yijie, do you feel any different after you joined Special Olympics and related events?

Sun: Yes, of course. I've changed a lot. I'm so happy and pleased to take part in group events with other people.

Q: Do you like to spend time with your teammates and friends?

Sun: Yes, I like to be with them.

Q: Did Yijie's social circle grow after she became involved in these sports events?

Sun's mother: No, I can't say that. To be honest, it's one of our great regrets, even though she participated in more events the new people she met were volunteers. It's impossible for her to find new friends by herself, very difficult. If she likes to go somewhere or do something outside the home, she still has to depend on her parents.

Q: Have you and your husband changed at all since Yijie became involved with sports?

Sun's mother: I'm so pleased about the way she has changed. I like to be a part of these children's events and I feel I'm still young when we're together, even though I'm quite old. Her teacher, Zhou, is the same age, and she does the same things as me, spends all her time and attention with her child and the other children. Yijie's father

is happier that she has grown up as well. Especially that Yijie has become closer to him and communicates with him better. Sometimes she'll tell him about her day and what happened to her in the competition or send him some pictures through WeChat.

Q: Is there anything you'd like to say about the Special Olympic Games?

Sun's mother: I hope more people get to know these events and get involved, because my daughter and her teammates who benefited from the events is just a very small group. Most people don't know very much about Special Olympics yet.

The Whole Family Looks After Her

Q: What did you do before you retired?

Sun's mother: My husband and I both worked at Shanghai Automotive. It's a good factory but some tough personnel management policy decisions meant that the women workers had to retire at 45 while the male workers could work 10 years longer. I didn't take a part-time job after I retired, but my husband worked until he was 60.

My husband said to me: "Our child is different and needs more attention, so please stay at home and look after her." He had to work harder for the family income. When he was younger, he didn't take a holiday for almost 2 years. His workmates thought this was quite strange and asked him why he had to work all the time. He told them that his wife had retired early and the family needed more money because of his daughter's condition. When their boss heard this and decided to give him some reasonable overtime. Usually the employees work 5 days and rest for 2 days every week, but my husband worked 6 days with 1 day of rest each week. He did this for years until last year when he just couldn't carry on with such a busy schedule.

I must say, our daughter is a very lucky girl, because her dad loves her as much as me. Her dad usually says: "I don't have any choice, because I have to look after our daughter. Her whole life depends on us." Today, even though he is retired, he still has a part-time job.

In our group, there are several pairs of parents our age and they're doing the same thing as us: the mother has retired and stays at home looking after their child, but the father is still doing a part-time job to make money for the child's future.

Q: Is Yijie able to live independently?

Sun's mother: Not at the moment, she can't look after herself. I taught her everyday skills when she was little, but the problem with Yijie is, when she's learned how to do something, if she doesn't get it right, it's very hard to get her to change. It's the same when she plays the side drum or a dance, correcting a wrong movement is a very hard job. We don't have any choice, we have to give her as much support as she needs. For people without disability, it's very difficult to understand these children's learning difficulties.

Q: Does Yijie help with the housework at home?

Sun's mother: She started learning housework very late because I looked after her too well. These days, she can wash her own clothes by hand after she's showered. Before dinner, she likes to help me set the table, that's all; she won't wash the dirty plates afterwards.

I know it's my fault, I never gave her a chance to do anything in the past, even though I know that one day she'll have to face life on her own. She's grown up into a lazy girl already, the only thing I can do is help her learn housework little by little. Some children in our group are really good at housework, one boy who can't read keeps his home tidy and clean all the time. He's also good at bartering when he goes shopping, even better than some adults. These children are very interesting, and everyone has his or her own different characters.

Except for the 4-day summer camp every year, Yijie and I are never apart. People always see us together, sometimes if they see only me at the Sunshine Home, they'll be surprised and ask: "Why are you here by yourself? Where's your little tail?"

My daughter is always with me, I never let her go out on her own. I'll be pretty worried if she goes out by herself. I know I shouldn't be so overprotective towards her, but I just can't stop myself. It's easy in theory, but too difficult in practice. She knows how to take the bus to the Anting District, metro No. 4 first then change to No. 11, but I couldn't let her do this journey by herself. But some other children are very different; for example we have a great child at the Sunshine Home who lives in the Songjiang District, he has to take a long bus journey to get here every day, nobody accompanies him.

Q: Have you ever thought about letting Yijie get a bus on her own?

Sun's mother: Yes, I've thought about it, but I don't dare to let her try. On the one hand, I'm retired and I have plenty time; on the other, her dad insists that I keep her company all the time. He always says, "Your primary responsibility is to take care of the child." If anything bad happened to her when I wasn't there, my husband would be so upset.

Sun: Once I was hit by a car.

Sun's mother: The same thing happened twice. Once I left her before they'd finished their exercises and one of the teachers said she'd send her back home afterwards. I got a phone call when I arrived home, she asked me to meet her down on the street because her bicycle had been hit by a truck. She was very scared after this accident. Another time, the same thing happened when she was riding her bicycle. She injured her foot that time. So, I always worry about her if she rides her bicycle without me being with her. Shanghai is too busy and there are too many bad drivers and cyclists everywhere. So, I have to keep her company.

Sun: My grandpa taught me to cycle; he encouraged me to learn.

Sun's mother: She learned to peddle the bicycle when she was very young, still at school. After that, she started to go everywhere with her bicycle. Many of our teachers and volunteers have bicycles as well; getting a bus here isn't very convenient for some people. If the teachers have to go shopping or somewhere, my daughter is always the only student assistant to go with them, because none of her classmates can ride a bicycle. She was pretty good at cycling before these two accidents happened. These bad experiences still haunt her; now she's timid and always peddles away when she sees a truck coming towards her. A child like her needs to pay more attention to understand the traffic laws and take them seriously, because they don't realize how bad an accident can be.

Sun (she's shy): I go through a red light sometimes.

Sun's mother: I have to keep an eye on her all the time. Anyway, I'll do anything for her, I don't care what she wants to do, I just follow her where she wants to go, so I can help. Basically, I'm not a very open and sociable person, but I had to change for Yijie. I became part of their team, the assistant for their costume and make-up. That's my new job (laughs).

Q: Do you go to every competition with Yijie?

Sun's mother: Almost every time. When they're preparing for a competition, the parents and assistants get very involved, too. The children can only focus on their practice and performance; the parents have to do everything else for them. We know that overprotecting them isn't good; for example, we know they should sort out their own food and other things when they go to a competition, but we just can't stop ourselves from helping. If you've been to one of their competitions, you'd see the volunteers and parents running around the stadium getting things ready, but the children just sit there and wait for the presenter to call their team's name.

I've been to the Unified Run, a biennial competition four times in the past, but this time I couldn't go for health reasons. I told the teacher in charge that I couldn't go with them, and said to my daughter: "Mom is too old to run around the world with you anymore." This time, we had three tall, strong and nice male volunteers, they took the day off to help with the competition and took on the heavy responsibilities for the team—running through the rain to do stuff. I suggested to the teacher in charge that we should recruit more young volunteers, because we're getting old. These young people are very different, they're smart, active and have good social skills as well. Also, as young people, they have a much stronger ability to accept new things. Compared to us, traditional and outdated old people, they're good at using the Internet as a new way of teaching.

Several years ago, when we were younger, some teachers and I became the first students to learn new things from the young volunteers who couldn't come very often, and we would teach our children afterwards. Now, I'm old and phasing out my teaching duties slowly. There's another teacher who's in her seventies; for the children's happiness she still comes to the class with her daughter every weekend.

Q: Parents sacrifice so much for their children!

Sun's mother: Definitely; but she's not the oldest in our group, the average age of all the parents is older than that, only a few are younger than this mother.

To be honest, compared to many families in our group, my husband and I are in a better financial situation than those parents; it's not possible for many to pay for their kid's birthday party or for a trip.

I think about things in a different way, with the child's condition, the parents are the only people who will take her out, we can't shake off this responsibility. We have some nephews in our family, but they are very different to my daughter. They are ordinary children for their age, they can book hotels online or arrange other things, but my daughter can't do that. She has to rely on us, so we have to try our best to take her out on trips, as many as we can.

Nowadays, my daughter has become much choosier than before and she has higher requirements as well. For example, if we talk about destinations for our next journey, she'll choose an overseas trip rather than visiting places in China.

Actually, we talked about this thing today, I told her it's not good if all she thinks about is going out or eating out, but it doesn't make any sense to her when I say she has to value the money her parents are earning. The teachers at the Sunshine Home always say we spoil the girl too much.

Sun: I haven't been to Beijing yet.

Sun's mother: Sure, her next trip will be to Beijing.

Sun: I've been to South Korea, Singapore, Malaysia, Thailand, Japan and Zhangjiajie.

Q: Did you all go to these places together?

Sun's mother: No, only Yijie and me. Her dad has to work and can't go on holiday with us. We'd like him to join us and asked him to save his holidays to go somewhere with us next time.

One time, when her dad was taking her on a trip, she was still having breakfast at home while the rest of the people in the group were waiting at the bus station. Her sense of time is bizarre; if you told her the tour sets off at 9 a.m., for her that would be the time to leave home. I tried to explain to her that she has to think about the time it takes to get to the bus station, but she couldn't understand me. Because of this, I've become the "Ms. Late" in the group. I always say to her: "Yijie, if I didn't push you along with the side drum band schedule, you wouldn't be successful." She doesn't have any independent initiative and needs somebody to keep her in line. Anyway, she depends on me too much.

Usually only Yijie and I go on the trips with the other parents, teachers, and their children. We go several times a year, because these children can't organize their own holiday trips. This year, we went to Singapore, Malaysia, Thailand, Sanqing Mountain, and Zhangjiajie. We didn't go on the last trip to Laozi Mountain because of my ill-health. Yijie can't go anywhere without me, so she missed the trip as well. When she saw the pictures that the other parents and children posted on WeChat after the trip, she was quite jealous. So, I told her that she shouldn't be upset because we can go with them next time.

We're members of a holiday agency who arrange the trips, so we have plenty of opportunities to go to places. I think while I'm still fit enough and before I get too old or sick to go with her, I should go on as many holidays as possible. One day I might have to stop, when I get too old or can't walk properly.

Q: Do you have a physical problem?

Sun's mother: I have a back problem because I did too much heavy labor when I was a young farm worker. It wasn't bad when I was younger, usually it took me a week to recover when my back went. The condition got worse as I got older, and it happens more often than in the past. It's very serious these days, sometimes I even can't walk or sit down. The doctor told me, the back is the central part of your body and you won't be able to move around properly with a bad back.

Classmate's mother: As parents, we don't have any choice, if we want the children to see the outside world, we're the only people who can do that for them. Nobody has the time to look after a disabled child. Even in our families, parents can't go on holiday with their children at the same time, usually the dad has to work and the mom is the only person who can go with them. In our family, it's the same situation

as Yijie, I'm the only person who can look after our son and take him on holiday. We've been to Thailand, Bali, Singapore, and other places. Tomorrow, we'll fly to Yunnan; we'll fly three times in a week this time.

Once my son asked me: "Mom, please take me out while you're healthy, I won't do any more trips when you can't go with me." How could I not feel upset when I heard this?

As healthy as you guys are, you can go anywhere you want to go, but my son can't go anywhere without his parents. Seeing your 30-year-old son waiting for you to take him out is a really sad thing!

To be honest, it's hard to describe what it's like, as parents of an intellectually disabled child we have to swallow the bitterness of life alone, it can be a vulnerable and miserable life. I keep hoping that society will give these children special attention, but nobody helps us, we're on our own.

There are eight adults and their eight children in our small, close group. We usually arrange some activities to keep these children happy, like singing, dancing, or eating together. Our children are not able to, or can't make friends with ordinary people, but they can have lots of fun with their own kind. It's great for them to get a chance to sing, dance, and have fun and relax with other children.

People keep saying we should let our children be a part of society, but who would want to play with them? Yijie speaks better than the other children and she's able to put together some longer sentences, but others, like my son, can only speak a few words. Sometimes, I feel very upset for my son.

S's mother: I used to think I could just enjoy the moment as much as possible while I could play with my child and not think about the future. In our group, different families have their own difficulties. For example, in Xiao Y's family, their problem is scorn and criticism from the whole paternal family; this is very annoying. My extended family has a very different attitude towards my daughter, they insist on the same thing—compared to the other healthy children in the family, this special child needs more love.

As Shanghai natives, we inherited a very big house from our ancestors, so our extended family can share the space together. We have three generations under one roof, my parents still living with their siblings; when I was young, I lived with many cousins. I have three siblings, and my uncle, my father's older brother, has six children; in addition, my aunt, my dad's big sister, has three children—all of these children grew up together. We only moved out of the house when we were grown up and had our own families. We still live in the same community and see each other every week. My dad didn't want my siblings and I to move too far away from his place, two or three bus stops at the most.

In our extended family, there are two boys the same age as my daughter and all of them come from a single-child family. The oldest boy is half a year younger than my daughter, another one is one and a half years younger than her. The three children used to do everything together when they were little. They went to the same nursery and school, saw each other every day and were only apart after school. They would play together at the weekend when we went back to a parent's house. They were very close and got on with each other very well. One time, when the government

demolished and relocated our old place, we had to move house, we even moved back to the family house for a while.

In this family, everybody loves and cares for my daughter very much. She is the center of the family, including my own parents, cousins, and their children; all of them are willing to do anything for her if she asks. Nobody looks down on my daughter at all, and all of them love her so much. For the adults and her cousins, she is the child of the family, even though she is the oldest of this third generation. Everyone understands that my daughter didn't choose her life, but unfortunately it happened to her, so why don't we try our best to look after her?

Since they graduated from the university, her two cousins have experienced a high pressure of life and work, my daughter will never have to feel this. I understand all about these young people and their stressful life and usually I say to Yijie: "You don't know how lucky you are."

Q: In some ways, her life offers a different kind of happiness.

Sun's mother: I agree with you, she's very lucky. She wouldn't get all our love if we'd had another child. There are some families in the same situation as us, they chose to have a second child, and this created a much more complex situation for the disabled one.

The children are sensitive to any unequal treatment from their parents; they might ask their mom: "Why don't you care about me and only look after the other child?" This situation could lead to conflicts and problems between the children. You might think this problem could be resolved by always reminding the second child, "You have to look after your older sister or brother when you grow up, she/he is your duty," and hope they adopt this idea as their own. But anything could happen when they grow up, they might stop listening to their parents one day.

We only have Yijie and we know she won't be able to become an independent adult, so I look to her two cousins to look after my daughter after we've passed away. They're very lovely children and quite close to me. Sometimes I say to them: "One day, when I get very old, I might ask you to look after me and Yijie."

In our group, some children are in a better financial position than my daughter, because they have found a way to get more governmental support. I only heard this news recently and didn't consider or ask about these policies in the past. Some people told me that making a complaint to the appropriate department is the right thing to do, but I disagree. I just accept this reality as my fate and tell myself to be calm. I don't want to be worrying about something that hasn't happened to us yet.

Q: Do your husband and you ever disagree about Yijie's education?

Sun's mother: No, we're always on the same side. I'm very pleased with our situation, and he never disagrees with me if I criticize the girl for something. If he wasn't on my side, there would be huge family conflict. Apparently, both of us support the child, he spoils the girl worse than me.

Q: Yijie's a lucky girl to have you, very lucky.

Sun's mother: I have to say she's a lucky child. Some families in the same situation as us might have very different stories to tell. There's a girl, the same age as my daughter, who comes from a divorced family and she gets less attention from both parents. The girl lives on her own, earns a little bit money, but often wastes it. She

just hangs out with other people; sometimes she even buys a coffee for Yijie and the other girls if she can't find other things to do. I really can't understand her parents, how dare they let this girl wander around outside like this? There's another child who comes from a broken family too, both parents abandoned him when they had new families and new babies.

More families are willing to have a second child, but they can't treat the two children equally. There's a family I know, who first had a disabled daughter and later a non-disabled son; after the son came along, they sent their daughter to live with the grandma and refused to look after her, even though they were quite wealthy people. Anyway, like I keep saying, if you decide to have a second child, you must treat the disabled one equally.

Q: What do you usually do during your family time?

Sun's mother: When we're together my daughter is always the busiest one, on the phone all the time, playing with WeChat and games.

Sun: I like to watch films, online films.

Sun's mother: Sometimes, her dad likes to watch TV programs, especially war programs, the War of Resistance against Japan and China's War of Liberation. I use WeChat from time to time, because the teachers and volunteers from the district DPF center have a WeChat group, but I haven't checked the group messages since I had my bad back.

If I'm free, I have to travel to the Anting District to look after her dad; my husband can't cook, and if I don't go there, he lives off takeaways or frozen dumplings. It's quite a journey between home and Dad's workplace, so I usually have to stay a couple days. At the same time, I can't stay with my husband for longer than 3 days because I have to come back for my daughter.

Q: Sounds very hard.

Sun: She always starts the housework straight away when she gets back home.

Sun's mother: I don't have any choice; I have to run between the two places. Some people talk about how their retirement is boring and I can't understand it at all, I'm so busy, I never have any time.

Compared with ordinary young people, these children are free from worry. When you graduate from university, you and your classmates have heavy competition for jobs and it's hard to be in control of your own time. You can't take a holiday or trip when you feel like it. My daughter keeps asking her two young brothers, "Why don't you go out?" I have to explain to her, they have to work, it's stressful, they can't go somewhere when they want, like you do.

Classmate's mother: As parents of these children, their happiness is ours as well, if they are happy, so are we. Parents are the only people who can look after these poorest children.

Better Not to Think About the Future Too Much

Q: Have you ever thought about Yijie getting married?

Sun's mother: Yes, of course, but in her group, every child has their own special condition and desire. For example, Xiao Y wants to get married and wants a wife, but my daughter, she's still like a child. She can't think about marriage or starting a

family yet, so I just let it go. If she got married to a person without disability, that could be a problem for their relationship. So, if she wanted to get married, a disabled man is the only choice for her. Sometimes when I think about what will happen after my husband and I pass away; I think maybe if she gets married, it would be a good thing for her and they can look after each other without us.

For some children in the group, marriage is something they want, but it isn't an issue for my daughter at all.

There was once a very nice girl who stayed at the home, she looked normal and nobody would have known that she had a problem until she started talking. Later, she married a taxi driver who lived downstairs. On their wedding day, the guy promised the mother, "Please stop worrying, I promise I'll try my best to look after her," but 3 months later this young couple started quarrelling. Before they got divorced, this was before their first wedding anniversary, they even argued at the subdistrict office. After that, she remarried a man with the same condition as her; they're a good match and get on with each other very well.

I have to say, it's very rare for these children to get married. Anyway, marriage is hard work even for ordinary people. There's another young girl in our group, she fell head over heels in love with a man, she'd cry and refuse to eat if she couldn't see him. Hard to blame the girl alone for this family issue, I think her parents had to take responsibility for this difficult situation.

Anyway, I won't let our Yijie out of my sight; if I did, I wouldn't stop worrying. She and her classmates are very innocent and naive, and the outside world is too complex for them; there are many good-hearted people, but quite a few bad ones who can be very harmful. When she studied at the school, I would collect her twice a day and never missed once. Her teacher told me that I loved my girl too much.

I always tell Xiao Y's mother, your son is independent because he has Down syndrome, but not intellectually disabled, otherwise he might have been cheated by some people many times. Xiao Y is a more sophisticated boy, very different from the other children in the group. He doesn't just say the first thing that comes to mind, he usually thinks about your question before he answers.

These intellectual conditions are the reason that parents and families give more attention and love to their children, but it mustn't turn into something that makes them a careless or nasty person who only think about themselves. As families, we have to reason with our children, maintain the correct standards of behavior and give them the right kind of family education.

Q: What do you wish for Yijie?

Sun's mother: I hope she can be a little more sensible one day, because sometimes she's too childish. I get older every day, sometimes I feel ill or too tired to do anything, but if I don't keep telling Yijie over and over to help me with the house work, she won't do anything.

I felt recently that my daughter is too naive, especially with her lack of social skills. She lives in the community and that makes me worry about her relationship with (open) society more; she needs better social skills; they are very important for her.

I don't want to discuss my expectations for her future, I would rather focus on her present life. To be honest, if people in our situation think about the future too much, they won't be able to sleep. The best thing is to forget about this, it doesn't mean anything to us: we just live for today and don't plan for the future.

In addition to the group of children like ours, there are other four groups of disabled people: those with a physical disability, deaf-mutes, those with mental problems, and blind people.

Sun: Association for the blind. (She corrects the title of the association that her mother just mentioned.)

Sun's mother: We usually say all disabled people are vulnerable, but I believe children with intellectual disabilities are the most vulnerable in the group. This intellectual condition that effects their brain, they need adults to think for them. In other subgroups, for example some deaf-mute people, they can be cleverer than ordinary people. They're very smart, and they know what they want and how to negotiate with other people. They know how to ask the district DPF office for something they need. Sometimes their demands make the district DPF leaders feels slightly awkward.

Intellectually disabled children (points at Yijie) don't know how to ask other people for help. They need their parents to help to explain their needs to the institute and the parents or guardians have to do everything for them. Compared to intellectually disabled people, mental patients are in a better situation as well, because they only lose their mental control while they're sick. The rest of the time they're almost the same as people without disability. As the most vulnerable subgroup of all vulnerable groups, I want my daughter and her kind to get more attention. That's all I ask for.

Q: I hope Yijie has a happy life forever. Thank you for the interview.

Sun's mother: You're welcome, it's been my pleasure.

Interview with Yijie Sun's Teacher

Interviewee: Yijie Sun's teacher

Interviewer and writer: Puyu Zhang

Interview date: December 7, 2016

Interview place: The Sunshine Home in Shanghai.

She has changed a lot since she joined us

Q: When did Yijie start coming to the Sunshine Home?

Teacher: She joined us around October 2005 when we opened.

Q: Do you remember the first time you saw her?

Teacher: I wasn't there at that time, because I hadn't joined the center. I knew their assistant, Teacher Feng (points at the teacher near the doorway), he told me Yijie was very quiet to start with, hiding behind her parents and didn't like to talk to anybody.

Q: I guess she's changed quite a lot since then?

Teacher: She is the student who has undergone the biggest change at our place. When I came to the center, she spoke very little. I remember she cried very often, cried for all kinds of things and she was a slower learner in her studies and handicrafts. Now she can do all of these things, she talks more, and she's become a good dancer.

She learned all kinds of sports here. For example, she didn't know how to play table tennis or badminton; at the end of their first badminton exercise, she couldn't even pass the shuttlecock across the net. The only thing she could do was serve and if the shuttlecock went over the net, her job was done.

The only problem for her now is that she's still a little bit timid when she meets people; she is only able to talk in a group if she is well prepared, otherwise she won't speak.

Q: What has impressed you about Yijie since you met her?

Teacher: Her behavior during Special Olympics in 2007 was very impressive. With such a tight schedule for the dance shows, as a dancer performing in several dances, she had to run from one show to another. In the hot weather, she had to change clothes and run from one stage to another, but she never gave up and worked very hard. I've never forgotten this.

A Popular Person but Has No Work Skills

Q: What do you think about Yijie's general character? Is she an introvert or extrovert?

Teacher: I think she's an introverted person, but she can be an extrovert and open when she concentrates on her dance or exercise. It's hard to tell which is the real her. Sometimes it depends on your relationship with her, she likes to talk with people she knows. If she thinks you're friendly and kind, she'll have a lot to say.

Q: Does Yijie have many friends?

Teacher: She has a lot of friends and she's very popular, though basically, she's a quiet person who gets on with all of her classmates very well. At our center, both Xiao Q and she are the most popular people, but Yijie has a better temper than Xiao Q. Anyway, she's a very innocent child, just like a child.

Q: Does she arrive on time?

Teacher: (He shakes his head and laughs) she's often late, quite often, but there's nothing we can do about that because it's part of her mental condition. She can think properly when she's in the right mood, but she can lose the control when her mood isn't right. For example, she can't wake up on time even though she knows she should get up, but she can't open her eyes.

Q: Do you think Yijie will be able to work one day?

Teacher: I don't think so. She does things very slowly. She can do some DIY work, but with no restrictions, she can't do things on time. For example, during mealtime, even if you sit next to her to hurry her along, it doesn't work. Compared to Xiao Q, she can't do a proper job; otherwise we would probably have referred her somewhere already.

We've helped several students find a job; one works at a check-out at McDonald's and another makes screws, but we can't find the right job for Yijie. We tried sending her to the Sunshine Factory, but she wouldn't stop crying from the time she arrived, and we had to bring her back home to her mother. There's an interesting thing, but it's

hard to explain, some moderately disabled people can do a proper job, but some with a much milder condition can't work. The latter group might be good at something different but not work, they can't be a part of society.

Q: Thank you for talking to me.

Teacher: You're welcome.

Interview with Yijie Sun's Classmates

Interviewees: Yijie Sun's classmates

Interviewer and writer: Puyu Zhang

Interview date: December 7, 2016

Interview place: The Sunshine Home in Shanghai

Q: How's your relationship with Yijie?

Classmate 1: Pretty good.

Classmate 2: Yes, we're good.

Q: What's she like?

C1: Pretty good.

C2: She can play Monkey King and she's good at handicrafts.

C1: Her handicraft work is super good.

C2: Most of the handicrafts in the room were made by her and our Teacher L.

C1 (She points at one piece of handicraft): This one was made by her, too.

C2: Yes, made by her mom and her.

C1 (Points at another piece of handicraft): She made this one as well.

Q (Points at a Chinese knot): How about this one?

C1: This one was made by her, too.

C2: All of these things were probably made by her, including the snake.

Q: Yijie is such versatile person and she's good at dancing too.

C2 (Asks classmate 1): She has a dancing partner, someone called D, right? (A kind classmate introduced Yijie's dancing partner.)

Q: Are you Yijie's dancing partner?

D: Yes.

Q: What's your relationship like? Do you play together often?

D: Well... We don't have free time for playing. We are too busy with studying or practicing the side drum or the flat drum. Sometimes LZ teaches us new dances, the Xinjiang Dance for example.

C3: LZ dances very well.

D: Because his mom teaches dance, his mom is our teacher. She's our drum team teacher.

Q: Did Yijie and you ever perform a pas de deux together?

D: Yes, of course.

Q: What did you dance together?

D: We danced *The Girl of Daban Town*⁸ and *Lifting Your Veil*⁹ and so on, quite a few.

Q: Do you make a good team?

D: Well... (He shakes his head) we danced in different groups. The dancers are divided into different groups, and we dance in several rows.

Q: I thought they were pas de deux?

D: Not really, only *The Girl of Daban Town* and *Lifting Your Veil* are pas de deux, but the rest are group dances.

Q: Okay, I see. Thank you.

D: Not at all.

Observation of Yijie Sun in the Drum Team

Observation date: 9:00–11:40, November 27, 2016

Observation place: Hongkou District Disabled Persons' Federation, Shanghai

Observer and writer: Puyu Zhang

Time	Content	Observed activities
9:20	The observed arrives and starts the first dance <i>Chinese Kung Fu</i> as the principal dancer, her body movements are fluid	The start time is 9:00, but Yijie Sun is 20 min late
9:23	Yijie is watching the teacher very carefully while the teacher corrects the other students' movements	
9:25	Break time	
9:35	Dancing <i>Bright Spring Day</i>	
9:45	Break time	The teacher says, she met Yijie in 2006. In the beginning, Yijie didn't move very much on the stage, but now she is transformed into a person with a good attitude, who likes singing and dancing very much
10:00	Dancing <i>Fist of Gymnastics</i>	This is a kind of martial arts gymnastics and students shout "Hey" and "Ha" during practice. But Yijie's voice is very low
10:05	Yijie says goodbye to her mother when she's leavin	
10:12	Break time	

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⁸It is a popular Uyghur folk song translated into Mandarin.

⁹Another well-known Uyghur folk song translated into Mandarin.

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Time	Content	Observed activities
10:15	Dancing <i>Seeing Off the Red Army Troops</i>	
10:22	Dancing <i>Little Apple</i>	
10:25	Dancing a part of <i>Horse Pole, Moonlight over the Lotus Pond</i> , and other dance	Yijie isn't familiar with one of the dances, and she has to follow the other dancers
10:35	After the side drum band practice, students prepare for a baking class	
10:45	Putting on face masks and gloves	
10:50	Yijie turns back to watch the volunteer while he teaches students in the other group	
10:51	The teacher shows Yijie how to roll up a bag by hand and fill it with chocolate sauce	
10:53	Stirring the chocolate sauce.	
10:55	Yijie leaves the classroom and joins the Branch League meeting	
11:03	People study the sixth Plenary Session of the 18th CPC Central Committee spirit together	
11:06		Observed sits next to the teacher who nods her head often when she's reading the newspaper
11:09		During the part of the personal statement in the meeting. Yijie says "We should love the party, love the country, care about the party and care about the work of the League Branch"
11:20	The meeting finishes	
11:35	Students stand in a queue for the freshly baked cakes	
11:40	The cakes are handed out and a picture is taken together	

Observation of Yijie Sun at the Sunshine Home

Observation date: 9:00–15:00, December 7, 2016

Observation place: The Sunshine Home in Hongkou District, Shanghai

Observer and writer: Puyu Zhang

Time	Content	Observed activities
9:09	Practicing the People's Radio Calisthenics	Yijie leads the practice
9:13	Yijie feels hot and takes off her coat after the exercise	
9:15	Practice the set-up Joint Health Exercises	
9:19	Break time	
9:21	Practice the new dance <i>The Red Star Accompanies Me to Fight</i>	The dance teacher is a parent of a student from the Sunshine Home
9:23	The teacher gives a special tutorial to Yijie and three other students	Yijie has a very good understanding and "one word to the wise is sufficient"
9:26		One of the movements is where Yijie and another girl stand facing palm to palm, to perform a circular dance. But there is always something wrong with this part, so the teacher has to stop and tell them how to do it the right way
9:30		Yijie gestures to a classmate who stands in the wrong position. She moves forward to the front of the stage a little bit
9:32		Yijie is quiet and watches while the teacher instructs the other students
9:39	Repeating the movements	
9:45	All students stand up and learn the new movement together	The new movement is mocking the monkey. Yijie demonstrates a cute monkey posture
9:49		Yijie learns the new movement very quickly and she laughs at the other students when they do something wrong
9:51		When she realizes her mistake, Yijie corrects her own foot movements by carefully watching the teacher's action
10:00		Her movements are very smooth after practice
10:01	Break time	
10:04	Rehearsals for the whole dance	
10:16	Break time	Yijie is quietly chatting with classmates while she puts her coat on and ties her shoelaces
10:24	Moving and arranging desks and chairs	
10:26	Yijie performs the monkey show for everybody	The Sunshine Home teacher says Yijie's monkey performance is very vivid
10:28		Yijie is a little bit stooped and the teacher corrects her

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Time	Content	Observed activities
10:31	Plays table tennis	Yijie is a very sophisticated performer and she can smash the ball well at the right time
10:43	Lunch time.	
10:47	The teacher helps her take out the tendon from the meat	Yijie has teeth problems and can't eat any hard food
14:00	Art class about "the secret of the color"	In the beginning, all of the students stand up and clap their hands rhythmically and say the slogan "I can do it if you can, I could do it if you could"
14:01	The teacher tells students that he'll take some stones for them for the hand drawing session next time	Yijie sorts out her paper and pencils, and actively interacts with the teacher. When lots of students ask him for some stones, the teacher jokes with them: "Who knows how big and heavy my stone bag will be next time?!" At this time, Yijie laughs and makes another joke about the teacher's words: "Piggy is doing the wife-carrying!" Her joke makes everybody laugh
14:08	From time to time, she turns back and looks at her good friend. She answers the teacher's questions enthusiastically and talks with her desk mate sometimes	
14:10	She's drawing with the teacher's guidance and replies to the teacher's question clearly	
14:11	The teacher talks about the first "secret": the weight of color	The teacher tells the students about light colors, light compared to dark colors
14:12	The teacher asks the students to draw a circle with the equipment they have	Yijie asks: "Can I use the bottle top?"
14:13	The teacher asks students to draw two circles positioned to the left and right	But Yijie draws two circles positioned up and down
14:14	Choosing the right color	Yijie borrows a color she doesn't have from her classmate
14:15	Mixing the color: students put some color pigments on the palette	
14:16	The teacher asks: "Which color is helpful to improve the lightness?"	Yijie replies "white" loudly
14:17	The teacher asks Yijie "What are you doing? Reducing the lightness?" She says yes. And the teacher tells her: "You'd better make a bright color afterwards"	The teacher's instruction is to make a lighter color but Yijie makes a less bright color
14:18	Coloring the circle with a color they just mix	Yijie colors very carefully, she paints the outer circle first and fills the inside later

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Time	Content	Observed activities
14:20		While she cleans the brush. Yijie asks her classmate: "How do you make a pink color?"
14:21	Squeezes some pigment and mixes a pink color	She murmurs to herself: "It's not enough"
14:23		She asks the teacher how to mix the right color, the teacher points out her mistake and tells her the right processes step by step
14:26	The teacher tells the students to look at the blackboard and Yijie raises her head immediately	Yijie cuts into the conversation while the teacher talks to her desk mate
14:29	She draws two colored circles up and down, then starts drawing a set of scales	Yijie gets two circles on the left and right by turning her sketchbook 90 degrees to the left
14:32	Yijie looks around at her classmates after she finishes	
14:33		She listens to the teacher keenly and nods her head. She's looking through her drawings
14:35		She shows the drawing to her teacher with a self-satisfied smile
14:37	The teacher reveals the second "secret" that color has taste	For example, red is associated with a spicy taste, green is linked to a sour taste
14:39	The teacher lets the students choose six different colors for sour, sweet, bitter, hot, salty, and plain	
14:42	Yijie names the mixed color of brown and green "bitter." The teacher asks her: "What's the taste of your color?" Yijie says: "Bitter, of course." The teacher tells her to write the word at the front of the color	Yijie isn't good at writing, she copies the words on the blackboard that were written by the teacher, but even then, she gets the words wrong
14:44	Yijie calls the color "sour" which was mixed with yellow and green	Yijie says the color she made is the color of a lemon
14:47	Yijie uses pink to represent "sweet"	When one student asks: "What's the color of sour?" Yijie replies immediately: "Lemon is sour, isn't it?"
14:49	Yijie uses red to represent "spicy"	
14:50	Yijie asks one classmate: "What's the color of salty?" The classmate says: "Soy bean sauce's color, reddish-brown." Yijie asks again: "How about plain?" The classmate says: "white, you don't need to mix it with another color"	

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Time	Content	Observed activities
14:55	Yijie shows her finished work to the teacher	The teacher comments on her work: “Well done, but it lacks imagination, you need to think about the question more openly”
15:00	The teacher sums up and announces that the class is over. All the students stand up, clap hands and repeat the slogan again	Yijie enjoys the class very much and she continues to discuss color and taste with her classmates after the class

*Translated by Huili Meng
Edited by Russell Murray*

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Great Expectations, Now that My Special Olympics Hero Got His Own Daughter



Jiaying Shen

Interview with Mr. Fangmiao Wu and His Family

Fangmiao Wu, male, born in 1988. The only child in his family. Grade IV intellectual disability. Graduated from a special school—Shanghai Yangfan School in 2007. Employed by a Sunshine Workshop in Pudong New District of Shanghai in 2009.

Interviewee: Fangmiao Wu, Guixin Wu (father), Ruiying Fang (mother), Ruicai Li (wife)

Interviewer and writer: Jiaying Shen

Interview dates: October 30 and December 17, 2016

Interview place: Wu's home

Finally Able to Walk at Seven

Q: Could you tell me, Mom and Dad, when you came to know each other and get married?

Mother: Right after we graduated from school, so it started on January 1, 1982, and we got married in 1987.

Q: Oh, 5 years, so not that quick.

Mother: Without our own house at the time, the conditions were not right for us to get married. Even when we were ready for marriage, we still had no house. Then we thought that since we had been together for a long time, why not just get married and simply live in my mom's place. Our family lived in a unit among the so-called

On July 20, 2007, after Fangmiao Wu participated in China Dragon TV's Program *Go for Special Olympics! Cheers for Heroes!* many media outlets started to address Fangmiao Wu as "My Special Olympics Hero". Related media coverage included "Touching Interactions between Fangmiao Wu, My Special Olympics Hero, and Boran Jing" at Sohu Sports and more.

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“Twenty Thousand Households.”¹ My uncle and my brother lived in the front room of the unit and we lived in the rear room. Units in “Twenty Thousand Households” were all old houses where kitchens and bathrooms were shared among every five households.

Q: What did you do for a living?

Mother: His father originally worked at Shanghai Machine Tool Works, and later he resigned because the company didn’t make much money. He resigned on December 27, 2009, and then went out to work again 10 years later; living expenses were high for us with Fangmiao Wu at that time. As for me, I worked at the state-owned No. 12 Cotton Mill, and wages were low. I have been working since retirement till now. Alas, Fangmiao Wu only makes a few hundred yuan at the Sunshine Workshop, not enough for him to raise his child, so we have to work harder. From this year onward, people like him with disabilities can receive subsistence allowances of 300 yuan a month. There’s also a child support subsidy, which is for his daughter. His wife is not a local Shanghaiese, and has not done any work before, so she has no social insurance. Now us parents from both sides are working to raise this child together. Oh, we have no other choice.

Q: After you got married, when was Fangmiao Wu born? According to a news report, Fangmiao Wu was choked with amniotic fluid?

Mother: We got married on November 7, 1987, and Fangmiao Wu was born on May 16, 1988. Yes, he was choked with amniotic fluid. Fangmiao Wu was delivered to me on May 16 after midnight at three o’clock.

Father: Delivered at 3:15.

Mother: I had no idea what to do at that time. I just felt rather uncomfortable. I thought maybe I was going to deliver the baby soon, so I sat up and called for the doctor. There were no bells at the bedside in hospital in those days, so you had to go for the doctor if anything came up. It was 3 o’clock. However, my water actually broke at 2:30, and I sat up. The doctor later said I shouldn’t have sat up. When giving me treatment, the doctor said, “Your water choked the baby.”

Wu: When I was born, my face was purple.

Q: Was intellectual disability identified in the test at first?

Mother: I had no idea then, as it was a natural birth. When I asked the doctor about the baby, he said the baby was okay. I thought things were fine then, and I was discharged from the hospital 4 days later. However, Fangmiao Wu was not discharged with me. According to the doctor, “The face of your child was red as blood, as if having drunk wine.” As a matter of fact, it was the result of being choked with amniotic fluid, but at that time we didn’t know. They said he had to be kept in

¹In 1952, in order to solve the housing problems of workers, the Shanghai government launched the project of 20,000 residential units for workers, commonly known as the “Twenty Thousand Households” project, through which 20,000 homes were built for workers in the east of Shanghai, the west of Shanghai, and on the edge of the Industrial Zone in the south of Shanghai. With a brick and wood structure, a building for this purpose usually had an upper and a lower level, with five units on each level, and it could house 10 households, with a kitchen and a toilet in the common area on each level.

the incubator for a couple of days more, but actually he spent a month in the hospital. He was not discharged until my confinement was done.

Q: Did you know that Fangmiao Wu has intellectual disability immediately after he was discharged from hospital?

Mother: We had no idea. He was just like any other newborn baby, sleeping after eating and eating after sleeping, nothing unusual. When he was 9 months old, he didn't know how to hold things, and gave no response when we taught him things. We couldn't figure out what was going on, but my sister saw something wrong, so we took him to Shanghai Medical University on Xietu Road. With help, we saw two doctors, Dr. Si and Dr. Bai. After diagnosis, they said, "Your child has cerebral palsy." What a shock. Since he was 9 months old already, the only choice we had was to help him get treatment.

Q: In the process of treatment, have you ever thought of giving up?

Father: Never, ever did it occur to me to give up. I've always had my personal confidence. Now that Fangmiao Wu has a child after getting married, I am putting this confidence in his child.

Why? I had thought about it, and I decided that we had keep his mind; as long as the brain could work, everything would be okay. My wife suggested, "How about having another one?" I said, "No, just him." When Fangmiao Wu was 9 months old, I asked my parents to take care of him. We lived in my mother-in-law's house when we got married, but in the end, life in the "Twenty Thousand Household" community was inconvenient. I moved everything over and told my mom, "Have a try and see if you can raise this child; feed him if he survives, but don't bother if he dies. I will not blame you for that. Do your best, but just do what you can." My mother said okay. When I brought him there, he was all bones, as if he wasn't eating enough. My mother prepared things like porridge to feed him. A 9-month-old is already able to eat staple food, and Fangmiao Wu ate the food bite after bite. My mother thought, alas, this baby was not very difficult to take care of! In this way, my aging mother brought him up to 7 years old, carrying him on her back or pushing him in a stroller. The stroller in the past had four wheels. Kids were supposed to sit inside. However, we had to heighten the side to keep him inside in case he fell out, since he still needed to be in it when he was over 6 years old, and he would stand up. It would be dangerous for him to fall off while standing in it, so that's why we heightened the side.

Q: According to the previous news reports, it was Fangmiao Wu's grandma who took him for treatment?

Mother: Yes, because we both had to work. My husband could not do it, because he worked on night shift. I couldn't either when working on morning shift, but I would take him to see the doctor when I was on noon or night shift. When I was working on my morning shift, I would ask my mother-in-law to take Fangmiao Wu to see the doctor.

Father: Yes. That's right. We were as wretched as those in desperate need, truly like them, when taking him to see the doctor.

It was a hard time for my mother as well. In the morning, my father and mother would take him out in the stroller to play, and sometimes they'd buy some snacks for

him. The most tiresome moments were when taking him to see the doctor, because they had to carry him on their backs and take three buses.

Mother: The hospital was on Fengxian Road.

Father: We used to live in the Puxi area. We had to first take bus No. 401, get off at the Bund for bus No. 49 to the Stadium, and then change another bus to the hospital. It took them a lot of time on the way there.² Taking him to the hospital was really hard, particularly for two old people... When my wife did not have to work, she would get up early in the morning to take him to see the doctor. We had to hold him in our arms, right? And we always expected him to get better as a human.

Two doctors from Shanghai Medical University treated him for more than 2 years, but he still walked like a horse, with his heels not leaving the ground, and forefoot and hind foot always crossing each other. The doctor tested his blood, but the results were all good. At that time Fangmiao Wu was about 4 years old. He took imported melatonin, as well as injections of imported medicines. What else could we do for him? What we were most concerned about was keeping his brain. That was the single most important thing. However, after taking injections for more than 2 years, he still could not walk, and then I began to wonder. Seeing two doctors taking blood samples from his ear, I asked what on earth was wrong with him, and the doctors said nothing was identified. What should I do about that? At that time my dad was in the Hospital Affiliated to the Second Military Medical University... for what problem? (Looking at Wu's mother)

Mother: For stroke.

Father: Right, stroke. We went there to line up in the middle of the night in order to see a specialist. I just wanted to try my luck to see what the hell was on with Fangmiao Wu. At the hospital... I heard my name called and I went in, and then a professor doctor said Fangmiao Wu had cerebral palsy. I said to him, "On what grounds do you say he has cerebral palsy? You say so without any checkup. That's it?" He said "Fine," and had Fangmiao Wu lie on the bed to examine him. After that he arranged him to have a brain CT scan.

After the test, I asked my wife to get the CT scan result the next day as I had to work. My wife took the report to the doctor, but the doctor was not there. Professor doctors like him would go somewhere else to treat patients. Anyway, my wife did not find that professor. I dialed the professor's phone number, which I got the other day, but I couldn't get through. I told my wife, "Don't worry. Just come to our factory where we have a sanitarium, pretty well equipped." Then I asked the factory doctor to read the result for us. The doctor said, "Oh whoops, looks like something's gone wrong with your son." I said, "What's gone wrong?" He said, "For your son, there's a transparent cyst on the edge of his brain."

Mother: As thin as a hair.

Father: Yes, very, very tiny. I was shocked. The doctor said, "Do not be afraid. There's a doctor named Ye at the kindergarten affiliated to our factory, who's a pediatric specialist. It is said the doctor is from Xinhua Hospital, and his teacher is

²There were no direct bus routes at that time from ChangbaiErcun, where Wu's family lived, to Fengxian Road. They had to take a number of transfers to get to the hospital.

the chief doctor of pediatric brain surgery at Xinhua Hospital, remarkably capable, so I'm going to ask him to get his teacher to help me." I said, "Great."

Then, my wife and my mother took Fangmiao Wu in their arms to see the doctor. I asked the teacher if surgery was needed. He said, "No, just take three shots daily for 1 month, one in the morning, one at noon, and one in the evening, 1 month in total." I thought my son's ass was going to be riddled with needle holes, but I had no other choice but to listen to the doctor. After a month of injections, my son would also need to take medications for another month, three times a day; that is, morning, noon, and evening. The doctor said to my son, "You should be able to walk after completing the medical treatment."

He really wore his grandma down during that period of time, who piggybacked him all the time and ran here and there. When he walked, he walked like a wild horse. We walk like this, but he walked like this (imitating the way Fangmiao Wu walked unsteadily), just crossing his steps, with no landing on the ground. What should we do with that? After treatment by the doctor from Xinhua Hospital, my mom let him walk by himself at the age of seven. He just started walking like a child, moving slowly on someone's support, then he could walk slowly with his hands on the bed frame. My mother thought to herself: this little guy can even stand up! She told us when we came back, then I became more confident, and took him to more treatment. I believed that we hit luck at last. For us, money did not matter that much, as long as the child could stand up and walk. Finally, we found a good doctor. I was really thrilled.

You see, money was... Oh never mind, and the moment my wife received her wages, all was spent on him; the moment I received my wages, all was spent on him. The two of us only spent, say, 5 yuan in total every month.

Mother: In the past our wages were very low, only a little more than 40 yuan.

Father: I started working in 1982, and my wife worked the hardest in the mill, but even so, she could only make about 200 yuan a month. You do the math. At that time, I did not make much money in the factory, and her mill at that time was running relatively well, but still 200 yuan was almost nothing. Back then all the money we got would be instantly spent on him. My mom and our sisters also helped with their money, including their monthly bonuses. In this way, total expenses, including medical fees spent on seeing private doctors and state hospital doctors, may well amount to at least over one hundred thousand yuan. One hundred thousand yuan at that time could not be compared with the same amount today.

The two of us were surely feeding off our parents. We couldn't help it, because we had no other choice. Our only expectation was for him to get better. Finally, finally, the dream came true, ha ha, finally it came true!

After Fangmiao Wu could walk, I took him to the lawn. There was a lot of grass in the garden of our community, like a lawn. He liked to play soccer when he was a child, so I bought a ball and put it in the center of the lawn. The grass was tall, so it wouldn't hurt even if he fell on it. He kicked and missed, kicked and missed. You see, his knees are not the same as those of others, and his right knee is a little bit thicker, which is the result of having fallen down too much. Again, we had no other choice. What else could we do? We also took him to the lawn of Yangpu Park, where

he would play and fall on the turf. Hey, gradually, he learned to kick. He moved very slowly, in a shaky manner, but it was good as long as he could keep his balance. Looking back, I think such forced exercises were very good for him.

Our Miao Miao Is a Smart Boy

Q: In addition to teaching him to play soccer, what else did you use for the development of his intelligence?

Father: Well, I took him out. First of all, I would take him to Xijiao Zoo where he would see animals like tigers, and I would tell him the names of the animals. Second, I would take him to see the big ships on the Bund, and tell him what these ships were like. There was a ferry dock nearby, so we would take him for ferry rides, and tell him here was Pudong and there was Puxi. I was working in the Machine Tools Works at that time, and there was a warship anchored at Wusongkou, just over there from the end of our plant's banner. I would tell him, "Daddy is going to take you over to have a look," and take him to check what the warship was like. Wherever I went, I always took him with me and talked with him about what he saw along the way. I wanted him to remember what he saw. That was before he began his schooling. Why did I talk about these things at that time? I tried my best to make him understand. I just wanted him to know what it was the moment he saw something. Generally, he could understand after I told him a couple of times, pretty smart. He could not run very far, and of course he could not run faster than those who had healthy limbs. He was inclined to play by himself at home, and sometimes did some writing.

Q: In addition to playing soccer, what else did he like to play when he was young?

Father: Just like other kids, he would play this or that for a while, nothing special, but basketball was his favorite. He also liked to bounce the basketball.

Mother: It was not easy for him to walk. Our kid had no particular hobbies. Why? Because he started to walk rather late and could not even walk very far at that age.

Wu: At that time my family lived on the first floor, and I just played outside.

Father: He could not walk far. When we saw other children playing outside, we would ask them to play with Fangmiao Wu for a while. At that time, he had just learned to walk. Many of our neighbors watched him grow up. They would tell their children not to touch Fangmiao Wu, as he was a kid brought up with money (laughing)... "This kid was raised with money," really funny. Then the other children became afraid of playing with him, worried that they might hurt him. Yet Fangmiao Wu loved to play with others. He felt bored staying at home all alone and preferred to go out and play with others. After I came back home, his grandparents would take him out and let him eat whatever he wanted to eat. It didn't matter much to be poor, as long as the child was happy, healthy, and smart. The rest is not important.

Wu: I liked to play with girls and didn't like playing with boys. Boys would bully me, but girls wouldn't.

Q: What games did you play with them? Hide and seek?

Wu: Playing cards and soccer.

Mother: Basketball, soccer. When he just started schooling, he could not even walk steadily.

Father: The school was afraid of accepting such a student who could barely keep his balance, and teachers were worried that something might happen to him, right? They rejected Fangmiao Wu at registration, saying that he could not study there. My mother and I were not convinced, so I argued, “Why can’t he study just because you say so? You must give him a place to study.” My mom went to the Education Bureau of Yangpu District. Fools cannot go to school—my mom knew it as well, but the problem was: since Fangmiao Wu’s brain was working perfectly, how come he was denied schooling? Now they saw our child walk a bit ruggedly for sure, but his brain was good. Then the Education Bureau gave the school a call and let him go there for education.

We went to the school to register him again, but when we got there, a teacher again said that Fangmiao Wu could not register. Then another teacher ran out and asked, “Which child could not register?” After sizing up Fangmiao Wu, he said that he could register, as the Education Bureau of Yangpu District said so. Well, finally he got registered. I believe Fangmiao Wu was quite smart. He had never gone to day care or kindergarten, and he didn’t even know what a test was. He had no idea about it, right? Yet step by step, he would learn, and I think our child would be like this. Now that his brain was saved, he was a smart kid, too, right?

Q: Which school did you go to?

Wu: I started at a special school. At school, we just studied some simple Chinese and arithmetic. *Pinyin* was also offered there. The level of learning was not the same as schools for normal kids.

Father: To put it this way, for the textbook of first grade, they would just teach half of it at special school. The progress was very, very slow.

Wu: Even less than half. The progress was truly slow.

Q: If Fangmiao Wu believed it was slow, it meant he had mastered the knowledge. (All laughing) What were other students like?

Wu: I was physically disabled, while they were intellectually disabled. That’s why I believed I did not belong there, but schools for normal kids wouldn’t accept me, afraid that I might cause trouble for them.

Father: Other kids indeed had low IQ. You went there simply because there was no other way, and you had to study at some place. Fangmiao Wu could not walk well, so he couldn’t go to a school too far away, but his brain was good. The school he went to was Changbai Yicun Elementary School.

Q: As a student in the special class at the school, did he learn together with normal kids?

Wu: There were three classes for normal kids, and we were placed in the same building with them, for 5 years. We had PE class together with the normal kids, and usually we wouldn’t fight if we were put together. Even if there was a fight, it was a very small probability. Anyway, I did not see any, and I was very cheerful. On the other hand, when someone saw me like this, certainly there would be something on his mind, and they choose to avoid me. I would not provoke others.

Q: Then how come you went to Yangfan School later on?

Wu: Our special school was run by the Education Bureau of Yangpu District, in a very small school building, so if there were too many students there, you would be

assigned to a general school where there were three special classes. I was assigned to one special class at Changbai Yicun Elementary School. We merged into the main campus of Yangfan School located in Yanji Wucun after we had finished the fifth grade.

Q: Your classmates and you stayed in the same class from elementary school to junior high school, right? Did you have any good friends? Did you have any outings in spring or fall?

Wu: Yes. As for good friends... how to put it, generally speaking, there were a few on good terms with me. Every year we had outings in spring and fall just like normal students; we had activities in both spring and fall, and usually we went to the park, like safari zoo, and we went to some places far away, like the American Dream Park in Nanhui.

Q: Did you go to school by yourself, or did your parents take you there?

Wu: I was taken to school from the beginning of elementary school till Grade 5. Sometimes by my granny, sometimes by my mom. I came back home for lunch at noon. For most people, it took about a quarter of an hour, but it would take me 20–30 min to stagger back.

Father: Yes, he came back for lunch at noon, and if he had class in the afternoon, we would take him back. So we walked back and forth.

Mother: There was quite a distance to the school at that time. The school was located in Yanji Wucun on Dunhua Road, but we lived in Changbai Ercun.

Q: When did you learn to dress yourself and brush your teeth? Could you do housework?

Wu: In my teens. I remember I learned to dress myself in my teens. I could do some simple housework, like cooking and making snacks.

Mother: He could wash dishes, and at school, they were taught how to cook and how to make snacks.

Wu: Simple tasks like using the sewing machine, ironing clothes, I could handle.

Q: Oh, how long had Yanfan School been in operation?

Wu: It had been in operation for more than 20 years, and it had been there since I was born, but it was relocated three times. It was a one-stop school, with nine grades in total. After finishing all grades, you could continue at a vocational school if you wanted to, where you were supposed to learn with normal students. If you didn't want to go to the vocational school, you had to find your own way to support yourself. In addition to the hands-on classes of labor skills in the school, language, arithmetic, and computer courses were also offered.

Father: When he just started schooling, a pen to him was heavy as hell. It's not heavy literally, but he used too much effort in using it. When he was writing, he would like to bite his hand to stop it from shaking. Oh, my, there was even a cyst³ on his hand. Actually, he used so much force that even the pencil lead would be broken, so I had to sharpen it for him again. When writing exhausted him, he would hold on to it with his sleeve between his teeth, so slowly and slowly he learned to write. It saddened me when I watched this poor guy writing like that, but I had to harden my

³Fangmiao Wu wrote with so much force that cysts formed on his fingers.

heart and let him complete his homework. He had to learn to write, anyway. Later on, it was just fine.

Mother: That was in grade one.

Q: After you came back home from school, did you need your parents to help you with your homework? Dad said he had to watch over your writing.

Wu: (Laughing) Tutoring was not needed.

Father: After he learned how to write, I would let him do his own homework. We had free time only at night, because we had work to do. After cooking and preparing, granny would call him, "Miao Miao, come for dinner." Then we would sit down to eat. After dinner, she would ask him, "What else do you need to do?" Generally, nothing, after homework was done.

Mother: They had very little homework, and basically it was done in the classroom. When he came back, there were only some words to be written from memory. Copying the words the first day, and writing out of memory the second day. That's where we came in. Nothing else except that. At that time, he had never attended any elementary school, never learned how to write, and we had no idea how to teach him to write, so he could only learn by himself.

Q: Were there any differences between you and your wife's policy about Fangmiao Wu's education?

Mother: (Laughing) We did not have any education policy; Fangmiao Wu just learned everything by himself, his own way.

Q: Were the classes offered on the basis of intelligence levels? What was Fangmiao Wu's favorite course?

Wu: Yes. Everyone's intelligence level was different, but we were mixed in one class, and classes were divided according to age. I loved PE the best.

Q: Oh, really. Speaking of sports, when did Fangmiao Wu start playing basketball?

Mother: When he started elementary school. In fact, when he was a child, he showed interest in basketball and soccer, although he would stumble as he walked at that time.

Father: When he played soccer, he kicked and missed, kicked and missed, and his pants got ripped when he walked and stumbled, so we bought some flower-pattern patches and stuck them on, always on the knees of his pants. No one would care much about the flower patterns, since he was only a kid.

I would be with him all along whenever he went to play basketball or soccer, even when he played basketball at the Machine Tool Works. He loved playing basketball, so we went to my factory. I got two co-workers to play with him, not a bad idea. When he first started school, we did not allow him to have PE class. Why? He was pretty frightening like that, so the teacher did not let him have PE class, either. However, this kid loved basketball so much that he always bounced the ball at one side when others had the class. The PE teacher would tell him, "Take your time bouncing the ball, just don't run." I could not watch over him because I was working.

Q: Between soccer and basketball, why did Fangmiao Wu choose the latter?

Wu: Because it was easier for me. Basketball shooting only requires the use of hands. You don't need to use your feet to kick. I began to like it when I was in Grade one or two. For basketball training, well, I just stayed after school for it. There were

PE teachers taking care of the training. From Monday through Thursday, he would stay and train us for an hour every day. On our team, all had good hands and feet but me, but their minds didn't work very well. I was not very good at using my hands, but had no problem with my mind, so I played guard. Besides playing basketball, I also played soccer, as a goalkeeper. I couldn't run well, but I could be the goalkeeper. My classmates were just the opposite. They had no difficulty running, but had a hard time kicking.

Father: Our Miao Miao was quite smart. His teachers were very nice to him, and took good care of him. Even now we are still in touch, with that music teacher who is still teaching at the school.

Wu: I liked my class teacher, and he's also our music teacher. The PE teacher was also not bad.

Q: Was your class teacher the one at Changbai Yicun or at Yangfan School?

Wu: He was the class teacher after I was transferred to Yangfan, Mr. Bin Gu, a music teacher, and he was the teacher whom I contacted a lot. From elementary school till graduation from junior high school, he was my favorite teacher, and he was kind of like a friend. Some children did not like to speak, but I like talking a lot, and I liked to watch national events, news, and I like to communicate with people about these. Sometimes when I encountered difficulties, like difficulties in life, whatever kind of difficulties, I would like to go to him for a chat, then he would share his ideas with me. When I was in Changbai Yicun Elementary School, I liked my Chinese language teacher, who was also my class teacher. As an active boy in class, unlike those reticent students who did not like to speak, I was eager to communicate with teachers, and teachers also liked to communicate with me.

As for the PE teacher, I began to know him in my junior high school. We had PE class all the way from elementary school to junior high school. In the beginning my body was not ready for PE, so I did not start my PE until I was in junior high school. In the beginning, as my father said, I was put aside when they had PE, and two classmates were dispatched to take care of me, and we would chat and play together. Although their minds were not good, their hands and feet were good, so physically speaking, they took good care of me. As I was more mentally active, I would help them with schoolwork. One good turn deserves another, right? For example, if they could not solve their math problems, I would explain very, very slowly to them, step by step. I couldn't have been slower. I did it very slowly so that they could understand.

Mother: His PE teacher has received media interviews and appeared on TV as well.

Wu: Yes, they interviewed him about me. His name is Wei Wu. He appeared on TV after I became famous.

Father: His PE teacher took good care of him. I can't remember when he said he would go to play basketball games in Harbin. When I heard this, I thought: "What? You are going to play games?" Later on came the World Special Olympics, and someone recruited him [shooting promos], oh my, a lot of things. I told him, "Handle and settle everything on your own, just the way you like."

One day Fangmiao Wu said to me, "Daddy, I'm going out for a run." I asked, "How could you run?" He said he would just go jogging. We lived in Changbai Ercun,

where you could jog around slowly in the community, so I thought it was okay for him to jog. If he could not even walk stably, how could he have PE class? Later on, after he could walk more steadily, we would allow him to do what he liked: “You can do whatever you like, but you are old enough to know how to protect yourself, and you can’t always stumble your way. It wouldn’t matter if you just bounced the ball. Just enjoy yourself.”

The “Hiding” Special Olympics Ambassador

Q: When did you first hear of Special Olympics?

Wu: I heard about it earlier than my parents, because we had our Special Olympics at school. I learned about it maybe in the sixth grade, and I wanted to participate the first time I heard of it, because I had a goal of participating in sports games. Our school participated in the 2005 Shanghai Special Olympics, and we won the championship. We were chosen to represent Shanghai in the 2006 National Special Olympics, just one level up after another.

Father: Fangmiao Wu also shot a promotional film, before the foreigners came to plan the Special Olympics opening ceremony.

Wu: It was a public service promo, and it was the product of a Sino–US cooperation, by an American director and a Chinese director. Although the shooting was very tiresome, I had a great time, because I could let people know about the people with ID.

Father: The advertising agency came to their school, for a visit... but he was timid, so the advertising company asked the PE teacher to get him to the office and asked him if there were any barriers in our home. Fangmiao Wu said no. The agent then asked if it would be okay to visit our home. He said yes very readily, and gave the phone number to the agent. So the advertising agency came to our home, shooting film and asking questions. This ad was shot before the opening ceremony of Special Olympics as public promo. At that time, all bus stops were displaying his promo, in which there was a motto written on his hand: Come on, Kids!

Q: Why were you chosen for the promo?

Wu: (Laughing) I was a little bit more active, and my mind was better than the other students; when they came to select the actor, they talked to every kid. My performance was more impressive, so I was chosen.

Father: After the promo, he was invited to Beijing to attend a press conference for Chinese and foreign journalists, and Ming Yao went there, too.

Wu: There were a lot of celebrities.

Father: Ming Yao gave him a basketball as a gift, which he held dearly as a priceless treasure. (Picking the basketball up off the living room display shelf and showing it.) You see, there is an autograph on it (see Fig. 1).

Wu: I never played with it after taking it back, and it’s too soft, anyway.

Father: There are a lot of photos here, Ming Yao, Xiang Liu, and Hong Kong celebrity David Wu, all autographed for him. And Yu Lu as well. This is the Special Olympics opening ceremony; this is “A Date with Yu Lu” after the Special Olympics; this is the autograph from the Hong Kong celebrity David Wu; this is his wedding photo, and this is his wife and child... (showing photos).



Fig. 1 Fangmiao Wu and NBA player, Ming Yao, 2006

Q: Wow, really nice. Just now we talked about going to Beijing to attend the press conference. Any details?

Father: Ah, there were the foreign journalists for the international press conference as well... could you recall any? (To Fangmiao Wu) Media included China Youth Daily and... really too many, all around him, interviewing him. At that time, we had not moved over here yet, we were still living on Jiamusi Road, Yangpu District. One group after another came to interview us. Shanghai TV came most frequently, and Dragon TV too. Shanghai TV formed a special team, specifically trained to follow Fangmiao Wu, and HKSTV was following him, too. HKSTV was the first media to follow him, as early as 2006 when he went to Harbin [to participate in the National Special Olympics].

Wu: As I went to Harbin on the 28th, just after the press conference (for the promotional film) on the 21st, HKSTV began to follow me. At that time the leaders from the Shanghai Federation of Disabled People met with us athletes, a delegation of 54 people, in Harbin. When I got off the plane, our leader told the TV reporters that this was Fangmiao Wu.

Father: With cameras in position, shooting began as soon as Fangmiao Wu turned back. They followed him to Harbin, and then followed him back.

Wu: After the Games they also sent reporters over for a home interview.

Questions: Of all the athletes, why did they single you out to follow?

Wu: Because I was the ambassador. I was chosen as the Special Olympics Ambassador after the promo was released in July 2006.

Q: Oh, how were you chosen to attend the opening ceremony of the 2007 Special Olympics?

Wu: When they came to pick performers for the opening ceremony of the 2007 Special Olympics, our school first recommended us, who had been to the Games, to those directors, but at that time I was a little afraid. So I went hiding in the washroom before it was my turn. Finally, I was pulled out by my classmates, and then they saw me.

Father: After the promo, whenever he went out jogging, people would know his name. When the Americans came to pick performers for Special Olympics, he was chosen. That day the Americans came to their school and picked Fangmiao Wu, and when they watched the promo at night, they said, "Oh, this guy is Fangmiao Wu, nicely shot." After a week, a phone call came for him, inviting him on a business trip. I began to wonder where such a young kid could go for a business trip, but then realized there was a team to go with him. We gave him permission to travel to Shaolin Temple in Henan, to climb on top of a "great wall," which was a wall made up of students from the martial arts school who were connected with each other through rods. I thought it was very good, and when this kid came back telling me this, I asked him if he had confidence, he said yes.

To walk well down the road, he had to have confidence first. Oh my, too many reporters came to my home for interviews at that time. Oh, he was really involved in so many activities back then, and as parents, we had no choice but to accompany him. Fangmiao Wu asked me, "Dad, what requests do you have?" I said I had no requests but a piece of proof, which I could use to ask for leave from work. Then they gave me a piece of proof, with a seal mark stamped on it. I took it to my factory and I was good to go on leave. As long as my son needed company I stayed with him, anytime, anywhere. That's the way it was. I thought that it was important to my kid, and Special Olympics was a very good opportunity for him to develop his abilities.

Q: I see. At the opening ceremony of Special Olympics, what was "the Great Wall" in particular?

Wu: It was a wall built with people. I have a film here, so let me show you.

Father: (Taking out a document portfolio) Here. Everything in this portfolio belongs to Fangmiao Wu, including the previous interview records and certificates he received. I put everything of his in a safe place. This is Fangmiao Wu visiting the local zoo when he went to Harbin... Oh, Fangmiao Wu has a good collection of stuff.

(Playing the video of opening ceremony of 2007 Special Olympics.)

Father: They were training really hard at that time.

Wu: There were four of us performing, two men and two women, in Team A and Team B, or a main team and a substitute team. It was made very clear that only one man and one woman would be finally up there on the stage at the opening ceremony, and the choice would be made based on performance during training. Therefore, I trained extremely hard.

Father: Once Shanghai TV came to interview him, and he was so tired after he went back that he fell off the “wall” in a training session. He got sunstroke, no joke, because it was outdoors. Oh, that was really funny, so we had to take him back and he rested for a couple of days before going back.

Q: You made it to the opening ceremony of Special Olympics with your own effort. Did your parents come to watch the ceremony? Was there anything particularly impressive while watching, uncle and auntie?

Wu: They didn’t go to the one in Harbin, but they did go to the Shanghai Special Olympics.

Father: My impression... we went there to cheer him on, looking down from the second floor, to cheer Fangmiao Wu. When we watched the training videos, we were sure everything would go well, but when it was your turn, we felt a little panicked, because so many people were watching you. That made us feel a little panicked. The performance in the video seemed pretty good, but when you performed live, there were some small errors.

Wu: I was a little bit nervous.

Father: I went to the opening ceremony, but I did not watch the games or the training. I had to work, and there was no way to get away from it. I didn’t go until I got the ticket.

Wu: I went to the training myself.

Father: Yes, I asked him to go there himself, and there was a car to take him back. I thought if you could go and come back by yourself, then I wouldn’t need to worry any more.

Q: Did Mom and Granny go to watch his games?

Father: Granny didn’t go, but Mom did, taking transit with a transportation card. It was the all-purpose card given by the Organizing Committee for Special Olympics. They could use it when going to the games. Oh, speaking of this all-purpose card, its balance ran out after only a few days, very fast.

Wu: There was a lot of money deposited on it, 1,500 yuan actually.

Father: After watching the games, they would go to his auntie’s house in Meilong. Round-trip taxi rides cost a lot of money. And then they would take a taxi to People’s Square, so the money on the card went very fast. When I finally settled the account, I had to give extra money to them, but I was willing to pay out of my own pocket, as long as Fangmiao Wu was happy and performed well.

The American director also took you to the park, and you tried something that went up and down. What is it called? (Looking at Fangmiao Wu)

Wu: After the opening ceremony, they were going back. On the last day before they went back, they took me to the park. I played turbo drop there, just near Jinjiang Amusement Park.

Q: Besides being the ambassador, did Fangmiao Wu do any other job at Special Olympics?

Wu: No. In 2007 I only attended the opening ceremony, but did not play in the games.

Q: Were the basketball games at Special Olympics different from the general type of basketball games? In addition to basketball, what other sports do you like?

Wu: There were differences. Our basketball games were divided into two categories, one for groups, the other for individuals. For groups it was five vs. five, and the time was shorter. For general games, a quarter is 12 min, but we had 24 min in total split into two halves. Besides basketball, I also like soccer. Actually, I like all kinds of sports.

Father: After he came back, when Special Olympics were over... when was that? (Looking at Fangmiao Wu)

Wu: October 2, 2007.

Father: After coming back, Shanghai TV called us, asking him to record a program. I told him to go by himself and raise requests, if any, beforehand. Although as a parent, I had many of my own ideas, I should not intervene. Let the kid go to put forward his own requests.

Three Generations with a Promising Future

Q: Were there any changes to your family after Special Olympics?

Father: As for changes, we were elected “Family of... something” after Special Olympics... and appeared on Dragon TV, and the trophy is still there. Let me show you. It’s pretty heavy.

(Showing the trophy off the showcase.)

It says “2007 Figure of True Love,” once there was a program on this, and Fangmiao Wu was in it. He was interviewed by Dragon TV.

Q: Have you found any change in Fangmiao Wu? For example, communication skills.

Father: As far as communication skills are concerned, I have always told him, you’d better communicate more with the normal kids and have fun together. But if there are more than three normal kids staying together, do not bother them. Why? I was concerned about his safety, so do not disturb a group with more than three kids in it. Communicate as much as you can within your own group, but avoid going out of your group if possible and do not chat beyond your limits. If something really happens, it won’t be easy to hold someone accountable for that. When I said this to him, he commented, “Daddy I know.” I also told him that it would be fine to communicate with people in your own circle, but you’d better not do so with people outside your circle, because you might have no idea if they are good people or bad people.

As for athletic skills, now that he has a child, and he also needs to work, his athletic skills have regressed a lot compared with before, honestly.

After the International Special Olympics, he thought there was nothing for him to do any more, so he needed to look for a job, as he was already 18 years old. We began to talk with him about a job, and he had to find a job to make a living. There was no point staying at home and “living off government money,” and how could he stay at home every day, doing nothing at all?

There were twists and turns in his job hunt, and Fangmiao Wu could not find a proper job in Yangpu. Just at that time we were to be relocated to a new home. My son said, “Dad, let’s move to Pudong.” I asked him if he was sure of the idea, and he said yes. So we packed everything and moved here. Now the head of this

household is Fangmiao Wu. Life couldn't have been more enjoyable for him. After all decorations were finished, we moved in. He began to look for a job again. My opinion is that no matter how much he could earn, it would be okay as long as the workload was light, he was happy about it, and there was a retirement pension plan. I need to be realistic about what my kid could handle, so I said to him, it would be okay as long as it can give you a pension plan.

Wu: It depends on ability, that is, I could make as much money as my ability allows me.

Father: You have to measure your ability. Frankly speaking, after his mother and I retired, I have continued to work very hard, and my wife has also been working as a traffic coordinator, so we both are still working. After our daughter-in-law had a baby, she takes care of the baby full time, so she does not work. But it takes money to feed a baby. My mother has a medical insurance and retirement pension, my wife also has a job, plus my salary, so we definitely can provide financial assistance to Fangmiao Wu's family of three. The most important thing is we live happily together. We are happy, with the whole family's attention focusing on his daughter. We do everything for our little baby, and she is also the youngest generation of this family.

(At this moment the child ran out, and everyone teased her.)

Q: Where is Fangmiao Wu working now?

Mother: Sunshine Workshop.

Wu: We sort out the soap instruction sheets here, taking the sheets out one by one and inserting them into soap boxes. I think this job is very easy for me. On the one hand, I can subsidize the family; on the other hand, I have time to take care of my family. We only have one morning shift and one afternoon shift. Generally speaking, morning hours are 9 to 11 a.m., and afternoon hours are 2 to 4 p.m. I can come back home at noon for lunch, since the workshop is just across the street. I can go back home to take care of my child at noon. It's very good.

Q: Are there any other Sunshine Workshops in Shanghai?

Wu: There's one in every community.

Father: There is a Sunshine Workshop in every community, and the only difference is that some offer better benefits while some do not. In a word, more money or less money.

Wu: No, one is "Sunshine Home" and the other is "Sunshine Workshop." These two are different, and the benefits they offer are also not the same. Sunshine Home does not pay for employees' insurance or pension, while Sunshine Workshop does. Sunshine Home is not the same as ours, and I don't know what they do there.

Father: At Sunshine Home, a bunch of people with "low IQs" are put together, and the community takes care of them for you. But for people like Fangmiao Wu, they go to Sunshine Workshop, a place of work. He was not so deft when he just went there, so day by day they told him how to do it again and again, and when they thought he was capable of working by himself, they just let him do it. Now he can work.

Wu: The money I make at Sunshine Workshop is extra money on top of subsistence allowances... (my work is) counting, that is, counting the number of instruction sheets, counting how many of them I sort out every day.

Father: That is his work results. For example, if he wants to make 50 yuan today, he has to turn in stuff worth 50 yuan, and if it is not enough, the money will be deducted.

Wu: No deductions actually. We make less than 3,000 yuan in total, but after deduction of the pension, three insurances and the housing fund, I only receive less than 1,500 net.

Q: After Special Olympics in 2007, did the Shanghai government give you any additional subsidies?

Wu: No. After Special Olympics, I rested for a year.

Father: Did you have summer vacation in your school?

Wu: On hot days, we couldn't go to school if it was above 35 °C. After Special Olympics, we were relocated here.

Father: Before coming here, we lived in Changbai Ercun, Yangpu District, in a decrepit house.

Q: How are you getting along with your colleagues now? Any good friends?

Wu: I get along with my colleagues very well, and I have good friends. Sometimes a phone call between us every day, to discuss where to meet and go to work together.

Father: Waiting for him... those two go to work together. They work very hard, waking up at 6:30 or 5:30 in the morning. His daughter would make noises around that time so he cannot sleep any longer.

Q: Do you have to take care of your child late into night after you come back from work? For example, to dress her?

Father: Even if Fangmiao Wu really wants to hold the baby, I would not allow him to do so, because his hands and feet are not reliable. I'm worried that he would drop her. When I don't have to work, most of the time it's me who takes care of her. If the weather is good, I would take her out for a walk in the park in our neighborhood. I like to let her walk more.

Q: When was the first time that Fangmiao Wu received his salary? What did he do with the money?

Wu: Let me tell you, my first pot of gold is this (pointing to atrophy). I got 10,000 yuan.

Father: This one?

Wu: Yes, this trophy, and I was given this much money after the award ceremony. The first thing for me was to buy a cellphone with the money, and then I deposited the rest in the bank.

Q: What did you do on weekends before you had the baby? Still play basketball?

Wu: I'd watch TV. I stopped playing basketball after we moved here. Previously when we lived in Puxi, I did play. My age is going up, but my stamina's going down. Normally we would go to my cousin's place. My aunt is very nice.

Q: When it comes to family, when did you and your wife start the relationship?

Wu: Oh, it started in 2015.

Wife: No, obviously it was in 2014, the end of March 2014.

Wu: Oh yes. We met online, as I usually played games, mainly QQ games. However, I didn't meet her while playing games. We met on Momo instead. I knew her at the end of March, and one day when we were chatting, I invited her to come to

Shanghai as my birthday was on May 16th. She was from Hunan by origin, so she came, and has stayed at my place ever since. She doesn't have a job, so she just stays at home. After we got married, we had our baby on July 30, 2015. At the childbirth, we were a little worried that there might have been genetic influence.

Father: Nothing to worry about, as you have your family behind you.

Wu: I was worried that my conditions would be passed down to the baby. I asked an expert later, according to whom cerebral palsy would not be passed to the next generation, and then I was assured.

Q: Does your wife think that your conditions cause some inconvenience in life?

Wu (Looking at his wife): Do you think so?

Father (Waving to daughter-in-law): Come here, come and share something with the reporter. I can tell you that my daughter-in-law is now very happy in our home.

Wife (Came over and sat down): Inconveniences? I don't think so, and everything's good.

Q: What did you do before you came here from your hometown?

Wife: I did not work in my hometown. I stayed out of town all alone. I wandered everywhere, used to work in Zhongshan, Shenzhen, Zhuhai, and Guangzhou, doing everything.

Wu: She does cooking and embroidery and almost everything.

Wife: After I met him in Shanghai, I've stayed here, but not working. Oh no, I worked as a subway security inspector for a month.

Wu: We helped her find a job as subway security inspector, but she quit after she got pregnant.

Wife: That was just a few months after I came here. I started working there between September and October 2014, as a security inspector for Metro Line 12. After a month, I found I was pregnant, so I stopped working. I got pregnant in October, and by the end of October I didn't work any longer. After getting pregnant, I just did grocery shopping and cooking every day at home.

Q: When you decided to get married, what in Fangmiao Wu attracted you?

Wife: After all, I am 2 years older than him, and at that time I thought it was time for me to get married. Also, my parents-in-law were very nice to me, so I thought it did not matter much how he looked like; anyway, about life, I am not so picky. I thought he was a very nice guy, so I agreed to get married. We got the marriage certificate first, and after half a month I found I was pregnant (see Fig. 2).

Mother: The child is super smart now, only 15 months old.

Q: Yes. What is her name?

Wife: Yuhan Wu, Yu meaning "rain," and the character "Han" having a grass radical in it.

Q: I think she will play basketball later. She looks very agile. Do you have any expectations in life now?

Wu: Just nurturing the child well. (Others echoed) We two will do our best to raise her.

Father: My ears are not good, so for this interview I have specifically put on a hearing aid.

Q: What's wrong with your ears?



Fig. 2 Fangmiao Wu and his family, 2015

Father: I got otitis media in my childhood, had three major surgeries since I was six. The inside of my ears has festered away, causing perforation in both ears, and nothing can be done about it. Just then, our factory was running a disability check, so I stuck my forehead out,⁴ and I was lucky. I showed to them the doctor's diagnosis on my medical record from when I was a 6-year-old. They had a review and identified me as level 2 disabled.

I retired after I turned 50 years old. When I just retired, my monthly income was 1,700 yuan. Since then, my retirement pension has kept increasing all the time with those eligible, and now I am also considered as a member of the retired. I am working part time now in the field of property management, and it doesn't matter if the money is not so good, as long as our family can be better. Taking into account the whole family, I wouldn't mind if life was harder for me. Most importantly, Miao Miao and his wife can have enough to support themselves. As for their child, we'll do everything for her. That's why I go to work early and come back late. I get up at five o'clock, but will not come home until 10:30 p.m.

Q: Are you still working like this now? Why do you work for such a long time?

Father: Yes, right now. Currently, I work every other day as a security guard in a different community. I do not work on night shifts, only on middle shifts, but there is no subsidy for middle shifts.

Wu: That is, one early shift and one middle shift, 16 h in total, 8 h per shift.

Father: Usually people work for 8 h a day. I'm now working one day for 16 h and taking a break the next day, so it's still like I work 8 h per day. Little money, hard

⁴Have one's forehead stick out: colloquialism in Shanghaiese, meaning "to try one's luck."

work, but I don't mind as long as the family's happy and I can support them with some money, or you tell me what I could do otherwise. You agree with me, right? It is most important to be happy. Fangmiao Wu had a poor childhood, but now he's doing well.

I think most of the credit goes to his grandma. Because most of the time it was her who took Fangmiao Wu to the doctors, carrying him on her back, taking Bus 401. Before that we took the "caravan"⁵ in front of our factory, then transferred to Bus 401 to the Bund, then changed to Bus 49. Oh, the bus was really packed like sardines, with so many people commuting at rush hour. We both had to work. I said to my mom, "Mom, all credit to you, I know it's really hard." I had thought that if my child was born healthy, I would nurture him well, and when he grew up I would send him to serve in the army, which seemed to be very good. However, my dream was shattered after Fangmiao Wu was born. Such an idea became unrealistic.

Wu: We still have the next generation.

Oh, it's hard to tell for this generation. Our granddaughter is super smart, and all I'm thinking now is making money for her. We'd like to send her to get an education when she's 2 years old, starting a collective life early. That's what's on my mind. Otherwise if you suddenly put her into a nursery or kindergarten when it's time for her to go there, it would be too hard for her. After 3 or 4 days, she would be crying, which would make my heart break, and I would take her back. That would definitely make my heart break. Therefore, to take advantage of the moment when she doesn't know much, we have to throw her into a collective life, so that she can adapt to that way of life before she knows it.

Our child is very smart, as I have been watching her. There are a lot of children upstairs and downstairs, but whoever sees her says that the child is smart, incredibly smart, even giving her a nickname "Smartie." Why? When someone calls my granddaughter, she would always give them a serious face, no smile at all. When they offer her something to eat, she would not touch it at all. But when at home, if asked, "Where are Grandpa's socks and slippers?" she will know (and get them for me) without being told twice. Oh, this kid understands so many things. The child next door is 2 months younger than ours.

Wu: 20 days younger.

Father: That one is not as smart. I have brought up four children: my nephew, my niece, Fangmiao Wu, and my granddaughter. My granddaughter is the "last empress." The most difficult to take care of was Fangmiao Wu; the second most difficult to take care of was my brother's child; the best was the eldest, that's my nephew; and then the second best down the line is my granddaughter. In our family, they have kept saying that this little granddaughter is growing up in her grandpa's arms. I truly love her. I already said to Fangmiao Wu, "You have to put up with me and understand your old man even if I am not being sensible sometimes. I am working very hard and

⁵Caravan: an articulated bus, usually twice as long as an ordinary bus, with a black rubber connection between its two cars, which bends when the bus turns. In order to accommodate more passengers, most of the seats on the articulated car are removed. Shanghainese usually call it a "caravan." In 2004, the last articulated bus on bus route 124 stopped service.

doing a lot of things, so if there are some chores at home, just handle them yourselves and don't expect me to do everything for you, right?" At the same time, I promise that I will take care of this child until I die, and I have to do so because my son's hands and feet are not good enough to hold her. I am a man of my word. What can we do with the money we have made? Why am I working again instead of resting at home after retirement? I'm doing everything for the next generation, right? You have to create good conditions for the next generation to make them happy. Oh, I cannot afford a house though. I won't be able to make so much money.

Wu: The poor change their life through the government's relocation program.

Father: No matter how you change, the problem is: can you really change your life? If you can, great; but if you can't, there is nothing else to say. The house we are living in is not bad, three bedrooms and one living room, although we tried to restructure it into two bedrooms and two living rooms for him. We didn't expect him to get married so early. Then so be it, and we aborted the plan. Let's not worry about other things as long as we are happy. We are happy to be Grandpa and Grandma, and happy to become old. Nothing is more important than happiness.

Q: Finally, I have a few other questions, one of which is: In what ways do you think Special Olympics can be better?

Wu: I think... in fact, I think people with intellectual disabilities should be given more opportunities to participate.

Q: What do you think of the Shanghai government's subsidies for people with intellectual disabilities?

Wife: It's all right, but it would be better if it could be higher.

Wu: No, no, my expectation is not too high, because everything depends on my personal ability. If there is 5,000 yuan in front of you, you have to have the ability to do the work. Now I am making a salary of 1,500 yuan a month, plus the Shanghai government's subsidy for my child.

Wife: It is not enough to feed our child in a family of three with a household income of 1,500, so the government gives us a child-support subsidy of 1,000 yuan.

Mother: And there is a new low-income subsistence allowance this year, so that for child support there's actually a total of 1,300 yuan in subsidy, plus Fangmiao Wu's 1,500 yuan, altogether 2,800 yuan a month, but still not enough.

Wife: We don't pay for food and shelter here, it's all on my parents-in-law. I do not have to worry about my child's support, but I do not make money because I'm not working, and I get everything from them.

Q: Okay, that's all for today's interview. I'm sorry I have disturbed you for so long time. Thank you for sharing.

Interview with Fangmiao Wu's Supervisor

Interviewee: Sunshine Workshop Supervisor

Interviewer and writer: Jiaying Shen

Interview date: December 26, 2016

Interview place: Sunshine Workshop, Shanghai

Q: When did you come to know Fangmiao Wu? What are your impressions of him?

Supervisor: I only started to work here in April this year, and Fangmiao Wu started in November 2013. Before I came here, another supervisor was responsible for everything, so I am not very clear about the situation at that time. As for me, I think he is pretty good, but I am not able to tell you anything regarding what he was like before. Although we have archived records, all the files are now sealed up, and there would be a lot of hassle if you requested a reading.

Q: Oh, I see. What do you know about the working hours and salary of Fangmiao Wu and others?

Supervisor: 1,495 yuan per month, not based on days or hours of work; as long as they attend as scheduled in a month, they get their money. They work Monday through Friday, 2 to 4 p.m. in the afternoon, and they don't have to work on weekends and holidays. If their task is finished early sometimes, or if the weather is terrible, I will let them go home early. For instance, it is raining today, and they come early, all arriving at 1:15, so I'll let them go home at 3 o'clock, in case the rain becomes worse. Yes, they are not the same as us, and they have no flexible days off. Sometimes we will work on Saturday or Sunday to rest on holidays, but they have problems with that. Even if there is a schedule switch, they don't work on weekends, and they can still take a rest on holidays.

Q: As I observed, they are grouped for work, right?

Supervisor: Yes, they are divided into four groups to fold the soap instruction sheets. Fangmiao Wu is in Team 2. The working pace is different between groups. Team 1 over there, the team sitting in the row next to Fangmiao Wu, is the fastest at folding. Fangmiao Wu's team folds the second fastest, and now only these two teams have finished folding, so their team members can go home first. The other people, who are relatively slow, will stay here for now, and after they finish, they can go back home. There is no fixed amount of work for them every day, and I haven't calculated yet, but they can fold up to four or five bundles of soap instruction sheets in one day. The workload for each team is the same, but their speed varies.

Q: Okay, what shortcomings do you think Fangmiao Wu has, if any, and what are your expectations of him?

Supervisor: No, no, Fangmiao Wu is quite good, and I don't think he has any shortcomings. He's doing very well now.

Q: Okay. Thank you for sharing.

Observation of Fangmiao Wu at the Sunshine Workshop

Observation date: 13:15–15:00, December 26, 2016

Observation place: Sunshine Workshop, Shanghai

Observer and writer: Jiaying Shen

Because of rain, Fangmiao Wu and others started work at 13:15, and went home early at 15:00 after they completed their tasks.

Time	Work observed	Remarks
13:15	Arrives at the Sunshine Workshop, sits down in his seat, ready for work	
14:00	Folds soap instruction sheets	Working very skillfully, Fangmiao Wu first folds some A4-sized soap instruction sheets vertically several times, and then presses the narrow slips to make them smooth with his fingers. Many of his colleagues like to fold one sheet at a time, while Fangmiao Wu likes to put a number of sheets in his hand and folds them all together
14:03	Folds soap instruction sheets	
14:06	Folds soap instruction sheets	Chats with colleagues, talking and laughing
14:09	Folds soap instruction sheets	Chats with colleagues, talking and laughing
14:12	Folds soap instruction sheets	Chats with colleagues, talking and laughing
14:15	Folds soap instruction sheets	
14:18	Folds soap instruction sheets	Chats with colleagues, talking and laughing
14:21	Folds soap instruction sheets	
14:51	Folds soap instruction sheets	Chats with colleagues, talking and laughing
14:25	Folds soap instruction sheets	
14:34	Folds soap instruction sheets	Chats with colleagues, talking and laughing
14:37	Folds soap instruction sheets	
14:41	Folds soap instruction sheets	
14:45	Folds soap instruction sheets	Team 1 sitting next to him has completed today's work tasks. Fangmiao Wu calmly and slowly folds the sheets in his hands, discussing with his colleagues the tour on New Year's Day

(continued)

(continued)

Time	Work observed	Remarks
14:50	Fangmiao Wu's Team 2 has also completed today's work	
14:52	Team 2 hands in the work results	Fangmiao Wu puts his folded soap instructions sheets into the storage box on the table
14:53	Off work	

*Translated by Zheng Si
Edited by Andy Boreham and Zijian Chen*

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May the Volunteers Help Her Be Included into Society



Shuwen Wang

Interview with Miss H's Parents

H, female, born in 1989. Only child. Grade IV intellectual disability. Graduated from a special school—Miyu School in June 2006. Joined the Quyang Sunshine Workshop in Hongkou District of Shanghai in July 2006.

Interviewees: H's father, H's mother

Interviewer and writer: Shuwen Wang

Interview date: November 13, 2016 and January 11, 2017

Interview place: H's home, Shanghai

Beloved Child Arrives by Natural Birth

Q: Are you Shanghai natives?

H's mother: H's dad is Shanghainese, I'm from Zhejiang Province. He's a Shanghai native, I came from Ningbo years ago and became a new Shanghainese later.

H's father: Actually my family's roots were in Zhejiang Province until my parents moved to Shanghai before the "New China," before the year of 1949, when they were young, but my siblings and I were born in Shanghai and we identify ourselves as Shanghainese.

Q: How did you get to know each other?

H's mother: I lived in Ningbo, but came to Shanghai after I graduated. A relative of mine, who lives here, worked in the clothing industry and I've worked for him since I arrived. After some years, my husband and I were introduced to each other

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by a mutual friend. We came from the same area and had a similar lifestyle, and we got married after we'd been seeing each other for around a year.

H's father: We were introduced by one of my business friends when I was a self-employed worker, she was my wife's friend as well, she thought we might be a good match.

(He's smiling) She was very pretty and gentle when she was young. We had a good feeling about each other and after a while decided to start our own family. We got married in 1988 and we had H on 24 November 1989.

H's mother: Her precise time of birth was 5.17 p.m., in the afternoon on 24 November 1989. On that day, before sunrise, I felt some pain and according to the old saying, the shorter the interval of labor pain, the closer the time of delivery. We got up and went to the Fourth People's Hospital, the baby was 2 days overdue. When we arrived, the doctor checked the dilation of my cervix and said I was ready to give birth. It was a long and painful process. I'll never forget the pain that morning.

H's father: She went to the delivery room in the morning and gave birth in the afternoon; it wasn't that long, about 10 h more or less.

H's mother: But I felt I had been in the delivery room for a very long time. My husband was told to leave by the doctor after they sent me to the delivery room, and he left.

H's father: It was our first child and we didn't have any experience with this at all. The doctor checked my identity and said: "Now she's all right but you can't come in. So leave your number with me and go back home till I call."

Q: Were you worried about your wife?

H's father: Yes, of course, but there was nothing I could do, the doctor didn't let me stay with her.

H's mother: It was an old-fashioned delivery room, there were a number of half-naked women sharing the space, so no family, especially men, were allowed to come in. The rule has changed recently, pregnant women get their own delivery room and the husbands are able to be there and support their wives.

H's father: She's right, there was more than one patient in the room, all of them were ladies and no man could go in.

H's mother: I gave birth around 5 p.m., and I was detained in the delivery area for another 2 h before the nurse sent me back to the ward. The doctor asked where my husband was because they couldn't find him. I thought he was in the doorway, but actually he'd gone back home. After 2 h under observation, a care worker came to me and gave me a big enamel cup of water to help with my digestion. I was only allowed back to the ward after I'd been able to pee.

Q: When did you return to the hospital?

H's father: I came back in the morning.

H's mother: It was the next morning.

H's father: I was waiting for the call from the hospital but didn't hear anything. I just thought my wife had there been for over a day, so I went to the hospital to check up on her, and the doctor told me when I arrived: "Your wife has given birth." For a newborn baby, it was hard to tell that anything was wrong with her, right?

H's mother: Actually, the birth wasn't difficult, it was natural and both the baby and I were fine. Just before the birth, I was sick and vomited my breakfast, longan soup—pushing for the baby upset my stomach. I was on my own and scared, the only thing I could do was follow the doctor's orders. Old people like to say, giving birth is a high-risk thing, like putting one foot in a coffin; some people hemorrhage and die, I was frightened.

I was so hungry after giving birth and even though I didn't know anybody in the ward, I still had to ask them for some snacks. I could have eaten a horse! The other patients were very nice and gave me some moon cake.

I was very upset when I saw my husband the next morning and thought I could have been dead and you wouldn't have known (crying). My husband arrived with empty hands, he asked me: "What do you want to eat?" I said: "Why didn't you bring any food with you? I was so hungry and had to ask people for food last night." So he went home to make some carp soup.

Back then, he couldn't cook, but nobody else was at home—his parents were retired, but were doing part-time work to help with the family's income—my husband had to ask a neighbor, an old lady who lived next door, how to make fish soup. Finally, he made the soup with her help.

Q: Was it tasty?

H's mother(laughs): Not bad, actually it was delicious.

Q: Did you live with H's grandparents at that time?

H's father: Yes, we didn't have our own place because there was a housing shortage. My daughter is now 28; 28 years ago, the Pudong New District Development hadn't begun.

H's mother: There wasn't a commercial housing market and people only got an apartment through their unit. My husband has four siblings, but he was self-employed, so my parents-in-law said, "All the other children have got their own apartment except for you and your husband, come and live with us at least you'll have a home." During that time, when my daughter arrived, we also had financial difficulties, but my parents-in-law were very kind and helpful, they never asked us to pay for the accommodation. They never complained. We couldn't pay for imported milk powder either.

H's father: In those days, imported milk powder was very rare because international trade wasn't common.

H's mother: There wasn't anything like a baby nappy, people had to use old sheets to make diapers for their children.

Q: Did you have other relatives in Shanghai?

H's mother: My parents and all of my relatives were living in Ningbo. My husband had siblings who lived in Minhang, Baoshan, and Pudong District, but after they got married, they lived far away from our place.

H's father: We lived separately.

Q: Was H a healthy baby?

H's mother: She was very fit and hardly ever got sick, only an occasional fever or cold, nothing more serious than this.

Q: Compared with other children of her age, how was her physical development?

H's mother: It was good, she developed well, there was no noticeable difference to other ordinary children of the same age. You can see she's a very big and tall girl. If you look at her pictures, she was very cute and pretty.

H's father: You can't tell she has a problem by looking at her face, you only realize this when she talks.

Q: How much did your life change when your daughter arrived?

H's mother: Our life definitely changed; we had a lot more family responsibilities.

Her Math Was Poor and She Was Disliked by the Teacher

Q: Do you know the reason for H's intellectual problems?

H's mother: No, we don't know. We really don't understand how we could have had a child that wasn't healthy. We'd heard that some children can inherit mental difficulties from their parents or grandparents, but we don't have a genetic problem in either family. I have one older sister and one younger brother and both of their sons are healthy. My daughter is the only one.

Some people caused problems for their children by using the wrong supplements or drugs during pregnancy, but we didn't have this problem either. Our daughter was healthy and normal when she was born. There was nothing wrong in the beginning.

But when she was very little, probably around 4 or 5 years old, she fell down the stairs. Her grandpa had brought her back from the nursery and carried her to the top of the stairs, but she lost her balance and fell down the stairs. She didn't bleed or have any swellings. They didn't tell us about this accident, we just heard about it from a neighbor sometime later.

When I asked them why they didn't tell me about this thing, my parents-in-law said nothing had happened to the girl, so they thought it wasn't worth mentioning to us. I said, "If you'd told me what had happened at least I could have taken her to the doctor and had her checked." This accident is the only thing I can think of, there is nothing else I can recall.

Later, I was told by some people the fall could have caused an internal injury and a problem without showing any external sign. We didn't have enough money to afford an MRI test at that time. We just guessed this accident might be the reason for her weakness.

Q: If you think the fall caused H's problems, did you have a problem with her grandparents after that?

H's mother: We complained occasionally. Sometimes I got annoyed with them when they spoiled the girl too much, it became hard to discipline her; at the same time, I couldn't really blame them, but I got angry with my daughter.

Q: Who looked after H when she was little?

H's mother: Her grandparents helped me to bring her up. After we had H, my husband and I had to go to work and her grandparents started helping me to look after her. In those days, both of us only worked every other day, so there was always one of us at home to take the girl with my parents-in-law.

H's father: I was a taxi driver and shared the car with my partner, so I had a day off every 2 days.

H's mother: Her grandparents were quite elderly, and they couldn't do much more than feed the girl, my husband and I had to do most things; for example, we would pick up the girl when she went to nursery and school.

Q: So, basically it was your husband and you who looked after your daughter.

H's mother: That's right; we had the most responsibility, because we didn't dare to leave the child with them. My parents-in-law were quite old, especially the grandpa who was sick all the time. Also, I felt bad after my daughter's accident. We also disagreed with the way they spoiled her, they fed her too much. We had to think about her health and make sure the child didn't overeat. We also had to give tutorials at home for her homework, especially to improve her poor math skills.

Q: How old was H when she went to the nursery?

H's mother: When she was two, 24 months old. We took her to there every morning and picked her up in the evening. She wasn't good at controlling her bladder and wet herself at the nursery all the time. So we had to give the teacher extra pants to change her during the winter. We did this for her for years.

Q: When she was nursery age, did she behave differently from other children?

H's mother: There was nothing that I could tell at the time, but at the kindergarten, before she went to school, we realized her math was poor. My husband and I were too busy to sort out this problem and her grandparents didn't treat it seriously either. They said: "It's not a big problem, the primary school teacher will find a way to teach her."

Q: Did she have any problems with communicating with her classmates and teachers?

H's mother: She didn't talk very much. If the teacher asked: "Are you full?" My daughter would only nod her head while the other children would say: "Yes, I'm full." She only spoke if the teacher insisted that she answered and not nod her head. She tended to avoid speaking and communicating if she could just nod her head.

Q: Did she play with the other children?

H's mother: She liked to play with her classmates, but she looked like a hyperactive (ADHD) child, sometimes if she touched a boy, he might hit her back, then she would get scared.

Q: Did you think that was a problem?

H's mother: No, we didn't think so, and we didn't go out of our way to correct her.

Q: How old was she when she went to school?

H's mother: She started school when she was eight; the Xiangde Road Primary School which is very close to our place.

Q: Did you need to take her to school at that time?

H's father: Yes, we did. We usually took her to school; my parents helped us if they were free.

H's mother: At that time, my registered residence was still based in Ningbo and according to the law the children have to register at their mother's address. Later, my daughter became a non-Shanghai student, so I had to pay a sponsorship fee

to the school; 2000 yuan every academic year. Fortunately, her teachers liked her a lot, because she was cute and lovely. At the same time, she was hyperactive and undisciplined.

Q: That's what the teacher said at the time?

H's father: Yes. She would play on her own in the class. She didn't make any noise or disturb other students, she just played with her pencils and rubber. She was quiet, but she wasn't studying either.

H's mother: After a while, the teacher realized she was a nice and honest girl, but the other children didn't know that; if she touched somebody gently and unintentionally, the child might hit her back. The teacher usually let my daughter stay with her during the break in case she'd be bullied by other children. My daughter was very sweet; she massaged the Chinese teacher's shoulders when she said: "I'm so tired because you guys don't listen to me." The teacher thought my daughter's big eyes were very cute and liked to give her false eyelashes (she's laughing) to make her look like a pretty doll.

Q: How were her exam results?

H's mother: She wasn't good at exams. In the first year, her Chinese was nothing special, but her math was poor. Her math ability was very weak. In the class, everybody could do adding up very quickly except my daughter, she had to calculate with her fingers, even though it didn't work sometimes. The math teacher didn't like my daughter and punished her by moving her with her desk to one side. It was a kind of discrimination.

H's father: All the other students got good results, 100% or slightly less; only my daughter got nothing!

H's mother: The day that the exam results came out, (laughing away) she was so naïve and told us, "I got an egg, a duck egg!"

H's father: Because she didn't write a single word.

H's mother: Even though the teacher told her to write her answers down, she wouldn't listen to him. The teacher said: "I really don't want to give up on her, but I can't help her if she doesn't write anything down."

Q: Did you give her private tutorials at home often?

H's father: She couldn't follow tutorials at all. Her Chinese wasn't too bad, because she could follow the Chinese copybook writing characters stroke by stroke.

H's mother: I kept her company when she did her homework until late at night, because she wrote very slowly and always put off doing it until the middle of the night. As parents, we were suffering as well. Having left school so long ago we'd already forgotten *pinyin*, so we had to relearn these things with my daughter and teach her afterwards. It was the same with math, after the teacher reported she was having difficulty, we started teaching her to calculate numbers with her fingers, but this doesn't work if the number is bigger than 10. Back in our time, my husband and I learned math in a very different way to my daughter. I had to study the whole thing again, but I have to be honest, she was falling behind with her math from her final year at the nursery and we didn't treat this problem seriously. It was partly our fault, but her low intelligence was also to blame. Other children wouldn't forget the formulas when you taught them, but my daughter could never remember them.

H's father: There was a problem for sure. My daughter definitely has a low IQ.

H's mother: Later, the teacher told us: "We can't keep your daughter here any longer," and suggested that we send her to a special school. We struggled with this thing very deeply at the time. She was inferior at the ordinary school and humiliated by her classmates, even by teachers. We were quite upset by the teacher's attitude, to be honest. So, we thought, if the special school students didn't look down on her, she might get her self-confidence back.

H's father: The pace of study was slower at the special school, and although there is a stigma attached to the school's name, at least she can learn something there. Compared to her humiliating experience at the ordinary school, she would feel more relaxed when she was with other children with the same condition. So we had to face the truth. We thought through all of the details carefully and realized we had another choice, so we made the decision to send her to the special school.

Q: You struggled quite a lot with the idea of transferring her school, didn't you?

H's mother: I can't remember how much I've cried since we had her (she cries). From her first school year it had been a very tiring period for us trying to teach my daughter. So my husband and I discussed our situation and decided to send her to the special school. She might feel worse staying at the ordinary school. Even though we didn't mind giving gifts to her teachers hoping that they'd treat my daughter better, but it didn't help very much.

Q: Did you send gifts to her teacher?

H's mother: Yes, of course, we only did that for her. We used to buy gifts to hope the teacher would be more tolerant, but it didn't work.

Q: Was she happy at the Xiangde Road Primary School?

H's mother: She wasn't unhappy because she didn't understand the meaning of happiness. To be honest, she quite enjoyed her school life and she never worried about failing exams or such things. She was joyous and carefree.

H's father: She looked like she was living in another world—I don't care if I study or not, I just like to play with my things.

H's mother: It would be true to say she couldn't feel bad things, because she was quite inferior and didn't like to socialize with her classmates, but nobody wanted to talk to her either. The main problem was that the policy of allowing a disabled child into a "regular classroom" had not yet been implemented; otherwise my daughter would have had a chance to grow up with non-disabled children, learning normal social behavior and lifestyle from them. She didn't get a chance to develop in this way at the special school because it was full of disabled children and some of them had a worse condition than our daughter.

Q: Did the special school students behave differently?

H's mother: Definitely, the special school children behaved in a strange way.

H's father: Those children used to do some things that ordinary children would never do.

H's mother: Intellectually disabled people usually behave weirdly, screaming or something like that. H learned some bad habits from the school after she transferred to the new place; it took time to correct her afterwards. Sometimes I got angry with

her when her manners were bad; my anger didn't stop her, it just made her angry. It was a very bad and rebellious cycle.

Q: Would you have insisted that she stayed in a regular class even if she thought she would have been humiliated or nervous?

H's mother: That's just what I thought.

Q: Except you worried about her learning some bad habits at the special school, did you worry about other things?

H's mother: She couldn't grow up, there was definitively no chance to develop her mind. Also, she couldn't learn normal things either.

She Developed Slowly but She Was Happy and Carefree

Q: Did your child have an IQ test?

H's mother: Yes.

Q: When?

H's father: One condition for joining the special school was the result of an Intelligence Test and we were told to go to the Mental Health Center of Tongxin Road to do the test. It's a special test designed to determine intelligence status and mental condition.

H's mother: To be honest, my daughter wasn't too bad. The Dean said her score was very close to the average rate.

Q: Do you remember the score?

H's mother: No, I can't recall the score after all this time, 65 or 70 I think.

Q: Do you remember the process?

H's mother: No, parents weren't allowed to observe the tests. The worker took her to a small test room and did the test with the doctor. We weren't allowed to know the details.

H's father: The parents couldn't go inside, but were given the result afterwards.

H's mother: They didn't let parents go to the test because the doctor wouldn't get a correct result if the parents helped their children. From what I understand, they gave different questions according to the child's age, if you were ten, you'll answer questions for that age. However, I believe her results were slightly lower than her real age.

Q: What's the difference between the special and ordinary school?

H's mother: The learning level and schedule are totally different.

H's father: The former is a special place for children who can't keep up with the pace of study or who've been left behind by the other students.

H's mother: Originally, this school was for deaf-mute children, but it changed to a special school when they were sent more and more intellectually disabled children. All the deaf-mute students at that time were transferred to a Shanghai deaf-mute school. Generally speaking, most district special schools are transformed deaf-mute schools.

Q: Did you keep driving her to school after she transferred to the special school?

H's mother: No, she went to school by herself. In the beginning, I walked her to school and let her walk back by herself. We didn't feel comfortable letting her walk to school at first, so I told her go to school by herself, but followed behind. After she entered the school gate, I walked to the guardian and checked with him about H to make sure she had arrived safely. After that time, she started to go to school by herself.

Q: What did she learn at school?

H's mother: Chinese, math, PE, and music and other basic courses, but the big difference from the ordinary school is the special school doesn't have a learning schedule.

H's father: The teacher had to repeat the same thing until they learned it.

H's mother: The main textbook they used is a Chinese textbook, one book used through the whole academic semester, but they didn't learn very much. I have to say, those students weren't ordinary children, but the teachers had their own problems, too. The pace of teaching was too slow! Once they had a substitute teacher who had taught deaf-mute students before; he said our children could deal with a faster pace of teaching after he taught my daughter's class once. But for some reason, the teachers worked at a slow pace.

Anyway, they didn't have a teaching program, the teachers had an easy job, and the students didn't learn enough. At the same time, their textbook was much easier than the ordinary school. Later, a nice teacher told me: "You should teach your daughter to develop her handwriting. People prefer a person with beautiful handwriting than a diploma." I totally agreed with his idea.

Q: What was H's experience at the special school?

H's mother: She enjoyed that time very much, really enjoyed it there. She wasn't that happy when she was at the Xiangde Road Primary School where she was always under pressure socially and in her studies. We felt relaxed at that time as well, because the teachers were very friendly to the students.

Q: Did you help her with her homework after she went to the special school?

H's mother: Yes, we did. Actually, she understood most of the things that she learned at school.

H's father: Because the teaching schedule was slower.

Q: Did Mom do this?

H's mother: Yes, because my husband was usually very tired at the end of the day.

Q: Did they have exams?

H's mother: Yes, they did exams.

Q: What were her exam results?

H's mother: Her results weren't bad, pretty good actually.

H's father: The exams were quite simple.

Q: Did she get on with the other students?

H's mother: Yes, she was friendly with the other children, because they were all the same, so nobody looked down on anyone or the other way around.

H's father: They are the same kind of people.

H's mother: All of them are very naive.

Q: Did she talk to you about her school life?

H's father: She didn't tell us anything when she was at the Xiangde Road Primary School.

Q: When did she start to talk about her school life?

H's father: When she was in her fourth year, after she transferred to the Special Education School—Miyun school. She started to tell us about some of the things that she learned that day, what class she attended, and so on. She could only tell us a brief story; if what happened that day was a long story, then she'd just tell us a small part.

H's father: At least she learned to talk about her daily experiences in a simple story at the new school, but at the ordinary school, she couldn't even remember her homework.

Q: Did she tell you anything else?

H's mother: If we asked her, she would talk about her lunch, what she had, and so on.

Q: Did you often ask her?

H's mother: We just asked some simple questions, such as what did you have for lunch, did you have some meat? She would answer "I had meat," but she couldn't tell us what kind of meat she'd had; she only knew that they had meat that day.

Q: When did she take the initiative to tell you something without being prompted?

H's mother: When she was in the seventh and eighth year at school, which had a nine-year education system. Especially, after she joined the Sunshine Workshop.

H's father: At dinner time, she liked to tell us what they'd had at lunch time and we didn't need to ask her anymore.

Q: Did she talk about anything else?

H's mother: Of course, she talked about other things too, but couldn't explain herself properly. Sometimes even we couldn't completely understand her when she tried to talk about something unusual or casual.

Q: Do you think H is improving gradually?

H's mother: Definitely, her speaking skills are getting better all the time, from rarely speaking and being unclear, to getting used to speaking more and more clearly. It's a kind of improvement, right? I remember once she was scared when her period started and I had to explain that it was a natural thing for every woman, including her and me. After that, I taught her to mark our "start" dates on the calendar: draw a red flag on the dates to remind us of our next period. I used this way to help her to sort out her problem with numbers. This kind of date is the most frequently marked date on our calendar.

Q: Red flag?

H's mother (she's laughing): Yes, that's right.

If She Can't Change, then I Will Change Myself

Q: Did H ever lose her temper?

H's mother: Yes, she was very stubborn when she was young and used to lose her temper sometimes. When she was angry, she might pull her hair or throw her

schoolbag to express herself. Sometimes when she lost control of herself in the street, she would pull her hair or cry loudly and lots of people would stop and look at her. It was terrible, but she stopped doing this after a couple of years. She's much better now, and hardly loses her temper anymore.

Q: She pulled her hair and threw stuff?

H's father: She had a very bad temper.

H's mother: She would tell us that at that moment she just couldn't control herself at all. For example, she might get unhappy and lose her temper if we refused to give her something that she'd asked for, but she wouldn't get angry if she got what she wanted.

H's father: But she doesn't lose control anymore.

H's mother: No, because she's grown up. Sometimes I tell her: "Don't be angry, you'll look stupid."

Q: At what age did she have her worst tantrums?

H's father: When she was around 12 or 13.

Q: So that was her most rebellious time?

H's mother: It's hard to tell. It could be her age that made her rebellious. To be honest, we were young and in a bad mood at that time, too. Nobody wants a disabled child, but we couldn't speak out ourselves. My daughter was getting more stubborn and losing her temper very easily when we blamed her for something. It's in her character not to cry or stop if she's punished, she responds well to friendly persuasion rather than force.

Q: Under what circumstances would you lose your temper with your daughter?

H's mother: When she didn't obey me, of course. She was stubborn and this put me in a bad mood, she got very upset if I blamed her using harsh words, like calling her an "idiot." She doesn't like people to call her "idiot" and her pride is easily wounded. But we stopped using this word.

Q: Was she disobedient with you when she was younger?

H's mother: Not really, she wasn't too bad, but sometimes she lost control for no reason and she used to say: "I just can't control myself." Sometimes she would only have an angry face, but wouldn't make a sound. If I said to her: "Are you angry?" she'd reply: "I'm trying my best to control my temper." She responds well to kind words, she'll calm down if I say something nice to her.

Q: Can she control herself better now?

H's mother: It's possible, I usually tell her not to get angry if she gets unhappy. My daughter will explain: "I know I shouldn't be angry because I might be more stupid every time I lose my temper."

Q: What do you do when you lose your temper with H?

H's mother: Nothing more than that and I usually regret it after I've blamed her.

H's father: We regret blaming her because she's different from normal people.

H's mother: It's our problem if we provoke her with strong words. These days, if she's angry, we usually try to calm her mood with kind words. It usually works. We keep learning from our experiences (smiles).

Q: Did Dad ever get angry with H?

H's father: Yes, it's happened.

Q: What did you do?

H's father: I criticized her: "Why did you do this? Don't do it again."

Q: Was your tone quite tough?

H's father: She usually gets angry if you talk to her in a strong tone.

H's mother: Back then, she might change her mood if I criticized her dad. Sometimes she wouldn't eat if she argued with her dad and I could only get her to eat if I calmed her down with gentle words. She could go on this way for quite a long time, not eating if you didn't calm her down.

Q: What kind of things make you lose your temper?

H's father: I don't criticize her very often. It only happened if she went too far.

H's mother: H's anger was always triggered by criticism that she didn't like, so we decided to change our attitude to solve the problem. For example, she usually got upset if we said "you're stupid," so we stopped saying this. I started to explain myself in a different way: "H, it would be smarter, if you behave in a better way."

H's father: We changed ourselves because we realized she wasn't able to change.

Q: Have you had any minor problem with H recently?

H's mother: Very rarely, or just some small problems; for example, she likes to take coffee to her office even when I tell her that drinking too much coffee isn't good for her skin and makes her face spotty. I suggested she take some chrysanthemum tea instead of coffee, but she insisted on coffee and got upset with me, so I've let it go. I thought about this thing later, drinking coffee isn't a big deal, the only reason I stopped her is thinking about the consequences, but it's not an argument at all. Our relationship is pretty good these days.

Q: How about her relationship with her dad?

H's mother: They don't argue either.

H's father: I usually let her do what she wants to do.

Taking Exercise Improved Her Intelligence

Q: Did H get involved with Special Olympics?

H's mother: Yes, she did. The first time, the Special Olympics workers went to the Special School to elect suitable athletes in 2006. There were a certain number of games that every special school had to get involved with. Those workers thought H looked quite tall and strong, so they let her join in several games, like weightlifting and races. That year, H and other athletes went to the 2006 Special Olympic Shanghai Invitational Games for a week and lived in a hotel in the Zhabei District with volunteers. She won a gold medal and received a 500-yuan subsidy. So she used this prize money to buy chocolate for the teachers and volunteers (she smiles). After that, she joined Special Olympics in 2007. Actually, Special Olympics has some regular events every year, like the "Special Olympics Day," "Special Olympics Week," and "Special Olympics Month." My daughter usually takes part in these sport events.

Q: In 2007, what events did she compete in?

H's mother: The 4 × 100 m relay and long jump, I guess. I wasn't there at that time, parents weren't allowed to go to the ground with them, they were accompanied by their schoolteachers.

Q: So they went to the competition with the teachers?

H's mother: That's right, they didn't live at home during the competition.

H's father: In addition to the teachers, there were also some volunteers who were college students.

Q: Did they have any pre-competition training for the Special Olympic Games?

H's mother: You mean collective training? They didn't have that. But they had PE teachers from the Special School to train them. These days, the training is supervised by the teachers from the Sunshine Workshop.

Q: Did they have weekend training then?

H's mother: She was a student, so the teacher trained them in normal school hours. Today, if we've been invited to join in the games, some teachers and volunteers supervise their practice. We train them for table tennis and bocce, at the weekend or when we're free. There's also some overtime training.

Q: Overtime training?

H's mother: For example, we used to borrow a school playground for training on Monday or Tuesday afternoons when those places were free. Sometimes, we trained with the students in Hongkou Park. We always find a way to practice before their competitions.

Q: What did you do in training?

H's mother: Before the competition, we let them practice table tennis for a long time every day. The teachers help them practice and count how many "goals" they score every time. There's a tiny hole on the table tennis table, they have to put the balls in the hole to score a goal.

H's father: They become skilled at the game through long practice.

H's mother: Yes, they have to concentrate on the target all the time.

H's father: For these children, the competition isn't the main thing, it's the participation that's the most important.

H's mother: They have to know how to play the game first. With bocce it's the same idea, they have to be smart to choose the right target and position, that's why they need plenty of practice.

Q: Does Dad get involved with their team training?

H's father: No, because most of the volunteers are female, you hardly see a man there. Usually the moms look after the practice and other events, so my wife works very hard.

Q: There are no dads at all?

H's mother: No, all of the children go to the events with their mothers. I quite enjoy practicing with her, actually, she can join in some competitions and I get exercise at the same time. Even if the competition is important, for me, the exercise is the best thing, because exercise helps her develop her intelligence, and develops her arm and leg coordination. Nothing is wrong with exercise, right? The parents are getting fit while helping their children practice. Sometimes, when we were dancing together, I felt I was becoming young again (she's laughing). The parents are learning a square

dance right now and teaching the children afterwards. We learned the Xinjiang Dance the same way in the past. For me, it's a pretty nice thing to do.

Q: Did H ever complain that the training was too tiring?

H's mother: No, she never said that. She usually told us what exercise they did that day; practice was always necessary before the competition. After the Special Olympics World Games was held in Shanghai, there are many events. We won second place in this year's Intercity Invitational Tournament of the Sunshine Unified Run. Each team has 12 people running together, 6 special children and 6 volunteers; people stand in a line and tie their leg together with the teammate's next to them. The training was quite difficult, we fell down from time to time, but everybody had kneepads. For safety reasons, without the proper training, we couldn't practice this game on the ordinary ground, sometimes we had to practice on the lawn in the park. I'm one of the team's volunteers, so I trained and went to competition with my daughter.

H's father: All volunteers are unpaid.

H's mother: That's right, we're unpaid volunteers. The main purpose of this is to help these children get out of the home and be a part of society, but we like to join in some of the competitions if we can. The Sunshine Unified Run is an annual competition; we won second place this time, but we won first place last year. Usually the competition takes place at the Rehabilitation Center for the Disabled Persons in Songjiang District and our team hasn't missed this competition since the first year.

Q: Which competition is the most impressive for you?

H's mother: Definitely Special Olympics, because my daughter won a gold medal at this international event. This year, she and other children representing Shanghai went to the Intercity Special Olympics Day events on 15–18 July.

H's father: Sure, they represented Shanghai.

Q: Are you proud of your daughter's achievements?

H's mother: I'm very pleased for her. I'm always happy if my daughter is happy. The result isn't a big thing for her, she just enjoys the experience.

Q: Did she change after she became involved in sports?

H's mother: It's remarkable, my daughter became much happier! She's loves telling our guests: "Aunt, I won a medal." She also receives 200 yuan for participating.

Q: Could you tell me more about her practice in the side drum band?

H's mother: She joined the band in 2005.

Q: Where did you hear about this band?

H's mother: Two teachers in the band approached her. They said playing the side drum is good for improving her intelligence. I thought it's a good thing for her, because my daughter has problems with arm and leg coordination, side drum practice is helpful. I joined the band with some parents who have children like my daughter. We became volunteers and teachers in the band and developed the band further from a few teachers and students through family visits to encourage other parents to join us with their children.

At that time, my husband and I worked at my sister and brother's factory in Ningbo. We left my daughter with her grandparents. In addition to looking after her, Grandma also took her to the side drum band practice at the weekend (see Fig. 1).

Fig. 1 Miss H practicing side drum



That same year, we quit our jobs in Ningbo and came back to Shanghai; the reason we took this job was for my daughter, it wasn't our intention that she should live a miserable life. So we moved back to Shanghai and spent more time with her.

Then I started to go to drum band practice at weekends, anyway I was free during the weekend. So we went to the practice and back home together. I started to learn the dance first and then taught my daughter and the other children afterwards. Even now, we still dance and practice together; the parents are also volunteers and teachers. We also formed another team called the Flat Drum Band. The difference between the flat drum and the side drum is the former is on a stand; the latter is tied to the waist.

Our band just performed at a sponsor's annual corporation meeting. An old gentleman asked the company to support us and that's why we were invited to their show. Our team played *Chinese Kung Fu*, one of our own choreographed dances. Usually

we, the volunteer/teachers, learn the movements and actions from other players who practice in the park and teach our children afterwards. Now we have ten teachers and all of us have one thing in common, an unusual child.

Q: So, none of the teachers in your team played the drum before, right?

H's mother: Nobody touched the drum before; everything was new to us.

Q: What do you think H's behavior is like these days?

H's mother: She's doing fine, but she could do better if she worked harder. For most unresponsive children, rhythm is very difficult. It takes them several months to learn one thing which only take ordinary students a day. The problem is they can't remember movements and rhythm, they learn one thing today but forget it the next. H didn't know anything about drumming, and started studying simple actions with a "one, two, three" routine. We usually repeat one movement again and again until they remember.

H's father: It's very hard work teaching these children; sometimes they have to repeat one action many times.

H's mother: From 2005 to today, they have studied the drum for over 10 years, but quite a lot of students still can't play standard patterns. These students started playing the simplest "nine points" rhythm, and learned more complex actions later. That's how we learned *Chinese Kung Fu*.

This has been my life, accompanying my daughter for over 10 years. The group exercise helps children to develop themselves. My daughter has changed a lot, she used to be quiet and didn't like to talk, but now she's happy and a chatterbox. What a great thing.

But if the parents aren't determined, the children won't have any chance. There was an autistic child in our group for a while who I met during a family visit and I told his parents that keeping the child at home wasn't good for him. The parents changed their mind and joined us for a short while, but the mother gave up after she came to our group exercises several times, because she said it was too much for her. Actually, every parent in the group is doing the same thing, this mother was retired, but I was working. For her, it might be easier to keep her son at home, but he suffers when he loses his self-control. Compared to intellectually disabled children, an autistic child lives in his own world and doesn't care about other people's feeling at all.

Q: How was your experience playing the drum with H?

H's mother: It was very hard, but now, after I'm used to this lifestyle, it's difficult to explain how difficult it is. It has become a part of my life now; I feel weird if I don't go there at the weekend. It's probably the same for my daughter; people get used to getting up late on cold days, or like to stay at home on rainy days, but she won't do that, she always insists on going to the group classes.

H's father: My daughter might be late for the exercises, but she has never missed once.

Q: Why?

H's father: Because she likes to spend time with her friends and play together. Home life is boring, because she can only chat with her parents or play on the computer.

H's mother: I think she's used to going there.

Q: Does she like the group atmosphere?

H's mother: She looks very relaxed there and she's comfortable chatting with the boys.

H's father: Everybody in the group is the same, she doesn't worry too much, and feels can say whatever she wants to say.

Q: Does Dad go to the weekend practice with H?

H's father: No, very rarely, my wife looks after this. I was a taxi driver and always too busy to look after her. Now I'm home but I have health problems after I had surgery several years ago.

Q: Do you encourage her to play the drum?

H's father: Yes, of course. When I had shifts, every other day, as a taxi driver, I took her to the center on my free day.

Q: Did you watch her perform?

H's father: Yes, when she was at school, we went to the practice together sometimes.

Q: Do you think the drum practice has changed her?

H's father: I think she's very happy being with people like herself where there are never any discouraging words, she feels happy.

H's mother: Sometimes she gets nervous and sweaty hands before she learns new movements.

H's father: Even her teachers know what she's like; they tell us: "Your daughter is very timid; she'll lower her head and stop talking to us if we say any harsh words to her." My daughter still lacks self-confidence, she always worries if she'll say something wrong before she talks. She doesn't feel confident in herself.

Learning While Working Helps Her to Relax

H's mother: H joined the Quyang Sunshine Workshop after she left the school in 2006. The basic work she does there is handicrafts; making red envelopes and sponge cup brushes.

H's father: They also make toothpicks sometimes, it's a kind of set of toothpicks for restaurants, two in one bag. It's very simple, a typical example of their work. The red envelope is for Spring Festival. They're paid for the work, but only a bit of money, probably several dozen yuan every month.

H's mother: The teachers at the Sunshine Workshop find this kind of work for the children through their social contacts.

Q: Do they work every day?

H's mother: Yes, they always have something to do every day.

H's father: When they don't need to work, they have handwriting or other classes.

H's mother: When they're free, the teacher teaches them to dance.

Q: Does H go to work every Monday to Friday?

H's mother: Basically, yes, but she might take a day off if she needs to go somewhere for a sports competition or social event.

Q: Do you still walk H to work every day?

H's mother: No, not anymore, because her workplace isn't far away. I asked her if she needed me to take her to work with her, she said: "No, that would be very embarrassing if you take me to work at my age." So she usually goes to work and comes back home on her own, even in bad weather, because she always has her umbrella, she uses it for sunny days and rainy days.

Q: When does she usually leave home in the morning?

H's father: She usually leaves around 8 a.m. even though they don't have regular working hours. People only need to make a phone call in the morning if they can't go to work that day. My daughter usually leaves home between 8.10 and 8.15 a.m., and arrives at the workplace at 8.30 a.m. She finishes around 3 p.m. and gets back home before half past three.

H's mother: Actually, they do have a working schedule that requires them to arrive before half past eight, but getting there late isn't a big deal for the workers if they can explain the reason to the teachers. It's not a formal job, but they need to report to the teacher if they have to take a day off, because the teacher has to know the number of workers before she orders lunch.

H's father: Sometimes the workers have to leave 10 min late because they have to clean the workplace.

H's mother: The children have to clean up the place?

H's father: Yes, they do it in turn, so she will leave late once a week. Except for that day, she always gets home punctually, around half past three.

H's mother: She has to practice the harmonica with her friend's band after working on Tuesday, and she practices dance for half an hour on Friday afternoon. Apart from these days, she comes home early.

H's father: Sometimes they have to cancel the practice if the teacher can't make it.

Q: Do they let parents know if the practice has been cancelled?

H's mother: No, sometimes H arrives home early if the harmonica teacher can't make it.

H's father: Their teachers are volunteers who don't work at the workshop.

H's mother: The harmonica teacher is from the Youth Center in Hongkou District, he set up this band with piano, saxophone, and harmonica.

Q: Have you seen their performance?

H's mother: Yes, I saw their show. They perform regularly at the Youth Center.

Q: Do you know what songs she plays?

H's mother: Well, I don't know very much about that, because H told me she doesn't know what songs they play either.

Q: Do you like her playing the harmonica?

H's mother: Yes, of course. But we don't know anything about the harmonica so we can't help her, she has to learn herself. She practices at home sometimes, but she's too shy to practice in front of us, she always stops playing when I open her door.

H's father: Playing the harmonica is part of her life and she likes to learn. As parents we have to support her. She got the harmonica from the teacher; we didn't need to spend anything and so there's no reason to stop her.

Q: Do you worry about H's work at the Sunshine Workshop?

H's father: There's nothing to worry about, we go to the workplace regularly for parent's meetings—we have to go there tomorrow evening again—and H tells us everything about what happens, what she eats, and what she does and all sorts of things. So, we don't need to worry about her.

H's mother: There is an annual parent's meeting to regularly update us about news and the children. The Sunshine Workshop belongs to the Disabled Persons' Federation (DPF) of Hongkou District; it's a proper company with a good reputation. The teachers are nice and caring people, they usually set up some activities after the children have finished their work.

H's father: Compared to other similar workplaces, the Quyang Sunshine Workshop is a pretty good one. Previous national leaders have visited the place, from Xiaoping Deng, Jiang Zemin to Hu Jintao, but Xi Jinping hasn't been yet.

H's mother: I remember Hu Jintao came in 2007 for Special Olympics.

H's father: The leader's visits are very special and proud events for the workshop, so they have a picture wall of the events.

H's mother: The name of the workshop was written by Xiaoping Deng, and his successors came here to remember him. It's why this workshop has become so famous.

Q: Do you worry about the people who H gets to know through her work?

H's mother: I worry sometimes, I just don't like her to be pick up some bad behavior from the other children, so I have to point out any problems to her.

H's father: It's hard to avoid it in this environment, because these children all have their own problems.

H's mother: Once I saw her giggle loudly when she was alone, and I asked her: "What are you doing, did you pick up this bad habit from your friends?" I said that because she behaved normally before and never laughed like this, but in the workplace, those children have all kinds of different odd habits. H is really good at imitating this kind of bad behavior, much quicker than learning good things, but if we point it out she correct her mistakes immediately. I think she's really good at picking up bad habits, I don't mean bad things but bad manners.

My daughter is so excited about the party at the workplace this afternoon, she'll be performing two songs, and one is *Firefly*. She downloaded the songs to her phone and she'll sing along with the music later. To be honest, it's not an easy job, I suggested she only sing *Firefly*, but she won't listen to me.

Q: Does she like cultural and musical events?

H's mother: Yes, she likes to sing and dance everyday (she's laughing). The Sunshine Workshop is a pretty good and safe place. Also, H isn't a bad person and won't make a fuss. She calls me every afternoon before she leaves work and I always tell her to be careful when she's crossing the road. She always comes back home immediately and won't go anywhere else on her way back.

Q: Does H have any good friends at the workplace?

H's mother: Most of my daughter's friends are children from the side drum band, because the parents get on very well and the children have become good friends. We usually go out for a meal or karaoke together.

Q: Did you have to think about letting H get a proper job?

H's mother: The Sunshine Workshop recommended her for a job once.

Q: Recommended employment?

H's mother: There is a "reemployment of the disabled project" through the district DPF office; usually they help mildly disabled people find a job. They can't stop the employers' bias against these children, they often get the most difficult and dirty work and usually won't get a contract after a 3-month probationary period.

H's father: People at the workplace usually look down on these children, they only keep our children for a 3-month probationary period. Some of my daughter's classmates don't like to take a second probationary period after they fail the first one, because it's a kind of torturous experience. My daughter is the same, she won't leave the Sunshine Workshop to find another job. Here the teachers treat her as an equal to their own children, some teachers' children are in the same situation. But in the world outside, it is totally the opposite.

H's mother: She's unsociable in the outside world, because she can't join in people's conversations at all. She was recommended for a job by the DPF office once, but she was lonely there, but at our weekend group, people feel at ease and carefree to chat with each other.

H's father: Yes, she went for a proper job once.

H's mother: It was a job at a bakery. I went to the interview with her at the Xinyu Bakery, at the Jiangwan Sunshine Workshop. After that, when the careers teacher at the DPF center asked my daughter about her work experience, she said: "I'd like to stay here because I'm not fit for the outside world." The teacher laughed and didn't put her forward for another job. My daughter is scared; one reason is the distance between home and the workplace. She didn't want me to go to work with her, and she wasn't sure she could cope with the journey by herself.

I guess she might feel better if she had a couple classmates to keep her company. I know this, because she worked with three other girls in the same area and she was very happy. They'd meet at the bus station at the Foreign Language College and go to work together on the No.875 bus.

H's father: Some other students at the workplace took the job, but quit later. One girl said the work was very hard and they had been given the most difficult work with the oven. They were also despised by other people. So the girl quit.

H's mother: This girl is more capable than our daughter, she and the other students went to work in the summer, and they worked in the hottest part of the bakery. She decided to leave and came back the Sunshine Workshop.

H's father: After all, there aren't that many loving people in our society. Hong Kong and Taiwan have more caring people than the mainland.

H's mother: In one training class, a teacher talked about a disabled person's life in Taiwan. They have some trained volunteers to accompany them when they go to work until they get used to the job, but Shanghai doesn't have this kind of social service yet.

Q: Does H still need a place that makes her feel secure?

H's mother: Of course, she feels more relaxed in a safe place. At the Quyang Sunshine Workshop, she feels free to speak, because nobody will feel the need to correct her. Maybe it's just because the children don't really understand each other, so they just let mistakes go. Everybody is the same.

H's father: My wife is right, our daughter feels safe and relaxed at her workplace. The low pay doesn't matter, because she's happy. It's a place where she can say or do whatever she likes.

H's mother: I really wish we had a caring person to look after my daughter to help her adapt to society, step by step. That would be a really wonderful thing for her.

H's father: But it's unrealistic.

H's mother: It's just my wish.

Q: How would a volunteer help her be included into society?

H's mother: For me, the ideal situation would be for her to work in a normal place with a female worker as her mentor, to teach her about the workplace and walk home with her.

Q: So, would you want her to be part of society even if she isn't in a safe space?

H's mother: Yes, I hope she can become a part of society one day. You can't tell that she has a problem by looking at her, especially if you're a stranger. Sometimes when we walk home along West Dalian Road after drum practice, some young girls ask her for directions—what's the way to Hongkou Football Stadium or the Foreign Language College or something like that—because they can't see that she's different. She knows the right directions, but she doesn't dare answer them until I come to help. She has a chance to have a normal life. One time, when some people came over to our place, they thought my daughter was a volunteer.

Q: But why are you so determined that she joins in society when she's a little bit afraid of the outside world?

H's father: We want her go out into the world in a slow way with some help, little by little.

H's mother: Experiencing a real environment and its difficulties is the only way she can improve her social skills; her current workplace is safe, but it isn't helpful for her development. If she gets upset outside, we can work out the reason together and find a way to avoid it next time, that would be an improvement. She'll have to live alone when we're old and face all the problems on her own. Rather than just going out alone one day and being hurt by all the things she can't deal with, it would be better to let her face smaller problems, little by little, until she's strong enough to face something more serious in the future.

It's the way we grew up. Years ago, after I failed the high school entrance exam, I came to Shanghai to learn tailoring and went back to my hometown afterwards. I found a job at a clothing factory, then moved to Shanghai and worked for my relatives. After they closed the business, I found another sales job at a shopping mall. It wasn't easy, but I went through all of these changes and I want my daughter to grow up in the same way. I believe H can develop herself if she has a good, normal person as a guide. Our daughter isn't bad; she's independent, but poor at explaining herself and has no understanding of money.

H's father: We wish she could engage with society, but we know it's very hard for her. It's too difficult to find a loving and caring person to help. Why do I say this? For example, in my family, I have four siblings—two big brothers, one big sister, and a little sister—their children are the same age as my daughter, more or less, but not one of them likes to talk to her. Even though they're blood relatives, they don't like her. If your own relatives are like this, and even they can't look after her, how can you depend on somebody else even if they have a very warm heart? We have thought this thing through and now we'll just get on with making sure she's a happy person, that's what matters for us.

How Can She Be Independent Without Understanding the Value of Money?

H's mother: H isn't fussy about food or clothes. If I ask her what she wants to eat, she always says whatever you're cooking. She has the same attitude to clothes; when we go shopping together, she is never picky about clothes or asks for branded stuff. She just lets me choose her clothes for the day. Of course, we don't buy her cheap stuff either, because shabby clothes would make her look poor. She wears the same things to her ordinary peers. These days, she has a salary and never uses it, but I don't mind spending money on her clothes, because as a one-child family parent, I care about her appearance.

Q: Are you close to your relatives?

H's mother: We very rarely see them, because everybody is busy at work.

H's father: I have a big extended family, three nephews and one niece, but all of them are busy with their own families. We're in contact through WeChat daily but only meet up once or twice a year.

H's mother: Usually we only meet at Spring Festival and Tomb-sweeping Day, and keep in touch by WeChat the rest of the time.

Q: Do they know about your daughter's condition?

H's mother: Yes, they've known for a long time, since H was at primary school and struggled with her studies.

H's father: At that time, we lived with my parents and saw our relatives more often when they came to see them. After my parents passed away, we didn't see each other as often as before.

H's mother: People have to concentrate on their own family, all of our siblings are parents and grandparents already. If our daughter was different, an ordinary young woman of 28, we might have become grandparents as well, but we won't have that experience now.

Q: Does H have an effect on your relationship as a couple?

H's mother: No, not at all. It's the way it is, so as a family we have to share the responsibility. Our parents suggested that we should have another child, and I could have had a second child, but I chose not to. Because most parents always have a

favorite child—the clever or healthy one—I can't say that I'd be any different. If we had another child, H's situation could have been worse and she'd be more vulnerable. It would not have been fair to H at all. So, the best thing was to only have one child in the family and give her all our attention.

Q: How about your circle of friends?

H's mother: My social life has always centered around my daughter. Except for our relatives, I've never mentioned my daughter to other friends, because I have to be careful about how they would react. I don't go to ordinary people's events if I can help it, but I go out with other families in our group quite often, because we have one thing in common, our children connect us.

Q: How about Dad?

H's mother: My husband has some ordinary friends too, but he doesn't go out with them very often either. Sometimes these friends ask about our daughter's age and say they know some good boys to introduce to her, but my husband can only say: "Thanks, but she has a boyfriend already." This hurts him deeply inside, but we can't do anything about it.

Q: Is H independent?

H's mother: She isn't bad with everyday life skills. She's okay with cooking, boiling hot water, and using the microwave to heat up food and so on. She can also make a vegetable salad in hot weather. Sometimes, she helps me with the washing as well; she doesn't have a problem with the automatic washing machine. Once, she was left at home alone when my husband went to hospital. We weren't sure if she could look after herself and called my mother who lived in Ningbo to come to our place and look after her. When she arrived, my daughter had cooked a meal and boiled water for her.

Q: When did you start teaching her life skills?

H's mother: When she was at primary school; in her first year she started washing her school uniform and red scarf. I helped her to hang up the washing afterwards; I didn't mind washing the stuff again if she hadn't done a proper job. I thought, she isn't a smart girl, but she has to grow up to be an independent person. I taught her these life skills step by step. Before she learned to use the vacuum flask, I let her fill up the bottle with cold water just in case she got burned by the hot water, until she got used to doing it.

Q: Can she cook?

H's mother: She can cook some simple meals like making rice using the rice cooker.

H's father: The most worrying thing for us, is she doesn't know how to use money, and how can she live on her own without knowing the value of money? In this world, we have to buy everything, oil, rice, and other things with money every day. If you can't deal with money, it's problematic. We keep teaching her to use the ATM at the bank—inserting the card, typing in the password—but she always forgets how to do it the following day.

H's mother: I usually take her with me if I need go to the bank and keep an eye on her to remember the password, or write out a form and deal with the account business by herself. My daughter is a timid girl and she isn't good at coping with

communication issues either. Sometimes she's even scared of people who ask her for directions on the street. So just in case she's cheated by someone on the street, I have to remind her that she mustn't talk to strangers when she goes out. With her condition, some terrible things could happen to her if she isn't very careful. Especially as she's a girl. Some girls like her have been abducted by bad people and were pregnant by the time the police found them.

Q: Do you teach her anything else except for life skills, how to use the bank and not talking to strangers?

H's father: Actually, we teach her everything we know or everything we can.

H's mother: We also taught her to respect the neighbors and how to address them depending on their age and her relationship to them; how to reply to other people and have a conversation or something like that. If I can, I usually take her with me to do most things, like going to the food market together at the weekend. I usually let her hold the money and pay for things, but with my help.

H's father: Her problem is she doesn't have a sense of numbers; for example, she can't work out how much change she should get.

Q: Can she use Alipay?¹

H's father: No, she can't.

H's mother: Because we don't have an Alipay account yet, I guess if we do, my daughter will learn how to use it.

H's father: We don't know anything about Alipay or the Internet or computers, we didn't learn this kind of thing at school.

H's mother: I applied for one account with the help of my nephew, but I didn't dare use my bankcard with it. I use the same password for several cards, if anything should happen to the password, I couldn't bear the consequences. I've been told if I apply for a new bank card and use a different password that will be fine, but for some reason the application didn't go through and I abandoned the plan. Anyway, at my age it's too difficult to remember too many passwords. To be honest, I know I should learn more new things to make sure I don't become disconnected from modern society.

H's father: Alipay is very convenient and you only need to scan the barcode to pay a bill when you go shopping.

H's mother: Didi Taxi² and bike-sharing are convenient new things as well, they make life much easier, but we're behind the times now.

H's father: We can't use them.

H's mother: What can we do? If our daughter was an ordinary child, she'd be able to help us learn these new technologies, but we're completely the opposite to normal families. Without Alipay, we have to use cash for delivery services and pay an extra fee if we want to shop online.

Q: So, H is able to take care of herself, but still needs a helper?

H's father: That's right, her main problem is with using money.

¹Alipay is the Chinese counterpart of PayPal. As well as using it for online payment, people also can use it to pay bills in many shops and restaurants.

²Didi Taxi is a Chinese equivalent of Uber.

H's mother: Another problem is she's been protected by us for too long. These children don't know how to follow the weather reports to change their clothes or bedding yet. Sometimes they won't know how to take off the duvet when the weather gets warmer without their parents reminding them. These days, if my daughter asks me what she should wear, I usually ask her to think about the weather first and tell her that she should choose the right clothes for the weather, rather than for taste. Wearing a T-shirt in winter or the other way around wouldn't be a clever thing to do, but it takes time to learn, right?

Q: Has H had a relationship yet?

H's mother: No, she doesn't have a boyfriend. I don't think she understands what the meaning of a boyfriend or relationship is yet, because she usually stays with her own people and doesn't have any real idea about what this means in her life.

Q: What do you think about her getting married?

H's mother: We discussed this issue and we think she'd be better off with a family, but if she has to marry to an intellectually disabled person, I think she'd be better off single. A light, physically disabled man, but with a normal mind would probably be an ideal choice if the guy is truly in love with her. Even though we worry that this type of man might only treat her well before my husband and I die; after that, he might send our daughter to a nursing home and sell our property and run away with the money. If this happened to her we'd never know or be able to help.

There are some intellectually disabled children who got married and some of them have children already. I met some of the parents of these families from Yangpu District and Baoshan District during a meeting. Usually they like to choose a non-Shanghai, but someone who works in Shanghai and comes from a poor family to marry their child, and they can help raise the baby if they have one. Things look pretty good for them at the moment, but who knows what will happen to these families in the future?

If we chose a man with the same condition for our daughter—a normal person but very poor—after we die and leave a property worth several million yuan to them... The man might abuse her or treat her very badly. Just thinking about this makes me very upset. We can't reconcile this and we feel a deep inner conflict (she's sobbing with grief).

She doesn't want to have a family right now, but who knows if she'll change her mind. One day, it could be an issue when she wants to get married or she reaches biological maturity. There's a girl who lives on Jiangwan Street, she insisted on getting married when she was in her thirties. Her mother had no choice and found a man for her. Their child was an intellectually disabled baby. That's a huge conflict, right? (crying).

For H, having a family is unlikely, but if the opportunity really comes one day, I'll fight for her and be very careful about the man. My daughter doesn't have any physical problems, but also, she doesn't have any desire yet. After all of her cousins were married, I asked her if she wanted to have a family of her own, but she said no. At some special occasions, like her cousin's wedding, she said: "I'd like to be a bride one day." She doesn't really understand the meaning of marriage.

Q: What's your plan for H's future?

H's mother: The future? We never stop worrying about her, especially knowing there will be a time when we might be too old to look after her (sobbing). She's independent enough, but she can't deal with money, that's her most serious problem. I can't stay calm whenever we talk about my daughter's future.

My concern led me to volunteer to work with intellectually disabled children, joining group events and meetings at the district DPF center. Later, I was elected as the chairwoman of the District Association of Persons with Intellectual Disability and their Relatives, to represent their thinking, gather complaints and suggestions, and make proposals to the Shanghai association.

Generally speaking, these children don't have financial problems when they get old, but they need looking after because after their parents pass away, they can't depend on their cousins; they will have their own family to look after. It's our biggest problem and we worry about the future.

H's father: We've thought about this issue very carefully. When we can't look after her anymore, the whole family will move into a nursing home together. It's not just our decision but also one agreed by other volunteers/teachers in our group.

H's mother: Right now, we don't want to make such big deal (crying seriously). At least we can go to a nursing home together—a family style nursing home—live there together. My daughter doesn't like the idea and insists she won't go to the nursing home with us; she promises that she'll take care of us when we're very old. She said: "It's my decision, I won't go to a nursing home and wait to die there."

She has a very bad feeling about the nursing home, because she knows her grandma went there when she was very sick. That's why she believes a nursing home is a place where old people go to die, and said she won't go there whatever happens (choking on her tears). Even though she wants to live at home with us when we're old, she won't be able to look after us, because she has problems with shopping and can't even buy vegetables, we might all die of starvation. She doesn't see it this way, so, unless we find a better solution, the nursing home is our best choice. It's the same for other families in our group. The ideal thing for a family like us is that the parents stay healthy and die after the child. That would be a real relief for the parents (starts to cry again). It's a common problem for all families like us, even some famous people are the same, Yi Qin—the famous actress—has an intellectually disabled boy.

H's father: Director Jin Xie's son is also the same.

H's mother: Actor Xu Huang has an intellectually disabled son as well. Yi Qin still had to bathe her son when she was very old, sometimes she was beaten by her son when he was angry. This man died quite early, in his fifties.

H's father: It's true.

H's mother: Actually, if we're healthy and live long enough, I would rather our daughter died before us, but right now, nobody can tell the future and we can only wait and see what happens.

H's father: We have to look after ourselves and make sure we live longer to be with her.

H's mother: In my mind, the greatest thing the government could do for us is to set up a special nursing home for intellectually disabled people, then the parents wouldn't need to worry that their children would be bullied by other people there.

Q: What would be the purpose of a special nursing home?

H's mother: Compared to people with physical disabilities, our children are more naive.

H's father: Those people might have problems with their hands or feet.

H's mother: But they can be clever and selfish. Intellectually disabled children make up the most marginalized group of all disabled people; they are the most vulnerable in the community. A developed mind is the difference, other disabled people are able to use money or ask other people to buy things for them, but our children don't understand the value of money.

Q: So, the basic worry is about other people being unkind and taking advantage of them?

H's mother: Yes, that's right.

Q: Does Mom worry about discrimination?

H's father: Discrimination is everywhere, but these days their situation is much better.

H's mother: They've been treated more fairly since the Shanghai Special Olympics. Before that time, discrimination was a very common thing, we even had to deal with bias from our own relatives.

Q: Does H feel discriminated against?

H's mother: She never talks to her female cousins, because she worries she might say something wrong. Usually after the family Spring Festival dinner, the children like go to a karaoke hall, but her cousins never invite my daughter. This makes us very upset (she's choking with sobs). My daughter won't socialize with them, but at least they could invite her. My daughter usually tries to reassure us: "It doesn't matter, because I know you won't feel relaxed if I go out with them." (crying).

I have to say, the volunteers we met at the events are much nicer than our relatives. At least the volunteers, some of them are college students like you, are willing to talk to our children, but her cousins won't treat her the same way. Our relatives treat us less kindly than outsiders.

Q: Acceptance by other people is very important for H.

H's mother: Definitely. The last time we took our children on a trip, some self-funded volunteers went with us and they were very nice to the children. What a lovely thing!

It breaks my heart when I talk about these things. I'm all right if I don't think about it, because this problem always upsets me... my heart has been broken too many times since we had her.

H's father: Compared to other people, our fate is so difficult.

H's mother: Sometimes we have to force ourselves to think about something nice; for example, if our daughter had no disability, she might have left home already and wouldn't be able to look after us if we became ill. It's a common story with parents who have a grown-up child, their children are always too busy to take care of aging parents, but if we don't feel well our daughter can make a cup of tea for us.

Under their parents' wing, these children can enjoy a carefree life; they also receive medical care and around 2,000 yuan as allowance or salary. It's pretty good, they can afford a basic lifestyle. The only problem we're concerned about is who

will care for them in their old age after their parents die. For our daughter, the main problem is about her inability to use money properly.

H's father: We mean if she doesn't know how to withdraw money and spend it, she can't live independently.

H's mother: Firstly, she has to develop a proper sense of value and use her monthly allowance in a sensible way; secondly, she has to be careful with change when she uses cash. There are bad people who might cheat her by giving the wrong change.

H's mother: H usually goes to the local store near her workplace, sometimes she gets the same change no matter if she pays with a 10 or 20 yuan note for the same thing, but she doesn't see that there's something wrong with that.

H's father: She can't live on her own without understanding the value of money.

Q: Do you worry about anything else?

H's father: Hospital is another thing, she's fit and healthy at the moment and hasn't had much experience with hospitals, but one day, when she needs to see a doctor, she might not be able to communicate her problems very well.

Q: So, basically, you worry about her seeing a doctor and her sense of money, right?

H's father: The money issue is the most important, because it is something she needs to understand for everyday living.

Interview with Ms. H's Teacher

Interviewee: Teacher Han

Interviewer and writer: Shuwen Wang

Interview date: January 3, 2017

Interview place: Office of Quyang Sunshine Workshop in Hongkou District, Shanghai

Q: Could you tell me the difference between the Sunshine Factory and the Sunshine Workshop?

Teacher: They're the same thing, the Sunshine Factory changed its name from "factory" to "workshop."

Q: What about the Sunshine Home?

Teacher: They have different objectives. The Sunshine Home focuses on study, learning, and entertainment; the Sunshine Workshop is about developing labor and labor skill training, basically.

Q: Do these two institutes share the same space?

Teacher: Yes, we're based in the same place.

Q: There is a mixture of work, study, and entertainment?

Teacher: That's right, the students at the Sunshine Home have lessons in the classroom and the workers at the Sunshine Workshop make products for outside clients.

Q: Which institute do you work for?

Teacher: I teach at the Sunshine Workshop and I'm responsible for production and work skills training.

Q: I saw the workers making red envelopes for Decathlon today.

Teacher: Decathlon is a clothing company, so I'm not sure about that, but we work with a printing house that has a contract with Decathlon. They print the envelopes and let us complete the process which is folding them.

Q: You have a working arrangement with a printing house?

Teacher: Yes, that's right.

Q: Do you get other jobs from them apart from making red envelopes?

Teacher: Yes, we get some different jobs, like threading a string on a label or adding double-sided tape to the back of a normal envelope or something like this.

Q: How do you choose the right jobs?

Teacher: It depends on several factors, basically we can't accept jobs that are too complex, or with a short turnaround or where the price is too low.

Q: Why do you have to give urgent jobs away?

Teacher: Usually the jobs from the printing house are huge quantities and our workers are much slower than normal workers. We wouldn't want to miss a deadline so it is better not to take the work in the first place.

Q: Except for the working speed, do they have other differences from normal workers?

Teacher: They're very different groups. For an ordinary worker, it's natural to correct errors and improve work efficiency when they become used to the process, but our workers can't think in the same way, so even our best worker can't compare to the average normal workers.

Q: You mean they can't think about ways to improve their work efficiency on their own?

Teacher: Very few of them are able to think about how they could work quicker or better.

Q: Did they receive some skills training before they join your workplace?

Teacher: We do have a pre-work training program, but few people can do a proper job after that, so we have to give some of them special instruction afterwards. It's a slow process.

Q: Do you have some teachers to train them?

Teacher: Of course, all four of our teachers can undertake training work.

Q: Take making red envelopes for instance, how long does it take you to teach them to fold the envelopes and put them in a bag?

Teacher: It doesn't take that long to teach them this job, even though they learn at a different pace; except for a few workers, most of them can learn this. For example, we can tell them how to fold and seal the different sections together many times, but some of them have to work in their own individual way to fold the envelopes. Working in this way they are never going to be efficient. They just fold up the envelopes one by one.

Q: Do you have any basic requirements for their work?

Teacher: Our basic requirements include trying their best to avoid damage, don't waste material, and following a quality guide if they can. For them, the last requirement isn't a very strict or precise rule. Sometimes a worker who fails the training has to be kept away from certain jobs. For example, we only have 13 workers that can work with double-sided tape. Usually, these children have shaky hands and this prevents them from doing precision work.

Q: So, not everybody at the workplace can do all the jobs?

Teacher: No, H can't work with double-sided tape. We have around 30 workers at the workshop; sometimes the students of the Sunshine Home come to help if we have too many jobs. The ideal situation would be half the workers doing the double-sided tape job, but the fact is that only 13 people can do this, even though most of the people here are mildly disabled. It's hard to tell, because their practical ability can depend on their intellectual condition; some people at the Sunshine Home are quite good at complex work.

Q: Is there a particular standard you need to achieve?

Teacher: The work is based on productivity, so we use as many as workers as necessary to finish one job at a time.

Q: Does the printing house pay you the same as the ordinary labor market?

Teacher: Our place is a commercial concern as well and we can't afford to take low-paid work, but sometimes some factories will cancel a contract because our price is too high—the workers are slow, but they are not cheap.

Q: How do you calculate their salary?

Teacher: We follow a piece-rate wage system; their workload and their income depend on how much they can produce.

Q: How do you distribute the salary, by card or cash?

Teacher: We pay cash.

Q: Do you provide lunch as well?

Teacher: Yes, but they pay a fee of 60 yuan per month.

Q: It's a pretty fair price. Do they also have a lunch allowance?

Teacher: That's right, we only can afford to supply lunch with their allowance from the Quyang Subdistrict office. We order meals from the Citizens Inn, a community service center. They also have a meal delivery service.

Q: What time do they finish?

Teacher: Normally they work from around 10 a.m. to 3 p.m.

Q: How often do they get jobs?

Teacher: Hard to tell, but we're quite busy at the moment. But our off-season will come soon, and our workers will have more free time.

Q: What do they do in their free time?

Teacher: We have a teaching schedule which includes classes in dancing, singing, and other things.

Q: Except for the salary from their work, do they receive any other income?

Teacher: That depends on their condition. Students from the Sunshine Home are usually severely disabled and unable to work, so they receive a monthly allowance of over 1,000 yuan from the subdistrict office. The students who work at the Sunshine Workshop have milder conditions and are able to work, so the government offers

them three kinds of social insurance and funds and also an allowance of 876 yuan and a lunch allowance.

Q: There are two different groups of people from the Sunshine Home and Sunshine Workshop?

Teacher: Yeah, there are two groups, those with mild condition who work for the Sunshine Workshop, but students with a moderate or severe condition belong to the Sunshine Home. Generally speaking, our workers have to pass a simple working skills training program to become low-skilled workers. The most agile workers also have a potential opportunity to be recommended for a proper job. We have some pictures of students in real jobs on our office wall, quite a few.

Q: Do you have fixed contracts with some companies? What kind of jobs do you usually get?

Teacher: No, we don't have fixed contracts with anyone, but quite a few companies come to the DPF office to hire a couple of workers. They are usually hotels or similar companies.

Q: Generally speaking, what kind of jobs?

Teacher: Basic hotel jobs like room service, collecting used bedding and towels for the room laundry, or working in storage in the kitchen. To be honest, the students from our workshop can't compete with piece-work workers from outside; if a worker's average production is more than 100 boxes, our students could probably only finish 20 or 30 in the same time.

Q: Can they become affiliated to a company?

Teacher: Of course, they can. Some of our students are affiliated workers and earn the minimum salary of 2,190 yuan a month.

Q: Could you explain more about this affiliated worker policy?

Teacher: Shanghai's employment policy allows a local company to set up 3% of jobs for disabled people and this means that 3 out of every 100 jobs must go to disabled workers. However, because of work efficiency, these companies tend to pay the salary and social insurances but allow the disabled workers to stay away. Special workers in the workplace might cost them more money and effort, so paying them not to be there is best for both sides.

Q: How is H's performance here?

Teacher: She's pretty good. She is an enthusiastic worker and highly adaptable socially.

Q: Does she like to chat with her colleagues?

Teacher: Of course.

Q: Does she like to communicate with her teachers?

Teacher: Not really, she seems to be afraid of the teachers, but gets on very well with her classmates.

Interview with Miss H's Co-Worker

Interviewee: Mr. Lu

Interviewer and writer: Shuwen Wang

Interview date: January 3, 2017

Interview place: Office of Quyang Sunshine Workshop in Hongkou District, Shanghai

Q: Do you know H?

Mr. Lu: Yes, we studied at the same school, the Miyun Road Special Education School.

Q: Do you remember what she liked at school?

Mr. Lu: She had short hair, shorter than now, she was active and open and liked sports, skipping, and other things.

Q: Did she have a good relationship with the teachers and other students?

Mr. Lu: She was quite close to our classmates, chatted with us quite often. She had a pretty good relationship with our teachers and liked to talk to them.

Q: How was her performance at school?

Mr. Lu: She studied very hard and always finished her homework on time. She loved domestic science and joined in the school's general cleaning sometimes.

Q: What happened afterwards?

Mr. Lu: She graduated before me and joined the side drum band. I graduated in 2009 and went on to the baking training program, but we met up again in the side drum band and the Sunshine Workshop in 2014.

Q: Had she changed when you met her again in 2014?

Mr. Lu: Definitely, she wasn't good at music before, but now she can play harmonica. And she's become more open.

Q: What are H's good points?

Mr. Lu: She's willing to help other people, she helps me with work as well. Sometimes she reminds me to wear extra clothes so as not to catch a cold.

Q: How about her bad points?

Mr. Lu: Her bad points are she likes to chip into other people's conversations (he's smiling), sometimes she might lose her temper.

Q: Did you ever see her get angry?

Mr. Lu: Hum, she might get angry if somebody criticizes her harmonica playing.

Q: What does she do when she's angry? Does she argue with people?

Mr. Lu: No, she doesn't argue, she never gets angry with other people, just gets upset and cries by herself.

Q: Does H have hobbies?

Mr. Lu: She likes dancing, she's good at *Grateful Heart* and *Little Apple*. She plays the flat drum and side drum. *Chinese Kung Fu* is her favorite.

Q: Are you close to each other?

Mr. Lu: Yes, we talk with each other quite often. We usually chat about music, news and watch her favorite cooking program together, *Popular Food*. We talk about the programs and the nice food as well.

Q: Do you talk about music and play musical instruments together?

Mr. Lu: Yes, I play harmonica and clarinet, so I became her harmonica teacher and help her practice.

Q: Is she a quick learner?

Mr. Lu: She's very good, we usually practice harmonica together every Tuesday at the Sunshine Home.

Q: Is she a good harmonica player?

Mr. Lu: She isn't bad. She can play, *Let the World Filled with Love*³ and *You Raise Me Up*.

Q: Is she close to the other colleagues?

Mr. Lu: No, she doesn't communicate with other people as much as she did at school.

Q: Why?

Mr. Lu: I don't know.

Q: Does H have any other friends apart from you?

Mr. Lu: Yes, this guy and other guys all are her friends (he points at some colleagues around the office), six friends altogether.

Q: Do you hang out together?

Mr. Lu: We go to Carrefour or have a wander on the way back home sometimes.

Q: Has she impressed you in any way?

Mr. Lu: Yes, she supports me as team leader and flag carrier?

Interview with Miss H

Interviewee: H

Interviewer and writer: Shuwen Wang

Interview date: January 3, 2017

Interview places: Office of Quyang Sunshine Workshop in Hongkou District, Shanghai

Q: What did you have for breakfast?

H (smiles): Cake, I had cake.

Q: What time did you leave home this morning?

H: 8.30 a.m.

Q: Did you come alone?

H: Yes, I came here by myself.

Q: What do you do here?

H: Make red envelopes.

Q: Do you also make rubber erasers?

H: Erm...

Q: Which work do you prefer?

H: I like making red envelopes.

Q: Why do you prefer making red envelopes?

(H doesn't answer but laughs.)

Q: Do you prefer to stay at home or come to work?

³*Let the World Filled with Love* refers to a very famous Chinese charity single, which became popular in 1986 when it was performed by over 100 singers.

H: Here.

Q: But why?

H: Because here I have lots of friends to play with.

Q: Who are your closest friends?

H: Xiao L, Xiao Z, and Xiao H.

Q: What do you usually talk about together?

H: Just small talk.

Q: Where is the food more delicious, home or the workplace?

H: The food here.

H: What hobbies do you have?

H: Singing and dancing.

Observation of Miss H in the Drum Team

Observation date: 9:00–11:30, November 27, 2016

Observation place: Cultural and Sport Center of Hongkou District DPF, Shanghai

Observer and writer: Shuwen Wang

Time	Content	Observed activities
9:00–9:13	All of the students practice on the second floor. H's mother and other volunteers stand at the front to teach them	H is pretty good at the dance, from time to time she takes a look at the floor or someone else. When they are changing the formation from one team to two teams, H seems to forget her movements and place, so she watches both sides and walks to her place quickly. At the end, H forgets a half squat movement, but she follows the other students
9:13–9:18	The second round of side drum practice	H doesn't forget her actions, but she turns around and watches the others all the time. H watches carefully and laughs sometimes when the teacher gives somebody individual instructions. She covers her mouth and laughs at a student who has a runny nose and gets a tissue from H's mom
9:18–9:24	Break time	H sits down and chats with her teammates while she uses her hand as a fan. Later, she stands up and chats with a tall boy. H gives the observer some hot water after H's mom reminds her

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Time	Content	Observed activities
9:24–9:34	During the group dancing, almost half the students have problems with movements or rhythm. The teachers give individual instruction to the students and help them catch up with the formation	H takes off her coat when she feels hot and only wears her red sweater. Practicing the group dance, <i>Moonlight over the Lotus Pond</i> and <i>Bright Spring Day</i> . H's movements are skillful and accurate. The teacher guides students to practice a cross step. H looks at her feet and walkson her toes
9:34–10:00	Practice group dances	The group practice another nine group dances together and H dances eight of them. She doesn't practice one dance because she hasn't learned it, so she stands at the left side and watches the other students. The teachers stand at the front and correct the students' actions from time to time
10:00–10:15	Preparing to bak	H takes out an equipment box, dresses in a pinafore, hat, gloves and mask. She stands at a table with five or six teammates
10:15–10:35	The volunteer shows the students how to make biscuits	The volunteer teaches one student to mix the ingredients with the mixer, then puts the mixed ingredients in a plastic bag, and pushes it into the mold. H watches very carefully
10:35–11:05	Making biscuits	H asks her teammate to move the mold closer to her side, this makes it easier for her to add some chopped walnuts to the mixture. The volunteers help the students correct the way they carry the bag. H takes a filled-up bag and adds the mixture to the mold while her mom stands by to help her
11:05–11:30	Washing the equipment	The volunteer puts the tray into the oven, at the same time, H and her mom take the used equipment to the bathroom for washing. The mother points out the places where H didn't wash properly and rinses the equipment one more time herself
11:30–11:35	Sharing the biscuits	People share the biscuits and take group pictures. H smiles and hands her biscuit to the observer

Observation of Miss H at the Sunshine Workshop

Observation date: 8:30–15:00, January 3, 2017.

Observation place: Office of Quyang Subdistrict Sunshine Workshop in Hongkou District, Shanghai.

Observer and writer: Shuwen Wang.

Time	Content	Observed activities
9:00–9:10	The workers fold red envelopes in a classroom. The atmosphere is rather exciting, people are talking and laughing	H gives the observer a hug when they see each other, then walks back to her seat to make red envelopes. H puts three bags together, aligns the lower edge, then folds the seals at the same time. Later, she separates the bags and puts them in a plastic bag separately and seals double-sided tape at the top of the bag afterwards
9:10–9:12	The teacher calls out the names for the register	H answers when the teacher calls her name. Then she puts packed red envelopes together, but the high tower of bags is leaning to one side, so H divides them into two groups when she sees the problem
9:12–9:30	Making more red envelope	H puts a rubber band on a bunch of bags. H fetches a bunch of unfinished bags from the front desk; after that, she walks to the door and takes a look outside. She takes out her water bottle and puts it on the desk. She chats with colleagues while making red envelopes
9:30–9:40		H spots an odd-looking bag and checks with the teacher, and she is told it doesn't matter. Two bags of red envelopes fall down from the desk twice and H keeps picking them up. She uses a rubber band to hold 33 envelopes together. She usually turns around and looks at the door while working
9:40–9:55		A colleague comes over and H greets her
9:55–10:10		While some colleagues are chatting across the aisle, H listens and looks at them from time to time. She walks to the front of the desk after she runs out of plastic bags

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Time	Content	Observed activities
10:10–10:20	The teacher checks the red envelopes	The teachers checks the number of H's envelopes, but finds out she has bundled over 25 bags together. So the teacher helps her count the envelopes and bundle them up again
10:20–10:40	Making red envelopes	When she hears a colleague's joke, H laughs away and joins in the conversation, then she counts out some new envelopes. The boy sitting behind H asks her for some plastic bags, so H walks to the front desk to fetch some bags for him
10:40–10:50		H bundles up more finished envelopes but the unfinished envelopes at the front desk have run out. H stands next to her seat for a while and gives an extra rubber band to her colleagues. She has a wander around the hall and chats with some colleagues when she returns
10:50–11:30	Lunch time	H and her colleagues start cleaning up the desks when the lunch boxes arrive. The lunch includes a set rice meal and a bowl of tomato and egg soup
11:30–12:00	Break time	H has a slow walk in the park, which is next to the Sunshine Workshop. She chats with a colleague when they meet in the park and watches somebody play a handheld game console
12:00–12:40	People have a rest in the classroom during the break. The curtains are closed and the room becomes dark	H walks back to the room and takes a rest
12:40–13:10	Making red envelopes	The afternoon duty is same as the morning, making more red envelopes
13:10–13:20	Break time	When the unfinished red envelopes run out, H sorts out her finished red envelopes and drinks some coffee from a flask
13:20–13:50	Making red envelopes	More unfinished red envelopes come in and H gets some as well. The teacher repeats working tips. H bundles up more envelopes after she's worked for a while

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Time	Content	Observed activities
13:50–15:00	The teacher lets the workers line up in a queue in the hall to wait to weigh the red envelopes they made today. Teacher Han is in charge of weighing and recording	H carries her whole day's work to the hall and joins the queue to wait for the teacher to weigh it
15:00–15:15	Duty off time	H and several other workers play musical instruments in the corner
15:15		H leaves the workshop with a colleague

*Translated by Huili Meng
Edited by Russell Murray*

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Be My Own Champion



Jing Zhang

Interview with Ms. Le Xing and Her Teacher

Le Xing, female, born in 1991.¹ An orphan from the welfare center who lives in a foster² family. Mild intellectual disability. Graduated from the School of Special Education in Pudong New District, Shanghai. In 2007 and 2015, she participated in the Special Olympics World Summer Games. She started working in 2010 with three previous jobs as working experience. She's now married, with a son.

Interviewees: Le Xing and Ms. Ying Wang (Le Xing's teacher)

Interviewer and writer: Jing Zhang

Interview dates: October 29 and December 6, 2016

Interview places: Starbucks in Pudong New District, Shanghai; Library of Pudong New District, Shanghai

¹Le Xing is an orphan from a welfare center who grew up in a foster family. Since she currently has no contact with the foster family, the interview with her teacher replaces that with her foster parents in this case; during the interview, Le Xing was fired, thus no working observation is included.

²Fostering is a care system in which a minor supervised by civil administration department is placed in a family that meets relevant criteria through prescribed procedures. The Chinese civil administration authorities have long considered the best way to bring up orphans and abandoned children. In the 1990s, Beijing, Shanghai, Anhui, and other cities launched experimental family foster care. According to the *Notice on Issuing the Interim Measures for the Management of Family Fosterage* (Civil Affairs Department Doc [2003]No. 144), a foster family shall meet the following conditions: it shall have a registered permanent residence and a domicile in the place where the fosterage service organization is located; the living area for each family member shall not be less than the local living level per person after the fostered child moves in; it shall have a steady income, and the per capita income of the family members shall be in the middle of or above the local per capita income level; the major fosterer shall be not less than 30 but not more than 65 years old, with good health, corresponding ability and experience in child fostering, and education of a junior high school level (or an equal level) and above.

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From the Welfare Center to a Foster Family

Q: When were you born?

Xing: August 10, 1991. I was born an orphan and sent to a welfare center. Later, I came to live in my foster mother's family, together with an elder brother, who was 5 years older than me. They didn't know about my intellectual state at that time.

I was adopted because my foster mother heard news about fosterage and thought it would be better to find a playmate for my brother. But at that time, my foster father was against this idea, as no one had time to take care of an extra child. Also, both of them needed to work at that time, which meant it might be inconvenient and unsafe for me to stay at home. Anyway, after a long discussion with her husband, my foster mother finally persuaded him. She went to the welfare center with her friends who also wanted to adopt children when she was almost 50. None of them heard about fosterage before, so they all wanted to have a try.

After I was adopted, my brother would sometimes look after me during summer vacation. But I was too little, feeling afraid of the new environment. If I didn't behave well, my brother would lock me in the room or inside the cupboard. That was horrible! Sometimes I felt upset, and when my brother thought he couldn't do anything with me, he would call my mother back.

Q: Did your foster parents treat you well?

Xing: My mother used to take me to her elder sister's home during vacation and cooked wonton or noodles for me, but not after I grew up. She gradually discovered that it was hard for me to learn things. Later, she separated from my father as she said he had affairs even before my fosterage. Coupled with some other tension later on, my mother finally changed the lock on the gate to keep my father out of the house.

When I came to this family, they already spent less time together, and my father left the home when they separated. Gradually, my contact with my father decreased, but not my brother, as he would visit Grandma near our home on the same road. I visited Grandma when I was little as well. The old house and the road weren't rebuilt back then.

After the divorce, my mother gradually grew grumpy. When she was in a good mood, she could still listen to me; otherwise, she would lose her temper and ask me to shut up if I talked too much or too directly. I'm bad at the art of talking. I can only be straightforward and tell the truth. So, I had quite a hard time. For most of the time, my brother, my mother, and I stayed at home, while my father seldom came back. He would quarrel with my mother due to some issues and me. Everything just got messed up. This made my mother annoyed.

Before I went to school, my parents thought I was obedient and would tell others that, "Well, my girl is really good. She can help us with housework." They indeed taught me about it. But as I grew up, seeing my abilities didn't develop as others, my mother was kind of...

Q: How did your mother treat you after you grew up?

Xing: When I was little, I lived in the Haiyang Village near to Shangnan Road School. I needed to take a bus to go to school, but my mother wouldn't give me the

bus fare. She said, "You're on your own." Thus, in the morning, without money or a public transportation card, I could only be a ticket evader by sneaking onto the bus among taller adults to avoid being seen by the driver. In the afternoon, however, as the school ended early at around three, I couldn't use the morning trick. So, I would return on foot. On Fridays, if the classes ended early, my classmates might carry me on their bikes. Going to school was even harder than going to work at that time. I loved walking home with my classmates as I could walk and chat with them in the park or visit my classmates' homes. I told none of this to my mother. She didn't trust me; and I didn't want to talk about it.

My mother worked from Monday to Friday and returned later than I did. Sometimes, when she arrived home, she would ask me when I left school and why I didn't pick up the phone at home. In this case, I would lie to her. I was quite a natural liar. Besides, I got a bad habit, which was stealing money! It developed because I had no pocket money at all to go out to play sometimes. Fortunately, I knew where my mother hid her money. Then my mother noticed the loss of money, discovered that I was the thief soon after she asked me about it, and beat me many times. I didn't care about it, actually, as I really had no other solution. If I ever asked her for money, she would ask me what for, and refused to give it to me on the grounds that I was a student instead of staff. But seeing other friends already had mobile phones and everything, I felt quite upset.

When we got along, I once said, "Mom, I want a mobile phone." She would say, "Why? You're always at home, why would you need it?" This made me quite unhappy. As I had been quite poor, it was only after I started working that I got my first mobile phone, a keyboard Nokia, which was given to me by a colleague close to me. I changed to better phones afterwards gradually. My brother once bought a SIM card for me, but no phone. His phone was an old one made of bad material. I didn't like it, either.

While I was at home, I had nothing to do and couldn't watch TV. My mother would watch me doing things. It was really boring. I could never go out at night, nor could my classmates come to my home, except sneaking in when my mother was out.

It was not until I went to the vocational department after I finished my ninth grade that my mother provided me with living expenses and a transportation card with a monthly top-up of 50 yuan. After I started working, my salary was also in her control. I got pocket money occasionally.

My mother hated it when I talked with others, especially about my family. She felt awkward. She thought what I said was different from her words. In the end, she wouldn't allow me to say anything, even the phone number of my home. Unlike my situation, my brother got everything he ever wanted. This really annoyed me.

My mother was always like this. After turning 50, due to her menopause, bad relationship with her husband, and other issues, she became quite grumpy. Also, she regretted adopting me, always mentioning that how smart I was when I was adopted, how it became harder and harder for me to learn things, and how I grew up a liar. I was still at her home when I participated in Special Olympics for the first time. She showed no interest in my gold medal, but became extremely happy when I told

her that she could go with me to receive a bonus from my school. Later, I suggested to her that we could save half of the bonus and buy a TV with the other half. She agreed. When I became a member of staff, she also kept my payroll card.

Actually, I thought she was really kind when she was in a good mood. She would also worry about me, talking with me about my future and my marriage, while I just replied, yeah, I know, I know. Otherwise, it was impossible to start a normal conversation. According to her, she wouldn't say things twice, the way other people treat and teach children. She was impatient and irritable.

Q: How did your mother educate you in your daily life?

King: Basically, there was no education and she thought I was a bad learner. She once said, "Even though I taught you once, you would forget by the next time." But you can learn simple things like cleaning the table, so that you can live on your own. She also taught me to do the cleaning. Therefore, I could take care of myself at an early age and knew how to wash my socks when I started to go to school. She was weird in that since I was little, she taught me to collect and wash the dishware and clean the table, but asked me to clearly separate the ones I used, and the ones they used. She seemed to express her repulsion. I didn't understand this until I grew up.

Q: How's your relationship with your foster mother now?

King: Now I don't live at her home. Previously, the welfare center provided us grown-ups with houses for rent. Mine was relatively far away in Puxi. This sparked some conflict. That is why I left.

Q: Ms. Ying Wang, do you know about Le Xing's foster family?

Teacher: The household registration of Le Xing is still with the welfare center. Her case is not adoption, but fosterage. In the past, our school was not free. All the tuition fee and insurance were reimbursed by the welfare center. According to the national policy, the welfare center shall provide foster families with monthly childcare expenses, while the children can experience family life. This amount of money could serve as a subsidy for some families, as there were a large number of middle-aged men who lost their jobs. Fosterage requires signing an agreement every year to make sure the family won't carry out physical punishment or abuse the children. There were many cases of fosterage in the same group with Le Xing, we had four or five cases as well, but now the numbers have declined. Normally, fosterage ends at the age of 18, when the children are independent.

I remember that when Le Xing came to our school, she already went to the first grade. She was about 7 years old. She was fostered before that and the fosterage lasted for a total of 13 years.

Le Xing was an obedient and cute child. She had a difficult time growing up as the education model of her foster mother could go to extremes sometimes. But on the other hand, her mother also paid a lot of effort since she became a single mother after her divorce, and she had to raise her son and foster child. We've always told Le Xing that she should be grateful to her mother who gave her a happy childhood. Without her help and upbringing, you may end up living with other children in the welfare center. After all, the mother brought her the warmth of family life. I think Le Xing was always thankful.

Of course, the relationship between parents and children is out of the control of the latter, let alone a special child. It requires the effort of both sides. Despite some issues gradually arising in the process, we wouldn't get to the bottom of it and judge. After all, Le Xing has become an independent adult with a family. She can integrate into the society. This is what we hope to see.

Le Xing is really grateful as she always informs her foster mother of her life, including when she found a job, had a boyfriend, and got married. Generally, she grew up smoothly despite some sad memories with her mother. But in my opinion, a home is at least better than the welfare center, right? So, Le Xing, don't carry a grudge against your mother. Someday when your mother gets old, I believe you should still go to visit her if she doesn't refuse it.

Twelve Years of Happiness in Special Education School

Q: When did you go to school?

Xing: I stayed in a small kindergarten next to my mother's previous company when I was very little for a short while. She would take me there on the way to work. At that time, she thought I was cute, and she loved taking me out.

After kindergarten, I needed to go to a primary school. During the entrance exam, when the teacher asked me what my name was and who brought me here, I performed badly. I either didn't respond, or I understood the question, but didn't answer correctly. So, I failed. Facing such a result, my mother replied nothing, but suggested I went to a special education school, where I started the first grade. Since then, my mother started treating me differently. I never asked her about my lessons, nor did I want her to teach me. I was afraid that she would scold me.

She used to take me to school on her way to work and pick me up after work. But since the third grade, I started being on my own. On Fridays when classes ended early, I would go shopping with my classmates to avoid going home so early. And I would lie to my mother about my whereabouts in case she wouldn't let me out. I always told her that I walked all the way home.

Q: Did your mother help you with your homework?

Xing: She didn't need to. Normally, I would finish it at school, or at home occasionally when I didn't have enough time at school. Teachers could answer my questions. There were also a lot of classmates who would help each other. My mother hardly did this. She didn't have the patience and she thought I was a bad learner.

Q: Did you get awards from your mother when you performed well?

Xing: Teachers would award and praise me and tell me I was great when I performed well. They knew I was not that good at studying, so they paid close attention to me and helped me a lot.

Q: How did the teachers help you?

Xing: Teachers were changed frequently. I've forgotten many of them. But starting from the sixth grade to the ninth, Ms. Zhu remained as our math teacher and the teacher in charge. She knew about my situation and cared about me a lot. I also

performed well so that she wouldn't worry. By the way, there's also Ms. Shi. During the first grade, when we were seven or eight, she wanted to make us do some exercises in the morning to strengthen our body. She took me to the PE room, actually the gymnastics room, to test my flexibility. I thought it was okay since I was little at that time. From then on, we exercised every morning before class and we needed to learn gymnastics as well. All the teachers considered us as normal people. They even took us to performances outside the school.

Teacher: She came to our school at the first grade, when I didn't work here. Her hair was quite short back then, looking like a naughty tomboy. That's why she was always assigned the role of a boy in dancing. There were a lot of photos (introducing photos in the album). She also took part in many extracurricular activities and foreign exchange activities. This is Tim, chairman of the Special Olympics Committee³ (pointing at the photo).

Xing: My mother didn't want me to wear my hair in plaits and I didn't know how to do it, either. Thus, I just kept it short. I was super like a boy, you know. There aren't that many photos left, in which my face looks big. Now I think the person in the photo doesn't look like me.

Q: How was Le Xing's performance at school?

Teacher: She wasn't that good in math, but performed much better during classes of life skills, right? She can make delicious steamed buns, much more capable than me. At that time, she was also a member of the gymnastics team led by Ms. Shi and the dancing team led by Ms. Yang.

In our school, since our strength lies in Special Olympics sports, we can offer more opportunities to students for learning and exchanges with other organizations. This helps improve their social skills. Teachers also consider students as their own children and give particular care to students like Le Xing and Zhang who live in a special family environment. For example, teachers would give the students new clothes outgrown by their own children. While at school, Le Xing would love to call her teachers mother, like Ms. Shi, Ms. Jin, and Ms. Yang.

Teachers from the welfare center are also very kind, treating these children like their families. Before the children turned 18, the welfare center would hold annual parties. Teachers, especially Ms. Dong and Ms. Qiu, would also ask them about their lives, study, and health.

Xing: I call the teachers mother. For example, I call Ms. Liu "Mom Liu". After I finished junior middle school, I went to the vocational department, where I met Mom Liu. Even though I've graduated long ago, I always contact her and ask her how she's doing. I also ask about the situation of Mom Wang (Ms. Ying Wang) (laughing). During weekends while I was at school, Ms. Cai would take me home to play with her children. She also took me to many charity events.

A few days ago, Ms. Shi asked when I would bring the performance costume used in Special Olympics to school, so I went to school for that. She said sorry for making you to come simply for this. I said it was okay, it was nothing. I could help you as long as I was still able to. Transportation to school is convenient. It's either a short bus

³Mr. Timothy Shriver, chairman of Special Olympics International.

ride, or my husband can take me and my child to school by driving an electro-mobile for half an hour. My teacher said my child looked a lot like my husband.

Q: How long did you study at Pudong Special Education School?

Xing: From the first grade to the ninth grade. Then I went on to learn pastry in the vocational department.

Teacher: She entered our school at the age of seven. First, she finished the nine-year compulsory education, then she went to the vocational department in our school for another 3 years of study. So, she stayed at our school for 12 years in total.

Xing: In the vocational department, we needed to choose the major ourselves. I didn't choose business since I was bad at math, nor did I like to deal with tablecloths as in the hotel management major. Pastry seemed to be better. I just needed to knead the dough. Now I've changed my job and I don't practice it at home, so my skills have become rusty.

Q: How about the relationship among classmates?

Xing: There were more than 20 classmates in a class. The number of boys and that of girls were close. In the fourth grade, based on the performance, teachers would regroup the students with around 15 people in one class. Then this arrangement would remain the same until the ninth grade. We grew up and studied together, all the way up to the fifth or sixth grade. After school, several classmates and I would always go to the park. Sometimes they might invite other classmates, including boys.

Among them, there was a girl who was my best friend. She was the same age as me, and she also seemed to come from a welfare center. She was really smart, moving to our school from a regular school after the first grade. We were so young that we always quarreled and fought with each other, even grabbing each other by the hair. Teachers would tell us not to do that again. Normally, we solved it between ourselves. She's also a mother now. As with other classmates, our relationship was just so-so. We just mind our own business as we grow up. Currently, I also get along well with another girl of the same age as me. There's something wrong with her feet, so basically, she doesn't go to work.

In addition, I used to be very close to another girl about the same age as me. She wasn't abandoned by her parents. During school days, if my mother found out I stole some money, she would go to the school and blame that girl as well, since the girl asked me to steal 100 yuan for her. Teachers would rebuke my mother for this, while after returning home, I would be blamed and beaten by my mother. But the lesson wasn't learned. I would steal again just a few days later. I guess I didn't know what I was doing at the age of 10 or 11 back then. I didn't hate that girl even with all the trouble. We cared about each other. Her mother, having been divorced, cared less about details, including her use of money. She was similar to her mother in this respect. Sometimes I lied to my mother, saying that I wouldn't go home but I actually lived at the girl's house, my mother didn't care about this at all. The girl took good care of me, allowing me to use her things, while I also treated her very well since I was born in August and she was about 4 months younger. We were like sisters.

Both of us practiced artistic gymnastics. We attended a competition in Shanghai in 2007 when we were in the ninth grade. She didn't win the gold medal, but she did

win silver and bronze ones. She thought this was no big deal and she had nothing to do with Special Olympics. She even told Ms. Shi that she wouldn't participate anymore. After marriage, she said she wouldn't attend Special Olympics even if she was asked to. It was meaningless. Her in-laws disliked this as well. Besides, she wanted to hide from her husband's family that she once participated in Special Olympics and went to a special education school. But in my opinion, that's ridiculous. A fact always remains a fact. Anyway, she thinks she's the same as other normal kids with the same level of hands-on abilities. And in terms of reaction and intelligence, she always outperforms me.

Until the ninth grade, we were in the same class. But later in the vocational department, she chose the business major in the context of supermarkets and dealt with numbers. Sometimes I felt she looked down on me. When we texted each other, she would keep asking me something, hoping to get a clear answer even if I didn't want to talk about it. Upon graduation, we gradually drifted apart. Later, she married a rich man in our class who was a year younger than her and owned two houses. She says she also owns a house; thus, she has three houses altogether. I don't buy it at all! She loves to brag, I know that. She also says she lives well as a conductor on the bus, working together with her husband. Actually, she doesn't get the job by herself, but through her husband's network. She's fat now. I seldom contact her.

She's still my WeChat friend, though. Her baby is 1 year older than mine. She always talks about her husband and asks me about the usage of diapers and ways of saving money. Just like her mother. They're both good at careful calculation.

Q: Do you still remember how your days in class were?

Xing: When I was in grade three or four in the Shangnan campus, the most annoying moment was when my teacher of Chinese asked me to recite poems, keeping me in the classroom even after class or after school. Actually, I could read them and remember them for a while, but when the teacher asked us to recite poems in the classroom the same day we learned them, I was so nervous that I was unable to do it. When all the other classmates left school, I was still there, listening to the teacher explaining everything to me carefully. I was a little freaked out, but the teacher was quite patient, asking me to read the poem again and preparing to answer my questions. Most of the teachers knew that I was bad at reading and learning Chinese and math, while super-fast in practical tasks.

Normally I finished my homework in school. If I encountered difficulties when I did the homework at home, I could call the teachers or ask them or my classmates when I went to school the next day. We had moments of relaxation and periods of heavy course load. Before the final exam, teachers would urge you to study harder, ask you to do the review exam paper many times, and review the mistakes or learn the textbooks more carefully. But actually, the review paper was the same as the actual one. Sometimes teachers might also invite me to the office to do the test papers. I remember them saying, "Le Xing, you didn't do this part very well. This method didn't work. As I said during class, you could ask me if you had questions." All the teachers were very good, as I recall. Ms. Jin, in particular, knew I wasn't good at studying. She tried her best to help me and taught me patiently many times until I could remember what we learned. Ms. Du from the Office of Educational

Administration taught us to beat the drums when raising the flag. Ms. Shi would come to the gymnastics room to ask me how everything was going and teach me the moves that I didn't know. Some classmates might hunch over the desk when writing. Then the teachers would ask us to sit up straight or pat us as a reminder.

The happiest time of day was during the lunch break. All the classmates enjoyed playing poker together. We got along well with each other. But sometimes, I would envy those who performed better than me. There were a lot in my class. While in the vocational department, our class had about 12–15 students with more girls than boys, gathering almost all students with strong hands-on abilities. Especially in terms of making steamed buns, the patterns made by some girls were much better than mine. This made me frustrated. Our pastry teacher Ms. Liu, who was also our deputy teacher in charge, would often encourage me.

A Seven-Year-Old Tomboy Practices Gymnastics

Q: When did you start practicing gymnastics?

Xing: Since I was seven or eight. At that time, I looked like a boy. Ms. Shi guessed I might be flexible since I was young, so she asked me to have a try in the gymnastics room. I didn't even know what she was going to do. Her original intention was simply to strengthen our body, without thinking about any competitions. In the old gymnastics room, she would directly step on your feet and try to hang you on the bars. Gradually, she gathered more and more students, while thinking carefully about how to teach the moves. But I didn't exercise much back at home.

Teacher: Ms. Shi believed that learning gymnastics might help to improve various abilities of these kids, so she established the first gymnastics team of our school. Le Xing was one of the members. The training was boring, but Le Xing never complained about it. Every morning, she came early to start training with Ms. Shi and stretch her muscles. She persisted in doing so through the years.

Xing: Ms. Shi thought the students she selected were satisfactory. Then the training officially started. Every morning, we came to the gymnastics room around 7 o'clock and practiced for 40–50 min, before we returned to the classroom and then did radio calisthenics. Under the guidance of Ms. Shi, we started from basic training, like stretching our legs, with figure and flexibility training, then it became increasingly difficult. Sometimes we might watch the videos on a computer to learn the moves. After I began these exercises, I also started to participate in various competitions. Without gymnastics, I wouldn't have those future achievements.

Back in 2007, I practiced artistic gymnastics, like uneven bars. It was difficult. Also due to the exercises, I got more muscles in my legs and bottom. Whatever trousers I wear, my legs don't look slim at all. But now there's nothing I can do. It's impossible to make my legs thinner again.

In the beginning, I didn't know how to do a cartwheel and couldn't perform it along a straight line. So, the teacher taught me to do it like this (demonstrating), just

like a boy. She would support my feet and help me to turn over. I gradually learnt it this way.

The same went for the backbend. I started from initial exercises, in which the teacher supported me up and pushed me down. It was hard as well. Sometimes, I felt under pressure if I couldn't do it well. I would say to Ms. Shi that, "I feel exhausted. Can I call it a day?" Ms. Shi replied, "All right then. You can stop for now and think it over when you go back home." I would just do what she said.

I once slacked off, thinking about giving up. Originally, gymnastics sounded easy to me. I thought I just needed to do some sit-ups, listen to the music, and watch some videos of basic rhythmic gymnastics, and so on. To my surprise, it could be so hard that I yelled like a pig about to be killed when stretching my legs. The teachers would ask me if I still wanted to continue. Some other classmates also encouraged me, saying, "Lele,⁴ let's exercise together, just for fun." Then I was convinced.

At that time, Ms. Shi was younger and stronger. I asked her to be gentle with me, but she said she already was. To me, however, it was still too much. She pressed me so hard and so quickly that my head touched my foot in an instant. Now, I can't stretch my body like that anymore.

Later, I imitated Ms. Shi to stretch other students who were not that flexible. As I got tons of strength just like a boy, all the kids cried, "Ouch! Don't be so harsh on us, Lele." If I beat someone, it also hurt a lot. Apart from one student with Down syndrome, I always invited all the other team members like me to stretch. They tended to avoid me, "Oh no, it hurts so much." I would tell them Ms. Shi asked me to do this, and stretch them one by one. It felt so good. At that time, there were many students practicing together in a lively atmosphere. We didn't feel it was too hard.

One girl in the team had the same experience as me. Her foster family already had elder brothers and sisters. Later when her foster parents decided not to keep her, she was sent back to the welfare center, after which she didn't come to the school often. But now she leads a good life, living in a house provided by the welfare center.

Another girl in the team was also sent back to the welfare center by her foster family before the age of 18. Now, she lives independently, though. She was one grade higher than me and came to our boarding school, the Pudong Special Education School, as late as the seventh or eighth grade. She studied well, with no serious issues concerning her IQ. It was just that she didn't like talking. In the ninth grade, her foster parents disliked her and sent her back to the welfare center. She never returned to school, nor did she go to the vocational department. Actually, returning to the welfare center is also good, enabling her to help kids younger than her.

Q: Apart from competitions, did you take part in any other activities during your school days?

Xing: I also learned dancing. It was quite simple. The school has always been organizing the dancing class, so I started to learn the basics, together with my training of gymnastics. Many kinds of dancing, including the traditional Chinese fan dance,

⁴Lele: nickname of Le Xing.

and street dance, were taught step by step by our teachers acting as the choreographers. We would then participate in the shows held inside or outside the school. Sometimes we might come back later than 10 p.m.

I also took part in inclusion activities, in which we students acted as the inclusion journalists to carry out interviews, or attended knowledge sessions of Special Olympics. Our teacher Ms. Cai regularly took us to other cities like Beijing and Harbin, where we interviewed other athletes to know more about their hard training. We would get so nervous when we did the interviews.

The inclusion activities broadened my horizons. I met and wrote a letter to the mayor of Shanghai, and also put on a performance in the Century Park together with the famous dancer, Mr. Doudou Huang. I've kept many certificates and photos.

Gradually, I got to know more about Special Olympics. Once, I was selected, together with some other students and led by our teacher, to be in a press conference on behalf of our school. It was there that I met Tim. As I recall, he seemed to be some VIP like the chairman of the Special Olympics Committee. I was still a tomboy when we first met. We didn't get too familiar with each other, but as an enthusiastic American, he gave me a hug.

Unforgettable Intensive Training in Tianjin

Xing: I heard about Special Olympics from our teachers. Though I didn't know what it was like, I just wanted to have a try.

I took part in Special Olympics twice. The first one was the 2007 Special Olympics World Summer Games in Shanghai when I was in the ninth grade. Before the games, we had a 3-month intensive training in Tianjin as members of the national team. Previously at school, Ms. Shi was unable to provide the same training as the national team. So, in 2007, she and Ms. Wang applied for training in Tianjin, where they had well-equipped training rooms and professional teachers.

We then had new coaches for both rhythmic and artistic gymnastics. The 3 months were really tough. Every day, we got up at about seven, practiced for a while, had our lunch, a break, and then repeated the whole set of moves. We normally started from the basic fundamentals and exercises, then we did the moves. Oh my! We really had a difficult time on the bars. It really hurt a lot. Some tough boys did the pull-ups with their hands, until the skin, and even the flesh, was torn. Their wounds healed gradually. My situation was a little bit better. I simply hung on the bar, which got me some calluses. Now they've gone away eventually.

One coach was responsible for controlling my weight, since gaining made it harder for me to do the moves. To prevent me from eating too much or eating secretly at night, she would ask me to sleep in her room. She also supervised me during the breakfast buffet to see what I had for breakfast. I always felt so hungry.

Q: How was your relationship with the teammates?

Xing: We got along well. We all came from the same school and helped each other. During our days in Tianjin, the birthdays of several teammates, including mine, were

in the same period. So, we celebrated together and had cakes. It was a lot of fun. Really unforgettable.

In 2007, there were two different gymnastics events in Special Olympics. Our team was also divided accordingly: some practiced rhythmic gymnastics; some others artistic gymnastics. My roommate Ms. Yang and I were in the latter. We still received training in the basics and flexibility together, but since I was in Level 2, a bit more difficult than her Level 1, we couldn't communicate that much or that deeply. In the final game, she didn't perform that well, with only one gold medal and some other silver and bronze ones. I won three golds and two silvers.

Q: Did you take care of yourself in Tianjin?

Xing: This was the first time that I travelled far away from home for quite a long time. Fortunately, we were independent enough, and we had washing machines where we lived.

Ms. Shi was with us throughout the training. She didn't even take care of her two kids, but treated us like her own children. Occasionally, Ms. Huang and Ms. Jin would also come to take care of us in turn, so that Ms. Shi wouldn't get overwhelmed. Besides, as we grew older, we were all obedient. We wouldn't wander around and make our teachers worry.

Of course, we had relaxing times as well. Otherwise, we would be worn out by the strenuous training every day. One day, the coach allowed for a day of rest, so we didn't need to go the gymnastics room. But Ms. Shi would still ask us to keep training in the hotel corridor with close supervision. She said, "You need to stick to it. Either flip, or handstand, just keep practicing your daily moves. Go, go." She was hoping that we could win gold medals for the honor of our school.

Normally we could rest on the weekends. But when we devoted ourselves into training, we never knew when it was Saturday or Sunday. So, the coach would grant us some holidays depending on the training progress. During the holidays, we either enjoyed talking, making some jokes or playing cards, going shopping or hanging out with our coach. Our coach was a local there. Our venue was close to her home, but we couldn't go visit. She had a harmonious family.

In 2007, she also came to Shanghai to be with us during the games. We once had her QQ number, but her husband didn't approve of our contact with her, and refused to give us her new number. This is how our contact ended.

We had so much fun during our 3 months in Tianjin. We had strict training, we were sore, we were tired, but a hot shower could relieve us; the constant encouragement of Ms. Shi kept us going. Actually, Ms. Shi got up even earlier. She trained with us, ate with us, with no rest and no complaints. She made a bigger effort than we did.

Eight Gold Medals in Two Special Olympics

Q: Tell me more about your first participation in Special Olympics.

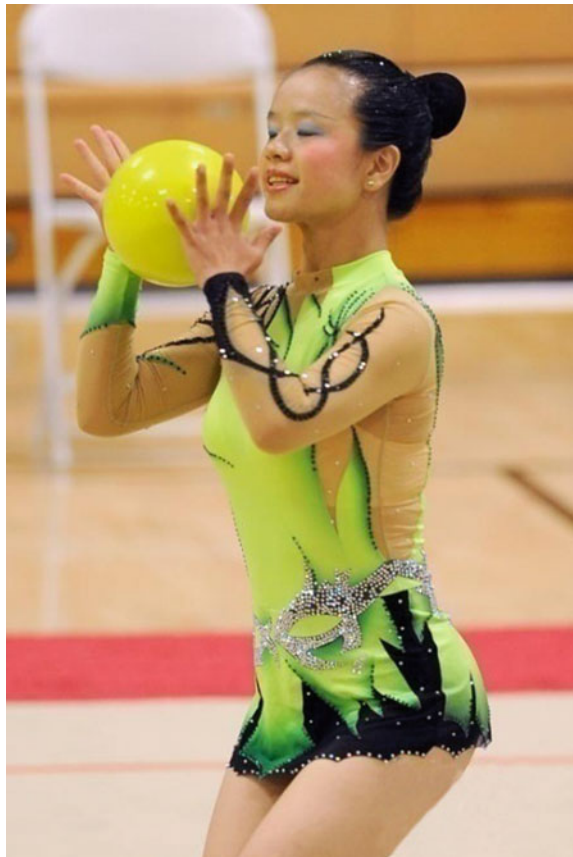
Xing: I took part in it for the first time in the summer of 2007 in Shanghai. We lived in a hotel during the event. Since I was strong as a boy, I competed in the artistic

gymnastics together with another girl. The rest of the girls normally took part in the rhythmic gymnastics event. We represented the Chinese team and I won three gold medals and two silvers.

I was so nervous at that time. After coming back from Tianjin, I even visited the competition venue in advance. I could perform well during my daily training; I didn't get stressed even during the opening ceremony, but in the final game, I got panicked. I've never seen such a big audience in the bleachers, or so much staff around me on the site. As a result, I made some mistakes in the vault and on balance beam. The moves were still finished though. In other events, like the floor and parallel bars, my performance was satisfactory. I had been confident that I was going to win five gold medals, but things don't always go as planned. Nonetheless, I thought generally, all our effort and the devotion of Ms. Shi during the training paid off. We strived to get more gold medals for the glory of our teachers and China. We must show our best, you know? There were some other team members who won five, or even seven gold medals (laughing heartily) (see Fig. 1).

Q: Did you participate in the next Special Olympics after 2007?

Fig. 1 Le Xing during competition



Xing: In 2007, I was already in the ninth grade. After the games, I graduated, and went on to study in the vocational department for 3 years. By 2011, when the European Special Olympics was held, I'd already become an employee and I was dating someone. As I worked in a shopping mall, it was inconvenient for me to ask for leave for training. So, I didn't go to Europe. There were several younger students who participated in it.

Later in 2015, I went to Special Olympics again. After I got married in 2013, gave birth to my baby in 2014, I rested at home for several months. When my baby was weaned around the age of 5 or 6 months, I was able to find time for training at school every morning. Then I started the intensive training in May and June, and went to the USA before the games in July and August. My mother-in-law was really supportive. I told her that, "I've never been abroad. Now the teacher invited me to a competition in the US, I want to visit this country." She said, "Of course, as long as you want to." She really supported me!

Then, Ms. Shi, together with eight of us, flew for 12 h to the US. We stayed in college dorms in Los Angeles for more than half a month. We won five gold medals, which was quite good.

I was the only team member who was married. But the other members were basically the same age as me, only a few months younger. The two training regimes in 2007 and 2015, however, were somewhat different. In 2007, it was unforgettable as many classmates were all together. I felt like the days were extended. While in 2015, though we lived in the same school in nearby dorms, we didn't get that close as adults. The relationship was just so-so. Time flew.

Teacher: She just gave birth to her baby at that time. We asked her if she'd enjoy participating in Special Olympics again, and she accepted our invitation happily. Our training started in May and June, until we headed to the US. She behaved in a totally different way than last time. She was more mature with her own opinion. She also had the awareness to take care of younger members during our training. It was really considerate of her.

Q: How did you feel going to the US?

Xing: Passport procedures were kind of complicated. Someone took us to the passport agency in the school's cars.

I felt much more at ease this time. I've never been abroad, so I wanted to have a look at the strict training of foreign athletes.

The Americans were careful in examining our stuff. They also showed great hospitality, giving us many gifts in the dorms. Two people lived in one dorm with bunk beds. I was with Ms. Shi. We would set a time, like we got up after seven, then volunteers would take all of us, including other foreign athletes, to the school canteen for breakfast. After that, we would go to our venues for competition. It was far away. So, a few days later, we moved to our competition venues, also on campus. Therefore, we lived in two campuses in total, one was for relaxing before the competition, the other one was the competition venue. There were people taking us to the venue every day. When we knew our way better, we went to have meals by ourselves.

Foreigners were really friendly. They tended to say hi and smiled to everyone they met, whether they knew the person or not. Chinese people, however, might be shy in

front of strangers. I couldn't speak English, so I didn't make any foreign friends, but we got to know some volunteers. They were Chinese students overseas who could interpret for us or taught us what to do. We all felt they were really nice. Before the competition, volunteers also took us for a visit on a ship. Sometimes, volunteers might tell us to take care if they didn't have enough time to show us around. Due to the language barrier, we either wandered around, or followed the mother of a student who could interpret as well. We might have a walk after lunch. Later, I discovered that there was Wi-Fi in the university, which enabled me to enjoy a video chat with my husband.

This time, I competed in rhythmic gymnastics. This was because I was a bit older, and all the other students practiced the rhythmic one, doing so could save some energy for Ms. Shi. During practice, I didn't get used to the soft and beautiful moves, as I was normally more boyish. Besides, I was kind of impatient, always making mistakes by not following the tempo. Ms. Shi provided guidance to me every time, and took us to other schools for training with professional coaches.

We competed in different levels and age groups. I was lucky to be in a group with the athletes of almost the same age. Just average players. I thought my performance was okay. But when I observed others, I felt like maybe I made mistakes, so I thought my score was low. In the end, when the score was announced, and we lined up accordingly, I actually did a good job. I got five gold medals; they were quite heavy.

The national team won many gold medals this time. Huai Wang, a male artistic gymnast, won seven medals. Among the girls, I won the most gold medals. Others got four golds and one silver, or one gold plus several silver or bronze medals (see Fig. 2).

We enjoyed a smooth flight back. All of us took care of each other. Since it took a long time, we sometimes got up from our seats to walk around when we felt uncomfortable. It was better when we finally landed.

After this Special Olympics, I also hosted the Special Olympics Unity Fundraising Gala Dinner in a hotel in Pudong District. It was held by Special Olympics East Asia, inviting Mr. Shiyi Pan, Ms. Lan Yang, Mr. Ming Yao, and some other celebrities and the Special Olympics ambassadors. I went there with my teacher, who wanted me to have a try as the hostess. Then the staff from the Disabled Persons' Federation also agreed with the proposal.

I think basically, I look the same as other ordinary people, but there might still exist some gap in terms of intelligence (pointing to her head). I was bad at Chinese and math, and I felt a bit nervous being a hostess for the first time, especially after seeing so many people. But it was okay. I wasn't alone. I was given a speech as the hostess before the event to practice reading it. There were also people guiding me if I encountered issues. On that day, I wore a qipao evening dress. I was with two other professional hosts: one man was the host of *Entertainment Online*, the other girl was a translator on an English channel. It was lucky that I performed well, with no big issues. At that time, I was already a mother (laughing).

Q: Does Le Xing still practice gymnastics?

Teacher: She was really good at somersaults, and loved the backbend a lot, right?

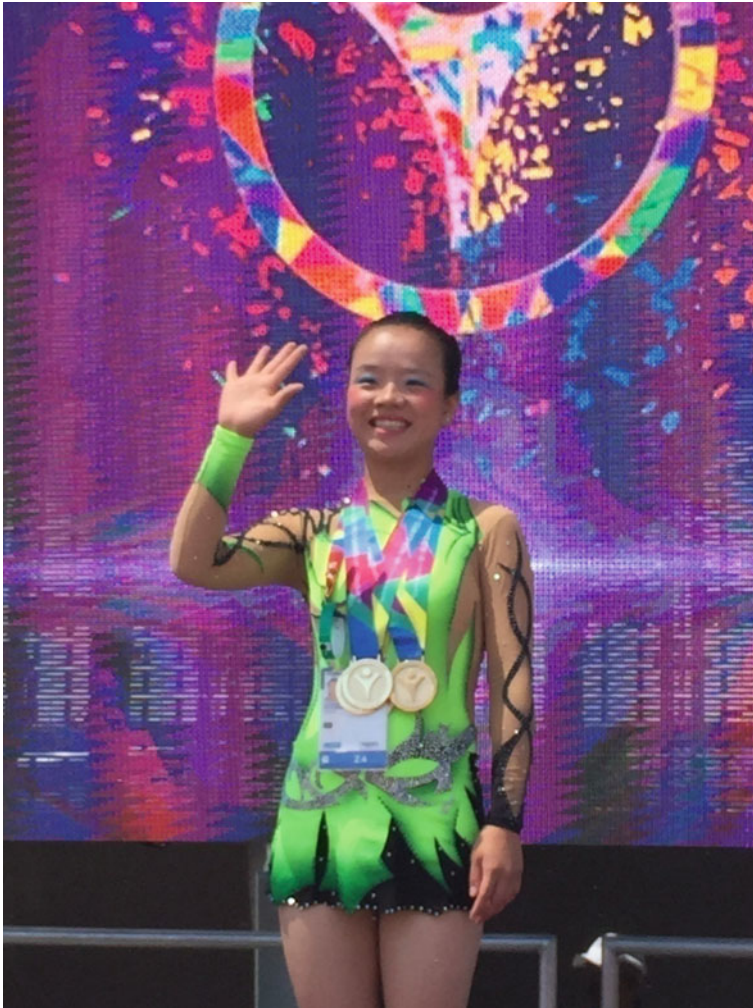


Fig. 2 Le Xing on the podium

Xing: I stopped practicing after the 2015 Special Olympics. I've been staying at home for a long time. Also, my health and my age don't allow me to participate anymore.

Ms. Shi has been the coach of our gymnastics team so far. She was younger and stronger when she taught us, so she was able to stretch us hard. Now as she grows older, while we become taller and heavier, she can't do that anymore. It also becomes harder for her to coach young students. Several days ago, I sent some costumes to Ms. Shi at school. She asked me if I still practiced at home, and if I could do the basics, like stretching my legs. I replied that basically, I didn't practice, but I might perform okay with the basics. Certainly, it can be hard when stretching your legs all

of a sudden. You'll feel sore after a week and you just can't go back to the old days, as your muscles won't be that flexible. Ms. Shi also said our backbend was not as good as before.

Q: What's the impact of Special Olympics on you?

Xing: I was able to keep a good figure during the whole process from initial exercises to the final games. I didn't even gain weight after giving birth. I still eat, but not that much. I have the same figure as when I was a young girl; none of my colleagues believed I was already a wife and a mother. Gymnastics makes me well-proportioned and energetic.

My confidence was also boosted. Though I may not be the best member of staff, I'm still a good athlete. I can still remember the moves, and pick up all that we practiced within a short period.

Began to Work After Graduation

Q: When did you start to work?

Xing: June 2010. That was my last year at the vocational department. I worked as an intern for a while, and then went back to school for a bit. It was an unpaid internship at House. As they considered my performance to be good, and I also passed the interview, I became a member of staff there. They knew I had the disability certificate.

Starbucks normally recruits two or three students every year in our school. Some other students work as housekeepers at the Novotel Shanghai Atlantis. At that time, I tried to adapt to the working environment outside the school and the job was basically okay, so I just stayed as staff.

It was the first time that XX House recruited people like us. I was the only one picked. Normally more classmates worked at Starbucks.

Q: What did you do at that time?

Xing: I worked at the XX House at the Thumb Plaza on Fangdian Road.

Though I learnt pastry, it didn't mean that I would work in the same area. I wanted to have a try in a new field. Surprisingly, I passed the interview. Also, our teachers have informed the company of our situation.

When I started to work there, I thought it was a lovely and lively place with many customers. The salary, however, was low. During my first days there, senior staff asked me to get familiar with what we sold, and taught me how to scan the price tag.

There was an elder staff member who treated us well. I should have called her my master, but after we got closer, I just called her sister. She would teach me how to replenish the stock.

Teacher: In our school, we first recommend students to employers, and then assign jobs to the rest of the students. There were failed recommendations, while the case of Le Xing was successful. Her first job was at XX House, where she worked for about 2–3 years. Everyone loved her as she was nice and friendly. In the end, she resigned

due to lack of salary increase, long commuting distance, late working hours, and a boring job.

Q: Could you please tell me more about your work?

Xing: The XX House operates from 10 a.m. to 10 p.m. The morning shift ends at 5 or 6 p.m.; noon shift is from 11 a.m. to 8 p.m. There was also an afternoon shift. Apart from printing the price tags, sometimes I also recommended goods to the customers, answering questions like, “Is it good?” “What’s it made of?” We used to have meetings in the morning.

I went to work from Monday to Friday, and rested on Saturday and Sunday. The welfare was the same for all: no canteen, no accommodation, and we needed to pay for five social insurances and the housing provident fund. All the other colleagues treated me like everyone else. When we got closer to each other, they all called me Lele. One salary scale applied to us all. Depending on the job grading, salary could vary, with that of department head or senior staff being higher than ours.

All the colleagues were nice. Knowing about my condition, none of them excluded me. But sometimes, I didn’t believe in myself, thinking that I still couldn’t master everything after working here for quite a long time. Colleagues comforted me, telling me it was nothing. Just be honest with what you’ve done. They didn’t take it seriously, either. The relationship among us was okay. Sometimes, I hope that they can consider me as an adult, instead of caring about me too much. I’m already a grown-up. I should be sensible and independent.

I quit after I got married and pregnant. It was already quite a long period.

Farewell to the Foster Mother and Gaining Independence Due to a Relationship

Q: When did you move out from the home of your foster mother?

Xing: 2013. When we become adults, if we can pass an IQ test organized by the welfare center, a house will be assigned. Therefore, at that time, I would go to the faraway children’s welfare center on Zhongchun Road in Minhang District for review class every day. I went there in a shuttle bus at similar hours like those going to work. The welfare center also helped us with the review, for fear that we would fail. My mother said I would fail for sure, but had no comment seeing that I passed.

I didn’t tell her about the house. She didn’t care about the location or the further arrangements either. When I got the house in Hongkou District, my teacher took me there, as she didn’t even know about it. She kicked me out later because she thought I lied.

My mother tended to check my phone. Whenever my Nokia rang, she would check it first, whether there were text messages or not. In response, I had to delete all the messages. But when I had a boyfriend, I had to read his messages. Gradually, I was caught by my mom. I had to tell her I had a boyfriend; the teacher was the matchmaker. She was upset as she thought I was still too young, while actually it was

already the right age. Living here, I wasn't allowed to hang out with my boyfriend. So, all I thought about was moving out, so that I could get rid of her control, enjoying my relationship, going wherever we wanted, and going shopping after work.

Gradually, I got so angry with my mother as she kept interfering with my relationship. That's why I told her about the IQ test and house. I said I could move to that house. She replied, "What would you do there? You have nothing there, how could you live?" But I'd made up my mind to move out for my freedom of relationship. She even told my brother about this, and my brother just said, "Go ahead, and never come back."

Then, I moved to my new house in Hongkou District, Puxi. My in-laws were so kind as to take some daily necessities to the empty house. But a bad thing was the house was quite far away from my workplace. If I finished at 9 p.m., it was inconvenient to go home. To solve this issue, I still lived at my mother's home for a while and took some personal stuff with me. Once, I wanted to live at her home again, so I asked if I could go back to have a shower and stay for a night. She agreed. But when I came back, she treated me like a stranger. She opened the door for me and gave me things needed in the shower, but I couldn't find my previous slippers. I had to walk in the bathroom barefoot. After the shower, she took away my keys to the house, and kicked me out. "You can go now. Don't sleep at my house," she said. I thought, well, whatever. I had my phone anyway. It was a weekend. When I walked out of the gate, I saw my brother playing basketball. He loved hanging out with his classmates, while I always stayed at home. At that moment, I didn't want to talk to him. So, I called my boyfriend and told him to pick me up as I was kicked out by my mother. This was how I moved into their house.

After taking away my keys, my mother threw out everything I've used, like bowls and mats, into the trashcan. She just couldn't stand the sight of things used by others at home. Therefore, I had to take away all the rest of my things. I couldn't go back any longer, nor did I want to talk with her. Shortly afterwards, she gave me my payroll card. There was not much left.

Q: Who spent your salary?

Xing: Previously, I respected her. I said, "Mom, just take my money. How about buying a TV?" If she spent it, it was understandable. After all, she raised me.

Q: Did your mother and brother ever visit your new house?

Xing: They didn't know, nor did they ask. They only knew I was in Puxi. It was quite far away. I couldn't tell the direction, so I really had a hard time taking the subway.

Q: You lost contact with your mother since then?

Xing: I was in the relationship for a long time. By 2013, when we got married and held our wedding, my mother-in-law told me to invite my foster mother to the ceremony. So, my husband and I visited my mother with some gifts, wedding candies, and the invitation.

She acted weird on that day. She opened the door for me, and gave me a pair of slippers of unsuitable size. I told her, "Mom, this is my husband. We're about to get married. This is our wedding invitation with the date and place. We hope you can come." To my surprise, she refused to accept anything. But we just put all the things

on the table, as what my mother-in-law had told us before we set out. My mother could do whatever she wanted with them. She also talked in a weird manner. During the visit, she suddenly said politely that, “Go get some water for your husband.” I did it as I haven’t been home for nearly a year. In the end, she didn’t come to my wedding.

My brother was out with his girlfriend on that day. But my mother must have told him about my visit and he could see my invitation. Anyway, he didn’t show up at my wedding ceremony, either. Similarly, he didn’t invite me to his wedding as well. I wasn’t even informed. Once, I encountered a friend of my brother in the hospital when my son was ill. I was told that my brother got married at the end of 2014 and lived well.

I know little about their current lives now. Sometimes, I suggest to my husband that maybe we could drive around in the Hai X New Village. We’ve not been there for long. It has undergone great changes. Though I can still recognize my old home, I feel somewhat distant from it and reluctant to approach.

Q: Do you still call your foster parents?

Xing: Currently no. I don’t call home anymore. It’s pointless. We ended the relationship with them when they didn’t show up at my wedding. Once, I met one of the buddies of my brother. The man told me my brother got married, new house decorated, and his mother was also well. So, I guess their situation is good. I didn’t save, nor could I remember my brother’s number, but he had my number actually. I haven’t changed it. As he doesn’t call me at all, I decide not to contact them.

Q: Could you tell me more about the houses distributed by the welfare center?

Teacher: The policy is like this: as the government funded the welfare center to raise the children, it will make an appraisal of the children’s ability. If there’s no problem, then the government will arrange accommodation and a job, indicating that the child becomes an independent adult; if not, the child may spend the rest of his or her life in the Chongming No. 2 People’s Hospital. Everyone only has one chance, so it’s quite critical. For those who perform well in the appraisal, they will be allocated to different districts based on the quota, just like the lucky wheel. We can’t predict their final destinations. In the case of Le Xing, she was assigned to the Hongkou District, whose people’s government was responsible for her housing and household registration as her job had been settled by our school. This way, her collective registered household was transferred to that district. The house was shabby in a poor condition, simply a shelter. She was just a girl who had never lived alone before. How could we feel at ease?

Xing: I was the only one in the Hongkou District. Another classmate was allocated to another different subdistrict. One of my friends was lucky. She got assigned to a subdistrict of the Yangpu District, receiving good care from the government. First, she was arranged to live in a hotel. Then the government provided free decoration of her house. It was a single room apartment with two floors. She was also provided a job as a registration staff in the library. She only needed to record information on borrowed and returned books. It was an easy job.

I don’t live in the house now. The condition and environment were unsatisfactory. At that time, I got along well with staff on the residents’ committee. I was allowed

in the house after informing the landlady. Later, as I didn't live there very often, she took the house back to avoid a waste of resources.

I didn't own the house. The government paid the rent, so that I had a place to rest after work. It was an old-style public house. I paid for the living expenses, including food. I was in the relationship back then. My future mother-in-law and other relatives took good care of me. They would bring many things from their home to my new house, traveling a long distance. We went there in two cars, one of which belonged to the brother of my mother-in-law. Actually, since I went to work in Pudong, sometimes I might return home at 10 p.m. after getting off at 9 p.m. It was quite inconvenient. That was why I seldom lived in the new house. I think I've lived there for less than half a year.

After I was kicked out by my mother, I just moved to my husband's house and registered my household here. The assigned house in Hongkou was taken back, as I said. The landlady decorated it and rented it to others. My things were all gone. Later, my mother-in-law tried to ask if it was possible to get the house back. The reply was that I was married; my husband had a house, and if that the area of this house was above a certain standard, then I couldn't get my Hongkou house...

Teacher: Actually, the government of the Hongkou District was trying to shirk its responsibility. I once told Le Xing that you were lucky as your husband and mother-in-law treated you well. Otherwise, you would have had nowhere to go.

Xing: Yeah, my mother-in-law was far-sighted. She once talked with the staff in the subdistrict of Hongkou, asking them what if I was excluded by the husband's family. She also asked if it would be possible to assign the house in Pudong; even a small one would do. This way, I still had somewhere to go if anything happened. But there was no reply from the government... So, I didn't get anything in the end. Currently, I mainly rely on my work. My household is registered together with my husband, mother-in-law, and my son. My father-in-law is registered in a separate household.

Teacher: Their house is okay (laughing). Fortunately, there's still a house, right? Otherwise... You need to cherish your life and be optimistic. Your life now is quite good, actually. There was a time when you were quite negative. But from a different perspective, you're better off compared with Ms. Zhang and Ms. Chen. Don't always focus on those who are more successful, okay? Think about what you have: a caring mother-in-law, a supportive husband, a lovely son, a good job. You even have more houses than me (laughing). Though I'm the headmaster, I bear much more pressure, right? So, just be content, happy, and grateful. Your life improved a lot. You don't come to complain, but ask me about my health. It makes me happy, as you know how to take care of me.

A Teacher as a Matchmaker

Q: How did you meet your boyfriend?

Xing: Ms. Ying Wang introduced him to me. He was also a student in our school (see Fig. 3).

Teacher: Her background was special as she came from the welfare center. At that time, she was suddenly allocated to a house far away on Liangcheng Road of the Hongkou District, and she had to live on her own. It was really... For us as her teachers, who treated her as our own kid, we worried about her a lot. During her school days, we've always told her that when you grow up, be careful in picking your man. This wasn't about being picky, but pragmatic. I told her do keep her eyes wide open.

I've known Mrs. Sun, her mother-in-law, for a long time. She was a driver in our school. In my opinion, this family was quite reliable and honest. Mrs. Sun was also a very nice and genuine Shanghainese. Her son is the husband of Le Xing, a quite handsome boy. He's the only son of the family. His parents are just common

Fig. 3 Le Xing (left) and her teacher, Ms. Ying Wang



people. The father isn't very talkative, while the mother, Mrs. Sun, is very capable. She considers Le Xing as her own daughter.

I thought that the boy and Le Xing shared some similarities. He also graduated from our school, two grades higher than Le Xing. They communicated well. Besides, the boy's family was living in harmony with good living conditions. I considered this was a good choice for Le Xing, as she could rely on the family in the future. I was really being practical.

After all these considerations, I asked Le Xing, "I've found a boy for you. Would you like to meet him?" She replied yes, shyly. So, I arranged their first date in a KFC. Surprisingly, the two schoolmates liked each other at first sight. Chen Zhu loved Le Xing a lot, right? They complemented each other, one was more open, while the other was more of an introvert. From then on, they started their relationship and got married smoothly. I was really happy. I guess they have some shared topics and similar interests. Chen Zhu also got his job through our recommendation. Sometimes they went to watch movies together... (laughing).

I once said to her mother-in-law that, "As you know about Le Xing's situation, I trust in you, believing that you can take care of her as your own child." She said no problem. Then I went on to say that, "You can also teach Le Xing about life. After all, she's still young. You can turn to me for help when she encounters difficulties or doesn't behave. She still follows my advice." Therefore, Le Xing would sometimes send me some messages through WeChat about complicated issues that she couldn't handle. I would talk with her and provide suggestions. One can never grow up without any obstacles; the key is how we cope with them and get through. Be nice and kind to others, and God would protect us. This is my motto, and I've always shared it with her. In critical moments of life, like your marriage and birth of the baby, I believe the motto always applies, right? Other teachers, like Ms. Liu, cared about her a lot. We were so happy to learn about her wedding, to see her in the beautiful wedding dress, and to share her wedding candies. We were so touched when we saw her in the dress, feeling like our own child was getting married. From then on, she has her own home and someone to rely on. We were all witnesses to her growth. She always had our best wishes.

Xing: My husband is the only son of his family. I was born in 1991, and he is 3 years older than me. My father-in-law only stammers a little bit, while my mother-in-law totally outperforms in terms of both IQ and EQ. She's also quite talkative, while my husband and I are just not comparable. So, I'm normally straightforward in expressing my thoughts. She herself knows she's better than us in these aspects as well. My husband is quite quiet. I'm much more direct; I talked a lot when we first met each other (laughing).

We enjoy our relationship a lot. We both worked when we started it. He helped in the kitchen in a holiday hotel in Pudong. I was at the XX House and got off late. Based on my shift, I was normally off duty during weekdays, while working on the weekends. So, we would go to watch a movie after work, or... (tittering).

After a year, we got our marriage certificates and held the wedding ceremony. We didn't choose a particular date for the wedding as local people, since we didn't think it mattered. We finally chose March, when my mother-in-law retired. We planned to

have our baby 1 year after the wedding, so that my mother-in-law could help us take care of the baby at home. We didn't invite too many teachers to the wedding. We would have been embarrassed if they gave us gift-money. Of course, the wedding candies were shared with everyone.

I really enjoyed the relationship, but I had less freedom after we got married. We needed to work after all. Predicting all the work ahead, we travelled to Xiamen City for a week together with my sister-in-law before I got pregnant. She arranged all the schedules and booked the tickets. We paid her afterwards.

Now that I have a family, I need to learn how to save money for my son. I can't go to the cinema that often as before and enjoy moments only with my husband. I have to go home after work, devoting all my time to my kid. Normally, the whole family will take my son to play and have dinner together. I don't need to pay.

Teacher: Married life is indeed not that easy, but you're also quite happy, right? You can travel to Hong Kong and Beijing (laughing).

Baby Son Brought Happiness

Q: How long after you got married did you get pregnant?

Xing: During the pre-marital examination, neither of us had any problem, but we didn't plan to have a baby soon. I got pregnant in 2014, a year after our wedding. At that time, I still worked at XX House. Normally, my period was punctual, and I would record it on the calendar. But one month, it wasn't on time. I waited and waited, thinking it might be late. Then I asked my colleagues about this, they told me not to worry and wait for some time. Some of the married, experienced and elder colleagues suggested buying a pregnancy test kit, which didn't show the result. Therefore, I told my mother-in-law about this. She didn't ask me in detail, but took me to the Renji Hospital, a public hospital next to the Children's Hospital, for a pregnancy test. Then I knew I was pregnant.

My God, I felt so nervous when I learned the news. My colleagues told me to take care of myself at work, and avoid abrupt movements. I just thought all this came too soon. On second thought, though my in-laws didn't urge us, they still asked about it. As they were getting older, it might gradually become harder for them to help us taking care of a baby. After my delivery, I basically stayed at home, without going to work.

In the past, when my mother-in-law gave birth to my husband, pregnant women still needed to go to work. Perhaps due to lack of rest, she didn't notice the cord around her son's neck. This, plus the absence of the C-section option, and the large head of her son, made her delivery quite hard, and at last, her son was somewhat... The baby also stayed in the infant incubator for more than a month after birth. Thinking about all these negative consequences, my mother-in-law asked me to rest at home. She was worried about me, and my baby, as I needed to stand for a long time and carry heavy things at work. My husband and I already faced some problems, what if there's something wrong with our baby...

Q: Did you feel nervous during the pregnancy?

Xing: As my belly grew bigger and bigger, I was a bit... nervous, actually super nervous, especially shortly before the delivery. The doctors bluffed us at first, asking us to sign some consent letter indicating the possible risks and consequences. I also did a C-section eventually. The delivery room was really cold; I felt scared. Then I felt nothing during the delivery as I was given anesthesia. But after that, I couldn't eat for 6 h. That was really painful. Then the next morning, I was asked to walk by myself. As the wound wasn't healed, it hurt a lot when I had to go to the bathroom. During that period, as my husband had to go to work, my in-laws took turns to attend me. It wasn't that convenient for my father-in-law to take care of me, like cleaning the body, and so on, so he took care of the baby occasionally. My mother-in-law made the most effort, staying in the hospital all day long.

She also took care of the baby when I breastfed. She slept with my baby son in another room and simply asked me to breastfeed when he cried. It was winter at that time... No, sorry, I gave birth in July, so it was in September. It was already getting cold. Taking my son to the bathroom in the middle of the night was really tough work.

Q: Did you run tests on your baby?

Xing: I did all the pre-natal exams, including the screening for Down syndrome, but no screening tests on him after he was born. During pregnancy, the doctors always suggested to have some check-ups in case of water on the brain, saying that my son's head was larger than normal babies. We were worried about this. So, we went to the Renji Hospital for a B-mode ultrasound, which wasn't clear. Then we went to another hospital in Puxi, did the ultrasound again to check my baby's head. This time, with advanced equipment, the image was clear. The doctor didn't mention anything wrong with the result, saying that we could wait after the birth of the baby to see if there was any problem. So, we felt somewhat better.

The doctor didn't point out anything wrong. I think my son should be... okay. He's a normal and smart kid. Now he's two and half years old, with quick responses.

It's just that people say his head is big, especially the back of the head. Also, he doesn't like talking. We've already signed up early childhood development courses in the afternoon for quite some time, hoping that he can become an independent ordinary kid. Now he can say "mom" and "dad." He knows the location of things at home. He also has his own idea of who he wants to sleep with, grandparents excluded.

Q: Does he look like you?

Xing: My son looks a lot like his father. I find almost nothing similar to me.

Q: How's your life been going after you became a mother?

Xing: My son is taken care of by my in-laws during the day, and me at night. He always takes his grandparents to the door and waits for me to come home from work. He also rummages in my bag to find out what's in it. On Saturday afternoon, I take him to the courses. Sundays are also devoted to him. The schedule is quite full. Sometimes I also complain, since he takes up all my time after work and always clings to me and my husband, especially when having meals. My son's closer to me. I also blame him sometimes. He'll cry, become naughty again, and behave himself if you just ignore him.

Teacher: Now she talks about her son all day long, telling us that she'll work hard to buy milk powder for him and save a lot of money for his future.

Q: You and your husband have been getting along well. How's your family life?

Xing: It's okay. We love each other a lot, but there has been some tension after we got married and had a kid. I sometimes think he can't do housework very well. He's an introvert. When you see his face turning red, he is getting angry. But if you ask him to help with something, he won't speak. Like when I insist that he showers my son, he'll say he can't. He's afraid that he can't do it.

Most of the housework is done by my in-laws. They buy the food and cook for us. I also want to cook, but as is known by all the teachers, I'm not like a gentle girl, but a rash boy. I'm bad at this kind of work. When I was at the home of my foster mother, she always told me to think over what to do first and what to do next before actually acting. I wasn't able to straighten out. I normally did things as I saw them. Now that I've become a mother, I try to act in an orderly fashion. After getting up in the morning, I'll first dress my son, sit for a while, then his father gives him some water before going to work. Next, I'll help my son wash his face, brush his teeth, and have breakfast. This is our daily routine. My son is also picky. He decides who can dress him. He looks for me from when he wakes up in the morning, refusing his father even when he's crying, unless there's no one else to comfort him. In the evening, we also have fixed procedures. I need to take off his shoes and change his clothes after I arrive home.

In terms of education, the responsibility mainly falls upon my mother-in-law and me. My mother-in-law teaches him numbers. Every day, I say "two," and ask him, "How old are you?" He'll answer, "I'm two," while making the gesture of "two." He may extend only one finger sometimes, then I teach him to extend the second finger. Besides, I teach him to say "mom" and "dad," and so on, asking him, "What do you call me?" I ask him to say the words clearly. Sometimes I let him call his dad, but he won't. He learned to call me "mom," though. He also knows where things around the house are.

I also bought a small toy house to teach him to put toys away. In the meantime, I teach him about colors. For example, I may say, "Give me the red car, dear." He'll choose one, think it over, and give it to me if he thinks this is the right one. He knows all these.

It's just that he's similar to his father in terms of character. I'm quite talkative, but if I take my husband to the home of a colleague, for example, he won't talk with people he doesn't really know. My son is the same, only talking to people he knows. His grandfather is also an introvert and honest. Considering his age, he has less energy taking care of my son than the grandmother. Also, grandmother pays more attention to his nutrition and cooks well. She does more in this respect.

My son has his own preferences. If neither Mom nor Dad is at home, though Grandma is more capable, he still asks Grandpa to take him to play at the door or in the grocery market in our community. If everyone's at home, he only comes to me. Even when I ask him to say Grandma, he still says Mom, calling everyone Mom. In this case, I ask him, "How many moms do you have?" "Five." "Which five?" He shows me one hand, counting all the five fingers (laughing).

If he doesn't sleep at noon, I'll take him in the cart and walk around in our community. Yesterday, I took him to Puxi in a bus and bought two pieces of clothes. His grandpa paid for it. My son knows how to play and everything, basically not different at all from normal kids. He simply talks less, and the back of his head looks bigger. That's no big deal. After all, we took him to have a brain test, where some hood covered you as you laid down, and the doctor didn't say anything. If there was really something wrong, the doctor would have said something...

My son also eats a lot, almost non-stop. For example, his grandma cooks porridge every noon and evening. He always finishes one full bowl, even more than we do. In addition, he loves noodles, including the wrappers of wontons, and vegetables, like potatoes, green cabbage, etc. He doesn't like meat, nor can he eat it, since his teeth aren't strong enough to chew, and he may swallow it directly. Now I still breastfeed him at night, but not during the day.

He's kind of independent. I train him to go to the bathroom during the day, so he doesn't even need to wear a diaper. I ask him, "Do you want to pee?" He'll reply yes. Sometimes, he doesn't know how to say "pee," then he covers the part with his hands, and may pee on himself if it's a bit late. He poos at night usually.

Q: Have you thought about making him a gymnast as well?

Xing: Currently no. It depends. I'll let him learn what he loves. My mother-in-law hopes he can learn swimming to strengthen his body. She actually guides the whole family. She hopes my son can be a normal kid unlike me and my husband, and become independent when he grows up. Anyway, he has opportunities to learn. He can just learn what he's good at.

Q: So, currently you and your husband go to work, while your in-laws take care of the child at home after their retirement?

Xing: Yeah, it was like this before. We go to work and they stay at home with the baby. In our neighborhood, it's always the parents looking after their children, and mothers normally stay at home until the children go to school. So now I decide not to look for a job. There aren't any good jobs, either. We'll see.

Previously, I got a higher pre-tax monthly salary of 3,500 yuan, with 300 yuan of tax. My husband works at the DQ, earning about 2,900 yuan a month. He works for 5 days and rests for 2 days a week. The holidays aren't on Saturday and Sunday, but two separate days during the week. He mainly makes ice creams and cakes. They also offer takeaway now. They're quite busy.

My in-laws suggested "that now you're both adults and have become parents, you should save some money." Normally, I pay for large expenses, like half of the course fee; while my husband pays for smaller items, like milk powder. But still, as we don't earn much, my in-laws actually pay more with their retirement funds.

Q: Who's in charge of the money in the family?

Xing: I'm in charge of us two. My husband decides how he spends the money, but he'll tell me if he receives the salary and how much after I ask him. Now I applied for a text message service, informing me of the salary either through email or short messages.

We may have difficulties in dealing with money, but we don't blow money anyway. We buy what we need. My in-laws tell us to save money for the kid's schooling. This

is true. Since we didn't receive much education, we must send our son to early development courses, which cost more than 100 yuan each time, and to formal schools. We need to start planning now, and give him a chance to learn as long as he can keep up. There's a teacher in the early development class who gets along well with us. I mentioned to her that I wanted to send my son to the kindergarten next year to see if he could fit in after maybe 1 day, and asked her to help us decide if my son can make it.

We still have another house in the Changning District. After it's decorated, we can have an extra source of income from the rent. Since we didn't perform well at school, the education of my son must rely on teachers in the future. The son of my husband's sister is in the third grade now. He goes to extra classes every weekend. A lesson from 1 p.m. to 4 p.m. costs more than 100 yuan! That's really a lot! We've spent more than 30,000 yuan on early development. Starting from March next year, we'll send him to the kindergarten, where he'll stay all day. This costs 18,000 yuan, including meals.

Q: Have you thought about having another baby?

Xing: No. We're not that capable. This child already has a big head, what if the second has the same issue... My in-laws are also too tired to look after another baby. Most importantly, though we have enough houses, we don't earn enough money, and we don't know how to educate children well. Even the couple of doctors living upstairs only have one daughter.

The two doctors major in design, leading quite a busy life. They also get along well with us. Once, they said, "Lele, after the Spring Festival, we'll try to see if there're good jobs for you." I said okay. They're from Xi'an City. Normally they go back to their hometown during the Spring Festival. They say nowadays, companies either recruit people with a diploma, like an undergraduate, or a postgraduate, or with certificates provided after you pass some exams. But we only have our graduation certificates, which are useless. As such, it's nearly impossible for us to find a good job. My previous job was good actually. If there were no customers, I could sit and rest, and sometimes invoice people. It was relaxing. Unfortunately, I was fired.

Q: Apart from your family and teachers, do you still contact other relatives or friends?

Xing: No, I only have one BFF. Among the family, I'm close to a cousin, the daughter of my mother-in-law's eldest sister, and my nephew. They're really considerate. Sometimes during festivals, we go to the home of my grandma (mother of mother-in-law), where my brothers-in-law and sisters-in-law gather together. Our generation have grown up; all the others know about our situation.

I call Ms. Liu occasionally, as I know she seldom surfs the Internet. I would ask her how it is going and chat with her. Previously, my husband had a fight with my mother-in-law. This made me worry a lot...

Teacher: There was tension between her husband and her mother-in-law and she felt sad, lost, and worried. I think this is quite normal. She suddenly lost her sense of security, right? What if they quarrel?

In response, I taught her some strategies. I said, "You should continue to get along well with your mother-in-law. Just treat her as your mother. It's normal that a mother

gets angry at her child. Now something happens, you and your husband should reflect on it together. This is not solely about your husband, but the two of you. You need to persuade him not to get angry, but to find out, together with him, what makes his mother unhappy. At least you know she means well, right? It's possible that you need to change how you speak and in what tone... You're a family, there's no good or bad, and right or wrong in terms of housework and daily affairs. As young people, I hope that you both can take into consideration the effort of your mother-in-law in taking care of your son and doing housework. You should tell your husband not to act like this. Both of you should respect her and be nice to her. Meanwhile, don't get involved in it. Everything will be fine after a few days." When I was free, I'd ask her how it was going, and she said all was fine. I think she's becoming more and more mature in dealing with complicated matters.

Early Childhood Development Courses for the Son

Q: When did you take your son to the early childhood development courses?

Xing: It was my mother-in-law's proposal, as she saw a kid in another community attend this kind of class. Therefore, we went to the Center in the Shanghai Expo Park, which is in a good condition and has acceptable service. We attach great importance to education, and we want to try, so that he won't repeat our own experience.

When he went there for the first time, he didn't talk to anyone. It was a new environment for him. According to our original plan, if he could speak, then we wouldn't send him to early development class. But in the end, we had to send him because he rarely talks, just like his father. At home, I was the talker, while my son seldom talks, unless you ask him what he wants to do.

If I don't go to work, I'll take him to the class. Each week, he has both interpersonal communication classes and music classes on Wednesday and Saturday. He loves the latter a lot. Actually, the content is basically the same each time. Teachers normally review what was learnt for two to three times, before moving on to new things. His father also takes him to class. If we're both available, he'll want to be with his father.

Currently he can catch up to the class. Sometimes, he gets lazy. In the first class, when the teacher asked him to introduce himself to everyone, he just wouldn't do it, however, you nagged him. When he grew up a little bit, I told him, "Go ahead," he could go to the podium on his own. The teacher would teach him how to say the sentences. All the classmates would applaud. After that, he would rush down to me. He actually felt excited, but he was timid as well. Gradually when he became more familiar with the environment, he could go up to speak, he knows where everything is, and how to go to the bathroom. He normally plays on the slide for a while before the class as a warm-up.

Among the class, my son is the only child who talks less. He may talk with some other children if they get along well. There's another kid several months older than him, who still uses a pacifier. We didn't use this since he was little, for fear that

he would get used to it and wouldn't let go. This girl is also very close to my son (pointing at the photo).

One thing I don't like about him is that he's too clingy. Once I'm home, he's simply attached to me. I can't fiddle with my phone, but only play with him, or watch him play, at least. He may drag me to play with his toy cars. He knows that I don't want to teach him about what he learned in the class. Occasionally, he would say, "I want to have the music lesson." If you say, "Dong dongqiang"⁵ to him, he'll laugh.

Now he can only say words like "mom," "dad," and "hello." He talks more with us at home, but becomes timid when he's outside. Today, I took him to a park to play on the slide. He only dared to play if I went up the stairs with him. I couldn't just wait on the ground. Last time, all the parents also had a class called the psychological security service. I knew that my son was timid and lacked a sense of security. The teacher told me, you couldn't tell a kid that he couldn't make it, as it would take away his confidence. You needed to talk more with him, and guide and encourage him.

Though he still doesn't talk that much and is unwilling to say hello, he has already made a lot of progress after the training he had in class. The teachers also agree. In the interpersonal communication class, the teacher asked everyone to introduce themselves. Some kids were able to tell others how old they were and their names. Our son actually knew it, but he was just scared, seeing that many people. When he was on the stage, the teacher asked him, "How old are you?" and helped him say the answer, "I'm two." Then he'd love to follow. It depends on the situation and his mood. At the end of the 45-minute class, I told him, "Haohao, the class ended. Go say goodbye to your teachers and give them a hug." He would do it, so long as you made it clear to him. We also added the teachers as our WeChat friends. Sometimes, I threaten my son, saying that, "Be a good boy. If you don't want to sleep, I'll tell your teacher." Then he'll go to sleep. He's obedient to his teachers.

He also likes pretty girls. Currently, he gets along well with a little girl 7 or 8 months younger than him. She lives upstairs. He may share things with her. As I've mentioned, he's more active with someone he knows, but won't talk with strangers at all. He would hug me and cling to me, including during the early development class.

Raising children is not that complicated in an ordinary family, but we're different. When I take my son to the class, I can sense that we're slightly different from all the other normal parents and families. I hope that they won't find out, and I try to do my best within my abilities. Sometimes, I'll state clearly to the teacher about our real situation, and ask her to pay more attention to our kid and teach him with more patience. I have to do so, since it can be troublesome if we can't explain what my son wants to know at home.

Teacher: This family really tries hard to raise the child. You have some photos and videos, right?

⁵The sound of beating drum.

Xing: Yes. This one is a swimming lesson in the early development course. In this picture, his father took him to the class, which was an introduction to Japan. My son carried an umbrella, pretending that they were in Japan. This picture is my son in a Japanese outfit. This one was taken when he played in the Expo Park. He loves playing with little toys and loves toy cars. This is him playing in a shopping mall. He actually has been to many places, but not abroad yet. These are him laughing, being lazy, being ill, drinking milk at home, and at the home of my husband's grandma...

This is the son of my BFF, who's also my classmate. He's younger than our son (pointing at the photo), and still crawls. So, I give my friend all the clothes outgrown by my son. That day, she came to meet me, and experienced the early development courses with me. She also wanted to send her son to it, but she couldn't afford it. She married a man from other places. No house, no strong financial background. They just bought an old-style house at a price of about 740,000 yuan and they needed to pay the mortgage. The house seems to be located in southern Shanghai. I once visited her house by taking the Hunan line, which took a long time. She's quite capable, as she works at Tesco now. But due to the long commute and low salary, she's always looking for a new job. Actually, changing jobs can be really difficult nowadays.

Two Jobs I Found by Myself

Q: Did you start working again after having your son?

Xing: I stayed at home for a while after participating in Special Olympics for the second time. I weaned my son off when he was 8 months old, then I tried to find some job in the catering industry and learn something. At that time, I was on good terms with our department head in the XX House. She knew about my situation, and treated me like her little sister, just treating me as a normal person.

I knew the Teahouse, but I didn't know she worked there. I went to visit her workplace, thinking it looked good, and the overalls were also beautiful. She introduced to me the job, and asked, "It's really hard. How can you bear it?"

My mother-in-law also went to the XX Teahouse with my son. She replied, "I'm sure she can." I thought it was okay. I needed to work for 6 days and rest for 1 day; the lunch was also covered. The salary was so-so. Then I became a waitress here, leading the guests to their seats and carrying plates. This was my second job.

I worked all day long for 6 days every week. That was really hard. I felt I couldn't carry on any longer after a month. Also, an accident happened during working hours. I was wearing a pair of black shoes and I was carrying bowls of soup, when suddenly I slipped and fell on the stairs in a narrow area. The soup spilled, and my legs got seriously burned and turned red.

My husband also worked there at that time after I made an introduction. When the accident happened, he was also on duty, so he took me to the hospital. My son was at home with his grandparents. Normally, it doesn't matter if you break something at work, but you need to avoid hurting people. I was just so unlucky... The company didn't provide any compensation, but simply reimbursed my expenses in the hospital.

I rested for a month at home. I thought the work was really exhausting, so I quit. In total, I worked there only for a month.

I actually had a great time at the XX Teahouse. In the beginning, we seldom talked as we didn't know each other well. Gradually, our manager and head waiters took really good care of me. I felt a bit embarrassed as we were of the same age. The manager just acted like my elder sister, saying that, "Just tell me if something makes you upset. Is there anybody who treats you badly?" I would reply, and tell her that I felt I wasn't capable. Ms. Zhou, the manager, said, "Don't look at it like that. Sometimes, it may be your illusion. No one looks at you differently. If you want to quit, just tell me." Occasionally, I might think too much, trying to pursue perfection. She was off duty on the day I got burned. Later, she was told by the head waiter that I spilled the soup. Only she knew I had the disability certificate. So, working there as a normal person in the eyes of other staff, I felt pressured due to their constant care.

After I left the XX Teahouse, I rested at home, took care of the baby, and found another job at X Home when my son was 1 year old. This was also introduced by my ex-colleague. At first, I read what she posted in the WeChat moments. I found that this was a German brand selling home décor for the balcony, like the spider plant. I thought it looked nice, so I asked my ex-colleague if they still recruited people. I also checked on their website and walked around in their shops to get a general picture. After all these, I considered it wasn't that hard. I needed to work for 5 days and could rest for 2 days. After being recruited, I was assigned to the branch in Shan X Supermarket, with an exhibition stall setting up at the gate. Every day, I sold goods and restocked. It felt okay. There were also morning and night shifts. The manager cared about me. She knew about my situation, and told me, "You're not that good at attracting customers and persuading them to buy our goods, so we decided to assign you to our experience store."

The experience store is located at Yanjiaqiao, near the Youxiang Furniture company. It's on the first floor of a building near our office building. I was so clumsy that I couldn't drive the electric vehicle. Normally my husband took me to work and picked me up. There weren't many customers. Most of the people in the building went to work here, including some of our company. The environment was okay. Just somewhat remote and old-style.

The experience store aims to show customers the products, the layout, and the design of a balcony. I also sold things there, introducing items to clients occasionally. I only succeeded in one deal when a regular customer came. The competition wasn't so fierce when I worked at the XX House previously. Except when the manager and some top heads came to visit, I was the only staff member in the store. Every day, I helped report the performance of Shan X branch, summarized the day's work, and planned for the next day. I also needed to do some cleaning. That's all. It wasn't that hard.

There were many departments in this company, such as the design department and HR, and so on. All the colleagues worked in offices. As I went to work in another building, and only had the chance to meet and talk with my colleagues at lunch, our relationship was kind of distant. When I was at the XX House, colleagues were closer, like friends. We ate together, hung out, and took care of each other. In this

company, however, they didn't know about my real situation, and I couldn't talk too much for fear of exposing myself. So, our relationship was more distant. Sometimes I had lunch alone.

Later, the company opened up a branch near the Shan X Supermarket. Colleagues working at the exhibition stall were reassigned there. They might ask me to prepare things, do invoicing, and fill in for some colleague who didn't come. It was good. Colleagues here only talked about work, not personal life. They didn't have many personal friendships. The colleague who brought me in was of the same age as me. She's also a mother now. We aren't that close currently, but she got along very well with other colleagues at that time. So I thought, whatever.

I was outgoing at work. After I got familiar with everything, when colleagues asked me for something or an answer, I told them I had a treasure box. You named it, I gave it to you. The communication with colleagues was just okay, not that intimate. I thought it would be enough that I handled all the work. If there was nothing to do, I just had a rest.

At X Home, no one knew I had the disability certificate in the beginning. But the colleague who brought me in told the HR department about it, as the company could enjoy some benefits with this.⁶

I enjoyed working at the exhibition stall at the gate of the Shan X Supermarket. It was just that I got quite busy during weekends. Then somehow, my colleague started to ask me about my disability certificate. I said it was about to expire and I didn't know how to renew it. Then this colleague told our manager, who later tried to persuade me, "Lele, are you a disabled person? Do you have a disability certificate?" I said yes, but it expired. Then she said now that you had it, go to the subdistrict and renew it. I replied I'd ask my mother-in-law. After listening to my sudden inquiry, my mother-in-law wondered why. I told her what happened in the company and said actually I didn't want to renew my previous certificate. So I replied to the company, saying that, "Sorry, I'm afraid I may not be able to renew it. My household is registered in the Hongkou District as a collective one. All my files are kept there." They thought about it for a week, and came to ask me again, I still said no. In the end, the manager came to me, asking me to check around when I was off duty to renew the certificate. It was so annoying. I went to the Hongkou District many times. Also, the certification of my collective household registration was only valid for about a month, I had to go to the police station to renew this as well. My mother-in-law accompanied me here and there, which was exhausting. In the end, we called the DPF. They told us we could go to an office in Pudong for registration. The files were also kept there. We finally succeeded. Then the company copied my certificate.

Q: Did this affect your work later on?

Xing: Of course. My sales capacity was thus affected. X Home focused a lot on your performance, namely your ability of promotion. Previously, though I didn't sell

⁶This benefit refers to policies concerning corporate income tax preference, subsidies for employment of the disabled, and the exemption of corresponding proportion of employment security funds for the disabled of the employee concerned, to encourage recruitment of disabled staff.

that much, I could still participate in the meetings with colleagues. But gradually, due to the certificate thing, everyone knew that I was a disabled person. This made me feel pressured. Why did it become like this? Our manager said, “This is no big deal. It’s nothing shameful.” So, I didn’t complain about it. Later, my supervisor thought I wasn’t a good saleswoman, and assigned me to the experience store, as I mentioned earlier.

I knew a deaf–mute person during my work here. She was in her thirties; we were both disabled people. She worked at the reception of the HR department in our office building. I could see her at work face-to-face as the two buildings were next to each other. Every day, she came for invoicing and wrote something on the blackboard. She was quite good at doing some practical work, but she couldn’t hear. When you communicated, you could only type, or ask her to read your lips. When we talked to each other, if she didn’t understand what I said, she would definitely ask me again. As we were similar, we were somewhat closer, but we still remained just colleagues. The majority in the company didn’t know about our situation. Some administration and HR staff might know; they must have reported this to the boss.

Q: Do you have any goals in terms of work?

Xing: We may not be able to get a promotion, but all I want is a year-end bonus or social insurances, as our monthly salary is fixed. I once heard that the company provided New Year dinner and this kind of bonus. I started working here in February 2016, around the Spring Festival. So, by next February, I will have been working here for a year. I might find out if I get the bonus by then.

We don’t talk about the salary in the company, as it’s confidential. When we get the salary sheet, we just check for ourselves, and ask HR if there are any questions. I earn about 3,200 yuan a month after tax deduction.

Q: How do you feel after experiencing different jobs?

Xing: I felt at ease working at the XX House. The older colleagues would take care of me and there were more Shanghai locals. I felt quite happy.

At the XX Teahouse, there were fewer local people. It was more tiring. When there were many customers taking orders, it could be quite busy, especially during lunchtime. I just couldn’t keep up with the pace. Though the managers didn’t blame me, I would feel bad and frustrated myself. It was uncomfortable and exhausting. I could only rest for 1 day and work for 6 days. I couldn’t stay at home for long.

At X Home, I work from 9:30 a.m. to 6:30 p.m. for 5 days, and rest for 2 days. Sometimes I may get off late, but there isn’t actually any customer. Besides, in a company just next to me, people work from 9 a.m. to 5 p.m., then there’s no staff in the building, either. I think I can just muddle along and see.

Teacher: The XX House is among the enterprises recommended by our school, in addition to Starbucks, InterContinental Hotels, and Novotel Shanghai Atlantis. We visited all these companies, and considered their environment, inclusiveness to our students, and their preferential policies of recruiting disabled persons, before we recommend them to our students. We need to be responsible for our kids. Her current workplace has nothing to do with our school, so we don’t know what it’s like.

After 2 or 3 years of work, many students have changed their jobs, which is also beyond our reach. We don’t have enough capacity to help them throughout their

future life. Luckily, Le Xing always contacts me, so I can remind her about important considerations at work. First, social insurances; second, welfare and bonus, monthly salary; third, inclusiveness of the environment and discrimination. They must bear these in mind, before they can make a living by themselves.

I think her capacity is improved after she worked at the XX House, XX Teahouse. Now, she can even find a job on her own. Every time when she wanted to resign, she would tell me about it and ask my suggestions. I told her, “Think before you leap. You can do so if you know what your next step is.” Teachers and parents should allow our kids to adapt themselves to society, experiencing the reality, with both the good side and the bad side. When she got burned in the second job, she also told me and said she wanted to quit. I agreed, telling her personal safety still mattered the most. After she gave birth, she wanted to go back to work again, I encouraged her to go ahead if she had really thought it through. Though the job people can do is related to their ability, I think it has successfully contributed for Le Xing in becoming who she is today. Her current state of work and life is really impressive.

Xing: Normally I don’t ask for teachers’ help. I try to find a job by myself.

Sometimes I want to change jobs, but I can only sell things, since I don’t have the qualification for administrative work or a diploma. I don’t rely on teachers a lot, but I’ll talk to them if I feel unhappy and bored. My teachers may ask me how my work is and whether I get along well with my mother-in-law, I say it’s okay. I still think the XX House was better compared to other companies. Currently, though the colleagues are about my age and communicate well, I still feel different from them, thinking that they’re more capable.

Teacher: She loves chatting with others, especially when she’s free. But actually, we’re quite busy. So sometimes, I told her, “I’m too busy to chat with you. Now that you have become part of society, you need to treat others sincerely. That’s true. But you also need to know that there remains a suitable distance in interpersonal relationships.” For kids like her, I also taught them some skills in terms of communication with others. I said to her, compared with the meagre salary of cleaning ladies, you already had a decent job and a good working environment.

Xing: There was a cleaning lady in my previous company. She came to work every day and also rested on the weekends like us. She was quite busy actually. That was why my teachers said I already had a good job with a satisfactory salary, and asked me to carry on, since finding jobs could be really hard. We’re not that competent. Even if I want to be an office lady, I’m bad at typing and I don’t have a good memory. Also, the working hours are basically the same everywhere. Gradually, I came around to the idea. Occasionally I may get narrow-minded in life, but now I’ve made some progress.

(During the two interviews, Le Xing was fired.)

Q: Did the company inform you of the layoff in advance?

Xing: Not at all. I was informed on the same day I was fired. The deaf girl and I were the first two people fired. In the afternoon, the deaf girl said, “I want to tell you something. I was fired.” Later at 6 p.m., HR sent me a WeChat message, asking me to go to the meeting room. And I was told that, “Lele, you must have heard that we’re laying off people recently. I’m sorry.”

I think they didn't tell me the real reason. They just made an excuse, saying that the boss thought there were too many staff and my department no longer existed. As I'd signed a contract with them, they'll compensate me with some money, given to us together with the salary on December 20. In our company, the strange thing is that in a particular month, we not only receive the salary of the month before, but also that of this month. Sometimes, the finance staff also make mistakes. I started to work here on January 18. On payday, I should only have received salary for 2 days, but I got 3,200 yuan surprisingly. My mother-in-law also said that was quite a lot of money. By the time they fired me, they discovered this mistake, so the extra part will be deducted from my December salary, and my overtime payment for October 2 and 3 will be added to it. All in all, it's a total mess.

Q: How much can you get as compensation?

King: Two months of salary. My pre-tax salary is 3,500; net income is about 3,200 or 3,300. This is okay, since meals are also provided by the company. Unfortunately, I have to return the 3,000 yuan given to me by mistake as I just mentioned. It's ridiculous. I received all the salary sheets through email, how do I know how they calculate the money? Though I only worked for 2 days, the email showed that much money, then that should be my money. No one made it clear to me until now. My mother-in-law also felt very angry about it, but she decided to let it go. Actually, the finance staff have made many mistakes. Once, they even asked us to return the money delivered by mistake. Considering all these, my mother-in-law always reminds me to be clear about the money.

Q: Is there extra subsidy provided by the government apart from the income at work?

Teacher: No. The government provides subsistence allowance to the severely disabled people who can't work, but Le Xing is mildly disabled and employed, so she doesn't have that. This is the policy. I think the mildly disabled also deserve some, but there isn't. If these people aren't employed, they won't have social insurance, which means that they have no financial guarantee after they retire or when they're old. Idleness does them no good, either. The subsidy of about 1,000 yuan is never enough for their daily needs. It's better that they go to work if they have the chance, which enables them to communicate with others. Now I think that this young couple really lead a good life. They have jobs, they have their child, and they can become more mature in their social interactions. What's the point of staying at home? They're still so young!

Happiness Lies in a Simple Life

Q: Do you have any other concerns in life? What expectations do you have for the future?

King: I'm worried that my son may not be able to study well. But we can only send him to the school. My mother-in-law once said that both my husband and I had difficulties in learning, so we never knew how our son would develop in the following

year, as kids grew fast. I also see many of my colleagues attend the parents' meetings at school. I worry that if I attend such meetings one day, what if I can't understand the teachers' words? I simply hope that my son is healthy, this is the priority, and smart. We'll support his studies as long as he can keep up with the class. We hope he can make many friends with other kids. I wish him all the best. That's all. In the family, I hope everyone can be happy, and talk with each other if there are any problems.

In terms of work, I have no expectations. Sometimes, I envy those colleagues who're close and eat together, since I'm alone. But the important thing is, I just need to do my work well. That's enough. As for friends, I once asked Ms. Yang of the dancing team to organize a party, but everyone was busy at work. I work from Monday to Friday, while some others may work on weekends. So, we couldn't get together. What a pity! Now I just go back to school occasionally. My in-laws told me that, "It's not that good if you visit school too often. After all, you already graduated and have a family. Don't go there bothering other people."

Teacher: Don't worry too much. Everyone goes through this when they grow up. Your current life is really good, right? Nothing bad happens. Simplicity is also a kind of happiness. Sometimes, I really envy her. She's strong, optimistic, and always enjoys herself. Just remember to cherish what you have now.

Interview with Le Xing's PE Teacher

Interviewee: Ms. Zhuoying Shi (PE teacher)

Interviewer and writer: Jing Zhang

Interview date: December 17, 2016

Interview place: School of Special Education in Pudong New District, Shanghai

Teacher's Confidence Boosted Thanks to a Promising Student

Q: Could you please tell me when Le Xing caught your attention?

Teacher: During my PE class after she entered school.

Q: What exactly attracted your attention?

Teacher: She looked like a boy with short hair when she was little. I thought she was a boy at first, then I discovered I was wrong, I became interested in her particularly. She's quite flexible.

Q: When did Le Xing start doing gymnastics?

Teacher: Quite early. It was around 2002 or 2003, when she was in the third grade. When our school started to add the gymnastics course, I invited her to practice with other kids together.

Q: I heard from Ms. Wang that you were the main coach of the gymnastics team.

Teacher: Previously, there was no gymnastics in our school, just table tennis, track and field, etc.

Q: How did you think of the idea, involving students in gymnastics?

Teacher: We got to know that there was this new event in Special Olympics. In addition, gymnastics is really helpful in strengthening their body in all aspects. Different kids have different weaknesses, either in strength, flexibility, or physical coordination. Therefore, previous group events may not be suitable for everyone, but gymnastics allows for individualized exercises and enables each student to bring his or her strong suit into full play. Le Xing, for example, can avoid her weakness in basketball.

Q: Did you ask all the students to practice gymnastics or did you select some people?

Teacher: There were many, actually. We had the morning exercise, basically all of her class came. We didn't start from gymnastics moves, but with some simple exercises, like stretching the legs, bending the waist, and doing the splits. We didn't have much equipment back then. It was just some exercises.

I once trained a team of six girls in rhythmic gymnastics in a regular school, so I did the same here, teaching Le Xing and other students the group free exercise, and starting from the basics, like stretching the legs.

This group of girls, including Le Xing, was the first "gymnastics team" I coached. We started our training before we ever took part in competitions. We stretched our legs on railings, kicked, bent our waist, and did push-ups. In case of a competition, extra training was added based on the specific moves, like ball routine or ribbon, etc. Initially, we only knew we should enhance the basics, including strength, flexibility, and coordination, then we decided on specific moves for further practice.

Actually, Le Xing was the one who encouraged me to carry on in the beginning. Every day, I asked all the students to lean on the wall, and hold up one foot to stretch their legs. They felt it hurt and it was boring. When we moved on to the ball routine, most kids flinched from it. What should I do? Of course, now that we've experienced many games with good results, I can tell students that we must work harder, instead of being complacent. But back then, we started from scratch. We never knew when or if we would ever compete, nor did the kids make much progress, as the moves designed for normal students were kind of hard for them. Eventually, only Le Xing was able to do half of the whole set.

Q: They didn't get it?

Teacher: No. Maybe the moves were difficult, and they couldn't carry on. After Le Xing learned half of the moves, there was an event in the school. I asked them to have a performance together, but no one dared to do it. At last, Le Xing went on to the stage.

Q: She performed alone?

Teacher: Yes, only her. Others weren't as good as her. She needed to roll the ball on her body while doing all kinds of moves. The show was quite a success. Teachers praised her; other classmates admired her; she herself became much more confident. This boosted other students' confidence, as well as my own. This performance attracted five other girls. Then the six of them kept practicing, later becoming our gymnastics team. They even performed the ball routine on TV.

At that time, we didn't know about the events in Special Olympics. Later, when we learned that gymnastics was added, we wanted to go, and received some simple training on parallel bars. Before this, our girls only practiced with balls.

Q: You've always been coaching Le Xing?

Teacher: Yes. Ever since the gymnastics team was established, all of us PE teachers trained them. Now we have a better division of labor. Some other teachers are training students in other campuses.

Q: Did Le Xing and other students supervise each other?

Teacher: Yes. Seeing others outperforming her, she would feel pressured and worried. She had her own goal to practice well, compete with others, and win medals.

Q: You've been coaching the students, so you did more than other teachers, right?

Teacher: I came earlier than other teachers for the morning exercise. In case of competitions, there would be extra training. I was willing to do all these. It wasn't a burden for me.

Q: It was you who demonstrated the moves to them?

Teacher: Sure. I either learned them from the beginning by myself, or together with them. At first, they might not have been able to understand the video, but gradually, smarter students began to get it, until all of them became better and better.

Q: Did the gymnastics team go through hard times?

Teacher: Of course. It was really tough. We started from scratch, with no equipment and no video tapes. We did it all by our own, step by step. Gradually, the school supported us with equipment, and training outside. We went through ups and downs. Sometimes I felt it was pointless, especially when everyone reached the bottleneck without any progress...But this could happen.

Q: So, you not only trained the students, but also cheered yourself up along the way?

Teacher: Yes, that's true. When we started training, we didn't know when there was going to be a competition. Even if we knew later that one would be held in 2007, we had no idea about who were the players and what the game was like. But I've always been highlighting one thing to all the team members: whether you could go to the games or not, exercise was for your own good. For some kids who couldn't compete, I would tell them that, "You performed really very well. You can put on a performance with other kids at school."

The first step is always difficult. If we gave up midway and only started practicing gymnastics in the 2007 intensive training, then we wouldn't be able to stand out, as no solid foundation would have been built, and we wouldn't have had the chance to compete again in 2011. In the 2007 Special Olympics, the nine athletes of the Shanghai team ranked among the top. One of the boys even won seven gold medals. We could perform better than the other teams, simply because we started earlier, worked harder, and persisted in stretching and practicing every day. We had a solid foundation. That was why our team was able to be part of the 2011 games as well. I owe all these achievements to the hard efforts of the first members, including Le Xing.

Q: Now you still tell kids to focus on physical exercises?

Teachers: Yes. I tell them that exercise always comes before the competitions. Of course, it can be good if we perform well, win gold medals, and make new friends, but only a few of the ten kids have the opportunity to compete in the games. Some kids and their parents might feel unhappy about this; some others just give up. From our perspective, as we need to achieve something during the competitive games, we won't choose those who are lazy or weak or whatever. Even Le Xing might slack off occasionally when she was exhausted.

Now as our gymnastics team grows bigger, not everyone can have a spot for morning exercise in the original room. In response, I just provide some basic sessions; students who are particularly interested in gymnastics can receive further training. In PE class, I also try to introduce a bit of my idea. We don't have to take part in Special Olympics as gymnasts, but this sport is definitely the foundation. At least, it's beneficial for the body, and girls can build up a beautiful figure. Other teachers agree that gymnasts stand straight and look good.

Special Olympics After All the Hard Effort

Q: Did your team ever participate in other games before the 2007 Special Olympics World Summer Games?

Teacher: Sure. We attended a national competition in Tianjin in 2005, and the national gymnastics competition for children with special needs in Changchun in 2006, when I asked Mr. Zhang from Taiwan about the gymnastics routines in Special Olympics and started to learn from a video disc.

Q: You've been the coach during this whole process?

Teacher: Other PE teachers also help me. I myself am not a gymnastics teacher. I only had some experience in a regular school. Therefore, guidance from professional coaches is often needed.

Q: When did you start to invite other people to coach?

Teacher: After we finished practicing the ball routine, we still hoped to take part in competitions, so we first learned from discs. The founder of Special Olympics, caring about the gymnastics training in our school, provided guidance in person once. Some of my ex-colleagues from an institute of physical education also provided professional guidance several times. I turned to these people for help in the beginning, as I didn't know much myself.

After we started attending competitions, we got to know many people from the physical education school, and professional judges and coaches. Sometimes, the school applied to have several training sessions in professional gymnastics rooms. There weren't a lot of resources at first.

In 2006, Shanghai held an invitational tournament, with several participating teams, including Russia and Hong Kong SAR. There was still a Shanghai team at that time, while our school represented the national team, of which Le Xing was a member. We were widely involved; all the PE teachers received training. After the tournament, the professionals confirmed our strengths, while pointing out where we

could do better. During practice, I felt it was already enough when students could do the moves, but the coaches paid more attention to details, like postures and straight legs. That's where the beauty of gymnastics lies. An international judge whom we met when he worked as the deputy judge in one tournament often provided guidance to us in our school as well.

Q: He's a Chinese?

Teacher: Yes. Foreign judges can only come occasionally.

Q: So, the gymnastics team got on the right track after Special Olympics?

Teacher: Yes. Special Olympics brought our team to everyone's attention. Our members were known, advantages recognized, and disadvantages pointed out. As the 2007 tournament was of particular significance at the national level, we were able to attend the intensive training in Tianjin. Gymnasts were also classified in the national team as Level 1 and Level 2 with an increasing level of difficulty. Le Xing belonged to the latter group, together with several other outstanding kids. At this stage, training sessions were divided based on specific events. Le Xing competed in artistic gymnastics, like uneven bars. It was harder, and Le Xing was really hardworking.

Q: Le Xing chose to practice artistic gymnastics, or you assigned her to it?

Teacher: I assigned all of them. Some kids were timid. One girl, for example, didn't dare to practice the uneven bars after one fall. Rhythmic gymnastics is relatively less dangerous and difficult. It focuses more on the beauty in motion.

Q: How many students did artistic gymnastics?

Teacher: In our school, only two girls. Initially, I required all students to learn both artistic and rhythmic gymnastics. In the Shanghai team, there were about five or six other kids doing artistic gymnastics. Though only six kids went onto the stage, more kids actually practiced together, as there were fewer intellectually disabled students back then.⁷

Q: You led the team to Tianjin for intensive training?

Teacher: I took our school's team there. After we started training, I was responsible for rhythmic gymnastics. We lived together, though. Several professional coaches were also invited to join us.

Q: What did you do during the intensive training?

Teacher: Mainly the basics, the moves. We had reached the basic requirement of all the moves at school, so our main goal in Tianjin was to improve the quality. There were assigned rooms and professional coaches. We trained for 3 months.

Q: All of you stayed there for 3 months?

Teacher: Yes.

Q: It was really intensive, right?

⁷According to Article 19 of the Compulsory Education Law of the People's Republic of China, implemented on September 1, 2006, regular schools shall admit to the classes disabled children and adolescents corresponding to the levels of the disabled's school-age, who are capable of receiving regular education and provide them with aid in study and rehabilitation. In addition, as the concept of inclusive education becomes popular, more and more children with mild disability are admitted to regular schools; students in special education schools are of a higher disability level.

Teacher: Indeed. When everyone stayed at the hotel, I would supervise their exercises. They just couldn't stop, otherwise, their flexibility, and strength, would deteriorate over time. I monitored them every day, asking them to stretch their legs even when watching TV.

Q: Were all of Le Xing's classmates at basically the same level?

Teacher: Le Xing was relatively more intellectually disabled. When she became involved in Special Olympics, we provided her with many opportunities, like hosting a ceremony, or acting as the Special Olympics leader. Nonetheless, she was still timid, feeling afraid of such an event. Later, Qiao Li, one of her classmates, became the hostess in many events.

Q: Le Xing already attended some activities before the 2007 games?

Teacher: Yes, but it still didn't work. She was shy and timid, and tended to stammer.

Q: What do you look at when you select students as the Special Olympics leader or to attend events?

Teacher: Generally, we encourage them to participate as much as possible. They all love to be part of the various PE activities. We mainly consider their strengths and characters and identify the suitable activities. Qiao Li, for instance, is better at expressive skills. Some other kids may be good football players.

Gymnastics also has several levels. Simple exercises were suitable for everyone. After we had formally set up the Special Olympics gymnastics class in our school, we tried to provide every kid with access to events and competitions. Based on the level of difficulty, gymnasts would compete in Level 1, 2, or 3. So we chose the best ones at each level, instead of sending all kids at Level 3 to the games.

Gold Medals Thanks to Persistent Learning and Exercising

Q: During the training, did Le Xing stand out?

Teacher: Yes. She was the first to perform, and it was her first performance ever. Though she felt afraid, she still presented tremendous courage. I comforted her, "It doesn't matter. You already outperform the other kids at school." Actually, her performance wasn't even a complete set of moves.

Q: She performed well because of her capability or something else?

Teacher: She was hardworking and careful. She also pushed hard when helping others to stretch the legs. Sometimes, I might assist her when she stretched her own legs, as it could feel sore. Difficult moves, like rolling the ball from one side to the other, require repeated practice. Some kids might have stopped when they couldn't make any progress, while Le Xing just kept on trying.

Q: Was Lele interested in the gymnastics herself, or you supervised her?

Teacher: I supervised every kid, but she made the biggest effort.

Q: Did she ever complain and want to quit?

Teacher: Occasionally. She could carry on for most of the time. After all, she was only a kid, just trying to get attention (laughing). Overall, she was excellent. All the team really put in a lot of effort.

Q: Did she get along well with other teammates?

Teacher: She could help others. We had younger teammates and some with Down syndrome. She took care of them just like a sister. Sometimes she also helped me clean the floor if she saw me doing it in the gymnastics room, for example. Students back then were thoughtful. Sometimes she felt depressed due to family affairs, but later, she became more open after taking part in many activities.

Q: Did she ever make mistakes and make you angry?

Teacher: She made mistakes once in a while. It was normal.

Q: Was there anything impressive?

Teacher: Her perseverance. As I mentioned before, a girl fell from the uneven bars and stopped training from then on. Lele was scared and affected of course, but she didn't and wouldn't give up.

Q: In what respect did Le Xing perform well in terms of gymnastics?

Teacher: Since she was hardworking, she could handle the difficult moves, like a single move of the floor. But when she performed a whole set, she tended to be faster than the rhythm and beats of the music. As such, she needed to practice again and again, which was quite boring. It made her worry.

Q: Did you have some expectations or set some goals for everyone, especially Le Xing, before the 2007 Special Olympics?

Teacher: During training, I told them that now that we are taking part in the competition, and in different events, we must strive to be the best in our own event and win the gold medal. Otherwise, no one would have the motivation. During the final games, scores could be deducted due to details. What we could do was to practice, practice, practice, and strive for our best, like trying to get 10 points in rhythmic gymnastics, as we never knew about other people's performance. Just ignore others. That was what I told them. This way, the training could be really tough and boring.

Q: Were you satisfied with everyone's performance in 2007?

Teacher: Of course. They were unexpectedly excellent, winning many medals. I was really optimistic. I always reminded myself not to expect too much, so that I wouldn't get disappointed. For these kids, encouragement and the process matter more than the result. One girl felt really frustrated and disappointed as she only got silver ones, and most of the other teammates won gold medals. This showed that the performance of our Shanghai team really ranked among the top nationally.

Q: Was Le Xing's performance the best among the kids?

Teacher: There were other girls winning five gold medals. She won three gold and two silver, which was good as well, as she competed in a more difficult event. My expectation was solely medals, whether it's gold, or silver, or bronze. Winning them, especially gold medals, was never easy when competing with so many athletes.

Q: After the 2007 Special Olympics, Lele got more chances to participate in activities, right?

Teacher: There were indeed many events, but Le Xing might not have been as talkative as Qiao Li.

Q: Was there any change after she won the medals?

Teacher: The sport made her happy and had a positive impact on her work. She once told us that she didn't feel tired after standing a long time at work, thanks to all the training and competitions.

Q: What other competitions did she take part in between 2007 and 2015?

Teacher: She also took part in an aerobics competition in Shanghai after the 2007 games. As the team from our school performed the best, we were assigned the task of aerobics choreography for special education schools in Shanghai. She was involved in it as well. That's all. In 2007, she went to the vocational department.

Q: There was no gymnastics class in the vocational department?

Teacher: No, but there were dancing and other courses.

Q: Apart from gymnastics, she also danced?

Teacher: Yes. Gymnastics and dancing are complementary; many basics of the former could be reflected in the latter. She was taught dancing by her music teacher and performed outside the school many times.

Q: When did she start to work?

Teacher: She went to the vocational department in 2007 and started to work in 2009 or 2010. From then on, she was kind of busy with personal affairs, like her relationship and marriage, plus we had six other athletes, so I didn't invite her back. There was also one competition held in Greece in 2011 when she still worked and just gave birth to her son. I guessed she was busy, so I didn't ask her about it, either. Later she asked me why I didn't invite her or things like that. She liked the competitions, so she always wanted to be part of it.

Q: Then why did you decide to invite her to the 2015 Special Olympics World Summer Games in Los Angeles?

Teacher: It's because we were really close and stayed in close contact. We considered this orphan as our own kid, while she called us mother, and invited us to her wedding ceremony and baby's birthday. She still came to visit us at school after she became a mother herself, so we told her about the competition. She really had the willingness and initiative, and starting training at school soon afterwards.

The 2007 Special Olympics had more participants. We sent several teams, including the rhythmic gymnastics team with ten, and the artistic gymnastics with more than ten athletes. By 2015, the number of contestants going to Los Angeles decreased. All the athletes were students selected from our school, instead of all over China. We established the team on our own with me being the coach. I didn't have enough energy back then, so all the four girls competed in rhythmic gymnastics.

Q: Was there intensive training before going to the US as well?

Teacher: We just exercised in the gym of our school. During the summer vacation, we temporarily practiced in the gymnastics room in another school before the games. One coach was invited to train the boys, while I guided the girls. The focus was to improve quality.

Q: The level of difficulty was also increased during training?

Teacher: Definitely. Though Special Olympics emphasizes participation, competitions still focused on the quality of your moves, after all. We must try to make progress in every move. Le Xing practiced artistic gymnastics very well, but this time, she had to start from zero, namely, Level 1. She was kind of stiff and couldn't

follow the rhythm, so I always corrected her... This repeated exercise made her upset and anxious.

I told her not to get worried as we still had enough time for training. We could divide the moves and do them step by step while following the beat. If she was too tired, I'd chat with her, and ask her to do some other moves that she was good at, or perform a handstand and a backbend to other younger teammates. This helped in refreshing her. She also knew to learn from other students who were better than her, and always listened to the music I sent her with her phone.

Q: She was new to rhythmic gymnastics and she just had a baby. What was your expectation towards her this time?

Teacher: She demanded to come here. Sure, I had some expectations, but she was also really strict on herself. As she had won gold medals in 2007, she still strived to achieve this goal in 2015. Therefore, she felt anxious, worried and pressured about what would happen if she couldn't win medals due to mistakes or bad performance. She pushed herself hard ever since the start of training, while I tried to comfort her and ask her to take it easy.

Q: What did you think of her performance in Los Angeles in 2015?

Teacher: Surprisingly excellent. She won five gold medals, outperforming all the other teammates.

Q: She performed so well simply after training for such a short time.

Teacher: On one hand, the challenges for her were that she had stopped training for a long time, and that she actually needed to start from zero, adapting to the new requirements of rhythmic gymnastics. On the other hand, she competed in Level 1 this time, which was less difficult. Her years of training also laid a solid foundation. So generally speaking, she was really a well-qualified athlete.

Q: In what events did she win the gold medals?

Teacher: Ball, hoop, ribbon, rope, and all-around. She won all the five gold medals accomplishing her own expectations, making her wild with joy. But during the training, she was still anxious as she tended to be either faster or slower than the rhythm. I constantly corrected her.

Growth Under Teachers' Care

Q: Were there any problems that gave you a headache during her growth?

Teacher: Kids in her class tended to act freely, doing whatever they wanted. Either it was me who took them to activities or training, or their music teacher went to performances with them, some of them might just go somewhere else on their way back home. This occurred frequently.

Q: Where did they go then?

Teacher: They just didn't want to go home. Some might wander around their community, some might date their boyfriends or girlfriends, some others had tensions with their families. One girl, for example, always felt sad due to things like being beaten by her mother. Le Xing had similar issues.

Q: Would she tell you about it?

Teacher: Yes. Her foster mother once even came to our school, waving her shoes and threatening us not to mess with her during her menopause. Perhaps she felt upset as a single mother with two kids, her own son and Le Xing. Though we talked with her mother, we mainly persuaded Le Xing, and another foster girl who often stayed out all night with her, to behave themselves, to appreciate the effort of their mothers, not to make their mothers angry, and told them that they needed to rely on their own when they become adults. We communicated with them a lot.

Q: Did Le Xing do as you said?

Teacher: Sure. Though she was angry when her foster mother beat her sometimes, she was obedient in general. There were unavoidable issues. What we could do was to take better care of her and take her out to have fun.

Q: You were also concerned about their lives, right?

Teacher: Yes, it's true. Some students weren't treated well at home. A girl wasn't able to take a shower, so we helped to wash her body; another student might not be able to study in the evenings since the parents turned off the lights; other kids might even be asked to collect garbage. That was mean. All the miserable girls talked and sympathized with each other. Lele was among them because of her mother, but we tried to let her know that it wasn't good for girls to stay out like this.

Q: How did you normally help her regarding her everyday life?

Teacher: I would ask her about her meals, like whether she had had her breakfast before training, etc. Her mother did well in this respect. In addition, when her mother was angry, or beat her with the heels of her shoes, she might become upset and talk back. I would teach her to give her mother a massage and communicate more properly. Basically, she was obedient, doing the housework ever since she was little. This was also a necessary experience for her.

Q: Do you think she gained her capacity from home or school?

Teacher: It's both. Our school provided education and guidance. Her mother also did her part by asking her to do housework. We're not saying that children should do nothing, but Le Xing might have done a bit too much. She was a foster child after all.

Q: How were her studies?

Teacher: Her IQ wasn't among the best in her class; especially in terms of memory, logic, and numbers, she was probably below average. During training, she also had extra lessons, and came to me for help. I would ask her about her studies, and told her to work hard and study, otherwise training would be discontinued.

Q: It seemed that she liked training a lot.

Teacher: Yes. Maybe due to the environment of her foster family, she really looked forward to and enjoyed participating in training and all kinds of Special Olympics events.

There were cases where students had to leave our school as the parents decided to stop fosterage. One kid from the welfare center had to transfer to another school, while another girl, who was as hardworking in training as Le Xing, had to stop training because her foster mother thought she wasn't smart and kicked her out. So, we always reminded Le Xing of the good side of her mother, who actually raised

her. “What if she wanted to return you to the welfare center? Then you would have had to leave the school,” we said. We comforted her and asked her to behave herself at home. After all, there were things that we couldn’t control.

Q: Would you communicate with her mother?

Teacher: I seldom did this. The teacher in charge shouldered more responsibility and might have talked with her mother if they met. The mother’s temper was kind of...

Q: Le Xing said her mother sometimes came to the school. Was this true?

Teacher: Yes, her mother normally went to talk with the teacher in charge.

Q: Was that Ms. Cai?

Teacher: No, it was Ms. Wang. Ms. Cai usually took Le Xing to various activities, like the Special Olympics Global Youth Leadership Forum. All of us teachers took great care of the students, especially those from the welfare center, as they received less care at home. We just treated them as our own kids.

Q: Le Xing told me that apart from you, Ms. Cai also looked after her throughout the years. Could you tell me about it?

Teacher: Before 2007, Ms. Cai took the students to all kinds of events, including acting as unified journalists, while I coached them in gymnastics competitions. Later, Le Xing rarely took part in events. In 2015, she was quite successful as the hostess in a charity gala dinner. She became more mature with experiences in other activities.

Q: What about the scale of the dinner?

Teacher: It was the Special Olympics Unity Fundraising Gala Dinner held by Special Olympics East Asia, inviting Mr. Shiyi Pan, Ms. Lan Yang, Mr. Ming Yao, other celebrities and the Special Olympics ambassadors.

Q: Why was Le Xing selected?

Teacher: I recommended her. I thought she could perform better in such occasions after experiencing many activities and working in different companies. Besides, the staff from Special Olympics East Asia helped her with the rehearsal.

Q: Do you think these events have influenced her growth in some way?

Teacher: Yes, she became more confident.

Q: Any negative impact?

Teacher: Not really.

Q: What kind of guidance did you give her after she graduated and started working?

Teacher: I would chat with her. She told me she was selected as the best member of staff, and shared with us the joy of her marriage and the birth of her son. I was also invited to her wedding ceremony, but I couldn’t make it as I got a fracture back then. She still tells us about her life now.

Q: Do you still care about her family life nowadays?

Teacher: As I know both her and her husband, who studied at our school, of course I often ask her about her life.

Q: Do you really support this couple?

Teacher: Of course, as long as she’s happy and they love each other. Her mother-in-law is just like a real mother, treating her very well; she also has a baby now. So, her life is quite stable and full of happiness.

Q: What’s your opinion of her and what’s your expectations for her?

Teacher: I wish she can be happy. Previously she came back to school and helped me in coaching many athletes. I would say, “Le Xing, I trust you with all these kids.” She would complete the task very well, since she was as strict with herself as with other teammates. I hope that she can visit the school often and help younger students in doing gymnastics.

Translated by Min Cui

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A Girl Behind a Closed Door



Mengying Yang

Interview with Miss Yi Shi's Mother

Yi Shi, female, born in 1992. Grade III intellectual disability. Has a younger brother. Graduated from a special school—Zhonghua Vocational School, and joined the Sunshine Home in Shanghai in 2013.

Interviewee: Yi Shi's Mother

Interviewer and writer: Mengying Yang

Interview dates: October 27, 2016 and January 4, 2017

Interview place: Yi Shi's home

I Couldn't Send Her Away Again

Q: When did you and your husband get married?

Shi's mother: We got to know each other through one of our friends, and we got married in 1990. I fell pregnant several months after that. Yi Shi was diagnosed with Down syndrome, an inherited problem, when she was born.

Q: How did you feel when your daughter was born?

Shi's mother: I was very glad without any doubt; I was one of the "late marriage and late pregnancy" generation. I didn't even feel the pain when my daughter was born by caesarean, but she looked very different to the other infants, her head was very small, her face was yellow, kind of odd-looking. I'd heard a newborn baby's first cry, just the wailing and no tears, but my daughter did both. Today, I can still see this picture. Before we left the hospital, the doctor realized there was something

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wrong with my daughter, but he wasn't sure what it was, so he talked to my husband and suggested that we take her for a proper check-up.

After I'd rested at home for a while, we took her to the Second Military Medical University Hospital and the doctor said she might be a Down syndrome baby. The final diagnosis depended on a chromosome examination. Before this, we didn't know anything about chromosomes, but the result revealed that our daughter had chromosome 21 trisomy syndrome, congenital dementia. The news hit us like a thunderbolt, my husband and I didn't know what we should do, we didn't understand why it had happened to us.

Q: Did your daughter have an IQ test?

Shi's mother: She's grade 3 intellectually disabled, a mild condition. The IQ test was a necessary condition when we applied for a disability badge.

I took Yi Shi myself for the test while my husband went to work. I covered most of the family's domestic duties during that period, I had no choice.

What can you do when you have a disabled child? The mother is the only person who cares for the child. Who else would help raise her? Can you depend on the maternal or paternal grandmothers? Is there anybody who would want to look after a disabled child? Nobody! I didn't have a choice and no support. My husband said: "Except for you and me, nobody likes her." I agreed. As her parents, if we didn't care for her, what could we expect from other people who looked down on her? The people might...

To have a child like her is very frustrating, but we don't have a way out!

Q: What was the first thing you did when you realized she had a disability? Did you want to hide her away or ask relatives for help?

Shi's mother: We didn't do either. We took everything on our own shoulders from the very beginning. It wouldn't have been helpful to ask around my relatives for help; the only thing we could do at that time was to accept the fact and try to solve the problems ourselves. To be honest, it was a very big shock and a difficult period when our daughter was born. I had a normal pregnancy just like every mother, but I had a child like this. I never came to terms with this.

I have a relative who lives in the countryside, when our daughter was 3 or 4 months old, she said: "There are some farmer families who wouldn't mind looking after a child like your daughter if you can pay more than 100 yuan every month." The place she talked about was quite far away, Haimen Town, further than Chongming Island from Shanghai. The foster families didn't know that the children they looked after were Down syndrome babies, but they knew that they had some kind of intellectual problem.

We didn't feel at ease after we sent our daughter to a foster family. After a month or so, my husband suggested that we visit her. All of her clothes were washed and damp hanging on a line in the yard when we arrived, we guessed the family had probably given our daughter a bath and changed her clothes just for our visit. When we saw our daughter, she was sleeping on a round bamboo tray, there was no expression on her face. After she had been with them for over a month, we sent the family a half bag of ground rice, it was still there untouched—at that time, ground rice was the

only thing she could eat and as a big baby her appetite was good. At lunch time, the family fed my daughter the ground rice we'd given them.

Her quality of life with the foster family upset us a lot, so we told them that my parents had been missing her as an excuse to bring her back home, and we've kept her with us ever since. The foster family came to see us later, but we didn't want to leave our child with them anymore. For us, our daughter might be a disabled child, but she has a right to a life. We can't let her live like those children who stayed with the foster families, a 12-year-old child still living with a dirty, runny nose, for example. We decided to raise her ourselves, it was the best thing for her and for us.

When she was a year and a half old, her dad contacted all of his friends to find some doctors for her. One of them told us to visit a traditional Chinese doctor, 89 years old, who lived in Beijing. The doctor was popular and sounded quite special, and we arranged to meet him just to try him out.

Q: What about this treatment?

Shi's mother: It was hard to tell. His therapy was quite different from normal treatments. It was neither a pill nor an injection, but a kind of pen-shaped needle acupuncture. During the treatment, under the stimulation of this acupuncture pen, my daughter couldn't keep still; it wasn't a very pleasant feeling for her. So I used to take an orange with me and let her suck it while she was treated to calm her down. For me personally, it was a miraculous treatment.

At that time, the apartment we rented was a long way from the doctor's place, so I would travel by bus using a monthly pass. It wasn't an easy journey having to carry my daughter who couldn't walk yet, and we were wearing our thick winter clothes. We'd arrive at the doctor's around 8 or 9 a.m., before he got up, and after he opened the door I had to cook him breakfast, just liked a maid. Do you know what he had? A cup of tea, a piece of fruit and two poached eggs every morning; he always had the same thing. After I cooked his breakfast, I would start testing my daughter's condition with a meter that the doctor had taught me to use.

He charged me 35 yuan for each hour, pretty expensive in those days. My daughter's treatment lasted 2 h every morning, starting with the test.

Later, the doctor would decide what that day's therapy would be depending on the result of the test. After the treatment, he would tell us what to eat and when, for the rest of the day. Following this diet for her everyday wasn't easy at all. But I was determined to do this, and for over half a year I had a life like a poor worker.

In this picture, you can see that my daughter couldn't walk yet; she would stand in a walker I bought for her. In the final month, my mom came to help me because she thought I was working too hard. After half a year, I couldn't see any beneficial effects from the treatment, so we came back home. Later, I broke my back while having a shower one evening at home, I was in pain for a long time, so we didn't go back to Beijing for further treatment.

Q: Did she get any other kind of treatment after that?

Shi's mother: No, we stopped looking for other treatment, because her problem, Down syndrome, is an inherited one. It's a problem with her chromosomes and there is no cure, unlike some diseases that children contract after birth.

Q: When did your daughter start talking and walking?

Shi's mother: She was probably able to walk when she was two. I had my second child when she was three, and I've stayed at home to look after both of them since then.

They played together when they were very young; I'd put a sheet on the floor and let them play on that, if I'd left them on the bed they might have had a fall. They were quite interactive and friendly with each other at that time, and their cousin used to take them out together. But their relationship changed after they grew up—they hang out with their own friends—and hardly spend any time together.

We never kept our daughter at home, she went to the nursery and then school when she was the right age just like ordinary children. But at that time, there was no special school for these children, and they couldn't go to a regular nursery either. Her dad found her a small family nursery through the Disabled Person's Federation (DPF) when she was two and half years old. It was small boarding family nursery, just two bedrooms, with only three to five students.

She spent two and half years there and when she was five, she went to the Public General Hospital charity nursery for children with special needs, the first nursery for intellectually disabled children in China. I'm not sure if the nursery is still there, but she spent a year there and then transferred to a special school later.

Compared with other children who have the same condition, Yi Shi was quite lucky to get the chance to go to a special nursery and school, there were few places like this at that time. Frankly, my husband and I had quite progressive thinking compared to parents who were unwilling to allow their disabled children to leave home. We were determined to let her go out as much as we could, because we knew staying at home wouldn't be a good thing for her.

Q: What did the nursery teach the children? Did they have some rehabilitation training?

Shi's mother: Something with dancing and singing, but they didn't have a proper course. I guess they had rehabilitation training or something like that, but I can't be sure, it was a long time ago. The charity nursery was pretty good, the teacher worked like a student's nanny, she looked after everything for the young children.

Q: Has the child ever said anything to you about the nursery?

Shi's mother: No, she was very young at the time; she was just a toddler who couldn't speak much. She could only speak when she reached school age.

Q: Did you feel any pressure when you took young She Yi outside?

Shi's mother: I felt a little stressed at that time because people would look at my daughter's face in a strange way. It certainly felt unpleasant when I was carrying her outside. These days, I'm quite stoical, I'm not aware of what other people do anymore. I just let it go, anyway, we have to face the facts about her condition; and we don't want to keep her at home just because of this. We thought through all of these things and decided that there was no point being secretive about it. Facing up to reality, rather than trying to escape from it, has to be a good thing.

Q: Do you remember any funny stories about little Yi Shi?

Shi's mother: There were many funny things about her, she was a very cute and funny child, you can see her childhood through our family pictures (takes out some pictures). You can see that she was completely different to ordinary children in this

picture, which was taken around the time she was born. It was the way she looked at that time. We didn't have too many toys but some miniature cars and dolls. That's my cousin playing with my daughter (points at a picture). She looks quite cute in those old pictures, but I can't recall any details about her everyday behavior, it was a long time ago.

Starts School at the Right Age and Never Falls Behind

Q: Where did Yi Shi go to school?

Shi's mother: She studied at a special school in Shanghai, which was in the same building as our apartment, on the ground floor. Her schooling was the same as any ordinary child, from nursery and pre-school to special school, and she never fell behind the children her own age. She went to a special school at six and followed the 9-year compulsory education. Then, she passed an interview for a special vocational school and transferred there after she graduated.

Q: Did she like the school?

Shi's mother: Yes, she enjoyed her school life. She went to school by herself and was one of the class committee members. She was the student leader and was involved with class management. A student guardian had daily duties and Yi Shi represented her class. She was very open and active, and she could flatter her teachers, always giving them a hug or a kiss. She was popular with both her classmates and the teachers, everybody liked her. Being coy is a kind of natural behavior for little girls but not for boys, her kisses would always soften up my husband straight away.

Q: Did she like to talk about her school life with you?

Shi's mother: No, she didn't say very much. But the school was very close to our place, I could see the campus through the window. It was convenient and made things very easy to communicate with her teachers. They had extracurricular activities all the time, my favorite one was their model show and Yi Shi won a medal for that. The teachers were very clever and had very skillful hands; they made all kinds of clothes for the children with cartons and used paper. They were attentive, paying a lot of attention to making costumes for the children; they were full of smart ideas, it would have been impossible for me to do things like this.

The students had a show and performance with their handmade costumes, with the parents as their audience. I rarely missed this kind of school activity if they invited me, it was about sharing nice times with the children and a good way to show our support at the same time. I would take some pictures for her during the show, but I didn't print most of them. Back then, documenting a child's life in photographs wasn't very popular. Apart from the events with students and parents, I didn't know very much about the school's business. It wasn't possible to learn about the school through my daughter.

She wasn't very different from the other children of school age, nothing stood out typically. I remember the teacher saying she wasn't a difficult student, but she had a stubborn character, and would refuse to do some dance movements that she didn't

like. The teachers were nice people who had plenty of patience with the students, they never got angry. (She takes out another picture) Take a look, it's a class picture from back then. It was a big group; the maximum was less than 20 students. In a regular school class, there might be a few dozen students, but for a special school teacher this would be too many. The last thing is special school students are different from ordinary children; you have to reduce your expectations of what they can learn and achieve in their exams. Compared with ordinary students, the exam results mean much less to them, learning as much as they can is more important.

Q: Did any of her classmates visit your place?

Shi's mother: Yes, of course. My daughter's classmates often came to our place, because we lived so close. Some of her classmates lived far away from the school; some of them even came from Chuansha, a town some way away.

One time, one of her classmates went off with my wallet; it was quite a shock, and I had to stop them coming after that. She didn't have many good friends at school, but she used to mention a boy quite often. He went back to his hometown after he graduated and lost touch with us. Years ago, we heard he'd drowned in a river. What a shame! He was my daughter's only good friend.

Q: Did you give Yi Shi family tutorials very often?

Shi's mother: Rarely; I'd explain some questions if she needed my help. They had Chinese, mathematics, music, and PE at school, but the learning requirements for them were far less than a regular school. For children like her, enjoying life is more important than other things like studying. It's a different story for my son. I let the teacher deal with my daughter's studies.

Q: Do you remember any impressive things that she did at school?

Shi's mother: She was a warm-hearted child and she never hesitated to help classmates who needed help. She was always willing to help and had a very good relationship with all her classmates.

She used to be a part of the school's charity events. They would visit an old people's home and perform for the elderly residents. She also gave handmade cards and cut flowers to her teachers on Teacher's Day. She was quite a conscientious child (see Fig. 1).

Q: Where did she go after she graduated?

Shi's mother: She joined the Zhonghua Vocational School after she graduated from the Shanghai Special School.

Q: Did they have an entrance exam at the vocational school?

Shi's mother: No, they only needed to pass one-to-one interview. Not everyone who had studied at the special school could go on to the vocational school, only the students who were able to pass the interview. The interview wasn't any different from a normal interview; the teachers sat in the classroom and waited for the interviewee to come in, then asked her some personal questions and they had some simple conversations. She didn't have any problem with speaking at that time, she was quite active and open; otherwise, she wouldn't be able to pass that interview today, she is much worse than she was back then.

Q: Did Yi Shi choose her major?



Fig. 1 Certificates of merit Yi Shi won at school

Shi’s mother: No, her major was decided by the school; the teacher chose the most suitable subject for the students based on their condition, capability, and interests. The teachers knew their students well, because the school leader was also the leader of the Shanghai Special School. They thought cooking was a good choice for a young girl like her.

Q: Did she study cooking for all 3 years?

Shi’s mother: That’s right. She wouldn’t have been able to do other jobs like a cashier or a waitress, so cooking was the best choice. Frankly, I didn’t pay very much attention to this kind of thing, because I never expected too much from her, so I let her enjoy her days, that was the main thing for me.

She grew up quite a lot over the 3 years. She used to bring home different dishes every day depending on what dish they were cooking that day. Sometimes, she brought home handmade biscuits for us. The parents paid for the cooking materials every year because it was impossible for the school to find this money. In addition to cooking skills, the teacher also taught them how to select meat and vegetables.

Q: Did she also like to cook at home?

Shi’s mother: She cooked at home in the beginning; she was able to cook fried cucumber and egg, fried tomato and egg, that kind of dish, but her favorite dish was fried tomato and egg. She would also help to tidy up at home. My husband and I were so pleased with her achievements.

I'm no different from any other conscientious parent; I like to do housework for the family. After she got used to being looked after by me, she stopped cooking or cleaning and stayed in her own room with the door closed.

The good thing about my daughter is she'll never refuse to help me if I ask her to. Sometimes, when she comes into the kitchen, I have a little fun with her, letting her cook, just stirring food in the pan. She's willing to clean up the house if I ask for help; anyway, she has quite a positive attitude to housework. But she won't do anything if you don't ask her, just like most ordinary children. So she isn't bad with household duties.

Q: Why did you send her to the vocational school? So she could find a job afterwards?

Shi's mother: We wanted her to keep learning something, going to school was ideal. What else could we do for her? What kind of work could she do in the future? There was nothing we could do for her but let her learn as much as she could. Some families with disabled children never let them go to school and leave them illiterate. Other families keep their children at home all the time. Both of these things are very bad for the child's development. But our daughter's experience was the opposite; I mentioned her childhood and pace of study was just the same as ordinary children. At least now she knows quite a lot of characters and is able to read properly. She never had reading problems like uneducated children. And she likes handwriting very much, her writing is quite beautiful. She wouldn't have been able to do these things if we hadn't let her go to school.

Q: What did Yi Shi think about studying at the vocational school?

Shi's mother: She didn't disagree about going to the vocational school; actually, she liked to go. It was a long journey from our place to the school, which was on the South Ferry, Pusan Road. Before she knew how to get there herself, I would walk her around until she got used to the route. Independent travel between home and school was a school requirement for the students, because the teacher said it should be a very basic thing for them to do. If they were really unable to do this, it might be a waste of time studying there. She also worked for a year after she graduated, the workplace was on the Longyang Road, quite a long way for her as well. She had to take a bus to get there and then walk some distance before catching the bus back, but she had no problem with this route at all. I have to say she was quite independent.

Q: Do you think Yi Shi was successful at her studies?

Shi's mother: She was pretty good. She started primary school when she was almost 6 years old, the same as an ordinary child. Actually, her birthday is later in the year, in August, she almost didn't go to school because of that slightly later birth date. After that, she did 9 years of compulsory education and then 3 years at vocational school. It was quite a good place for her, she met some nice teachers who liked her very much, and treated her very well, too.

But now, she's gone into herself, she isn't interested in talking to other people anymore. I really don't understand why, others have commented about this, some young girls can become too shy to talk when they grow up.

Q: When did Yi Shi start to become independent in life skills?

Shi's mother: When she was very young. I taught both of my children to take baths by themselves when they were very young. If they couldn't wash themselves properly by this time, I'd make them take another shower until they learned how to do it. Some children at the Sunshine Home who are older than my daughter still need their mother's help with bathing. Some students are still driven to school by their parents, even though they could walk by themselves. I really don't think I need to worry about her so much and I'm determined that she does as much as she can: I have to let it go. Otherwise, what would happen when the parents get too old to help them with these things? To be honest, I'm getting old now, I can't say how much longer I'll be able to look after her.

I also taught her to hand wash her underwear, she learned from watching and practicing. I told her that her underwear is the only thing she mustn't put in the washing machine. I won't wash the stuff for her, but I still check it after she's washed it. Now, she's independent enough and she'll be absolutely fine as long as you cook for her. I'll teach her to cook sometime. Sometimes, these days, I like to let her wash some plates and she usually does a good job.

Another thing is letting her buy things for herself. She's pretty good at shopping already. She's been to most of the shops nearby by herself—my husband and I know the owners well—we usually give her some cash to buy small things she needs like notebooks or pens. But she can't go to the supermarket on her own yet. I'm usually quite relaxed with my daughter; I let her do everything she can. I treat my son in the same way; he became quite independent when he was in his second year at school. Both of them went to school on their own when they were quite young, crossing the road by themselves. I never picked them up like some parents do, not when they were able to travel by themselves. As a parent, I have to understand when the time is right to let them go.

A Special Olympics Dancer with Down Syndrome

(The mother takes out Yi Shi's pictures from when she was young.)

S's mother (holds the picture of a time when her daughter was a presenter in a show): This is a picture of my daughter presenting a show with her teacher; she looked very different in those days. (Takes out another picture) It's a picture with Bajia Pu, a winner of the first season's *My Hero*.¹ Both of them were actors in the Special Olympic propaganda film in 2007. Renliang Qiao, another boy from *My Hero*, who died recently, was there with them as well. At that time, Yi Shi was a warm and active girl; she greeted the boys from *My Hero* without any prompting and had pictures taken with them. She spoke to them by herself: "Big brothers, would you like to have your photo taken with me?" Then, she took these pictures. (Finds

¹*My Hero* was a popular national TV singing competition for boys, which was broadcast by Dragon TV in 2006 and 2007.

another picture) It's Meili Qiao, who was very popular as the Goodwill Ambassador of Special Olympics.

When she became involved in the Special Olympics propaganda film, I was my daughter's assistant during the filming. The director would call me anytime they had to film a scene with my daughter. We followed the teacher's guide and were able to visit different places every day. It took quite a long time to make the film, sometimes we had to stay at the television station until late, and it was a very tiring job for me following them all over the place in that hot weather. This picture was taken from the ninth floor of the station.

Please feel free to copy these pictures if you like. We don't have anything to hide with our daughter, facts are facts. We have so many pictures of her, most of the pictures that you are looking at were taken in 2007, almost 10 years ago. But now she's become a very introverted girl, I really can't do anything with her.

Q: Who went to the film recording with the boys from *My Hero*? All of Yi Shi's classmates or just the athletes from Special Olympics?

Shi's mother: There were only three or four children who were picked by the director's team. But I don't know what the selection criteria were, I guess because those children were good at dancing?

Q: Did Yi Shi take part in some of the Special Olympic games at that time?

Shi's mother: No, she didn't. She was too fat for sports and she only attended the Closing Ceremony. She was chosen to be a part of the ceremony, because the director of the program was determined to let her be there. She almost didn't make it, because she was too stubborn and wouldn't follow the dance teacher's instructions.

Q: Why did the director insist on having her in the show?

Shi's mother: I didn't know very much about this at the time and only heard the story after she was transferred to the vocational school. Later, I was a member of the parent's association at the school and I attended school meetings. One time, I chatted with the school leader who told me the story. He said my daughter's disobedience during the practice session made the dance teacher unhappy and she was thinking of dropping my daughter. But the teacher withdrew her decision when the director said he wanted my daughter to be involved. Yi Shi was the only child in that big group of children who got a close-up shot during the live broadcast of the Closing Ceremony. She was also the only child with a close-up image in the autograph book from the Shanghai Special Olympics.

Q: Well, it sounds like she was a stubborn girl, but did she want to go to the performance?

Shi's mother: She's a hard-nosed child and hardly listens to other people, but she's much better with her family. She usually listens to us, her parents. She ignored her grandma completely last week when we visited her. But she wouldn't do that to my husband and me.

Q: How long was the Closing Ceremony practice session?

Shi's mother: I forget how long; we were waiting for a phone call from the director of the team all the time. They had a daily shuttle service for rehearsals, but the parents weren't allowed to go to the rehearsals or the final ceremony, so we could only watch the TV program. The main rehearsal was for the dance, my daughter didn't have any

problems with that, and she liked to dance very much. She was the school's leader for the people's radio calisthenics every day.

She's still a big fan of dance, even now. She has a talent with musicals; for example, she danced quite a complex dance using hand language, some movements were impossible even for the adults to remember, but my daughter remembered all the sequences. Children like her can be very receptive to music and have a special ability and interest in it. Zhouzhou, an exceptionally talented conductor, is a Down syndrome boy as well; he's a better conductor than many normal musicians.

Q: Did you notice any change in your daughter after she became involved with Special Olympics?

Shi's mother: Not really, it was a special and joyful experience for her. To enjoy the experience was the most important thing; she was very happy during the event. The teachers were thoughtful and caring, and, for the parents, it was a valuable opportunity to meet each other. It was a wonderful experience for everybody involved, and to be part of Special Olympics was a wonderful memory for her. In addition to this, she attended the summer camp which hosted Special Olympics last year, the International Special Olympics East Asia Camp Shriver in 2015, which took place near the Stadium in Yangpu District.

Q: Do you remember what kind of event it was?

Shi's mother: A Special Olympics event, I have some pictures of it. It was a summer camp for children with intellectual disabilities. They didn't have to have proper training; the children could just play games together. My daughter joined in throwing balls and running races.

Have a look at these pictures (points to a picture). It's a picture of the unified walk, where the players use ropes made from newspaper to tie their legs together and walk. The fastest team is the winner. They are helped by volunteers. It was a week-long international camp; the children came from various places and countries. We went to the camp every day, my daughter and the other children also had two camp uniforms. There weren't any professional competitions, just some games and events to allow the children to enjoy group life and get closer to the outside world.

(The mother shows the interviewer an extract from a video of Yi Shi taking part in a shuttle run game. She's trying very hard and concentrating on the game. At the same time, the mother is cheering for her all the time.)

Q: Yi Shi plays many different games, which one does she play the best?

Shi's mother: To be honest, she isn't an active person at all. I haven't noticed any game that she's typically good at. She doesn't have a lot of sporting talent.

Her Autism Gradually Became More Apparent

Shi's mother: Yi Shi got a job through a friend's recommendation at the Sunshine Workshop in the Pudong New Area after she graduated. That workplace doesn't belong to our subdistrict, it's a municipal charity institute, I guess. It's a workplace for people who have a range of disabilities, intellectually disabled, physically disabled,

or dwarfism and blindness, all kinds of disabled people, you name them. She cried for the first several days before she got used to the place, but she started to enjoy it as time went by.

Q: What did they do there?

Shi's mother: I don't know much about what they did, because the place wasn't convenient for parents. If you insisted on staying, you had to wear special slippers. I didn't like this place and didn't go there very often, but Yi Shi talked about their work with me; basically, they did some simple jobs like making bibs, packing disposable chopsticks, folding gift bags, and wrapping soaps. These children can't do anything too complex and this simple work is pretty good for them. You don't know about people with intellectual disabilities as much as we do, some people are in a much worse condition than my daughter. As parents of disabled children, we are quite miserable, the chance of giving birth to a child like this isn't common, but if you do have one, then you have to look after this young life. For my husband and me, we really wanted to give her a happy and carefree life.

Q: What is the Sunshine Workshop?

Shi's mother: It's a kind of charity institute, an interim place for these children, but they can't stay longer than 2 years. The workers have to be recommended for a proper job or quit within the 2-year period. My daughter wasn't really employable, so she didn't get a job recommendation, but some of the children got a pretty good job. At the Sunshine Home there are some children who are more independent than my daughter. It would have been impossible for my daughter to find a proper job before they did.

Q: What was her relationship like with her colleagues at the workplace?

Shi's mother: She had a pretty good relationship with them, harmonious enough.

Q: Do you know what kind of work your daughter wants to do?

Shi's mother: Her condition won't allow her to do too many things; enjoying her life is the most important thing for her. She doesn't want to work; at least she never mentions a desire to work. Her favorite thing is staying in her room without doing anything. These days, she has become quite big, a little fat pig! You'll be surprised by her size when you see her (laughs away).

The teacher told her she had to quit her job after she'd worked there for a year. Perhaps she was too young and didn't have enough ability for that kind of work. So she came back home after that. I didn't pay enough attention to her during that special period. It was my fault, I was very busy looking after older family members and two other children in the family.

It was a very difficult time for her. She stayed at home all the time, no friends but herself, it wasn't a pleasant experience. Later, she was probably depressed, a kind of mental problem, and, little by little, she isolated herself. I took her to see a doctor, but the doctor said there was no evident sickness. He couldn't tell what her problems were precisely, but that it was probably related to her intellectual disability.

She became a different person, it was the biggest change in her life: now, she doesn't care about things anymore, she's stopped talking to people. Even her personality is totally different from before. It used to be my son who always hid away when guests came around, my daughter was never shy with strangers. She was a very

attentive hostess, liked to make tea for the guests and chatted with them. But these days, their characters have completely swapped around.

She used to be a very open little girl, chatting and playing with people very much. When she was the student leader of her class, she enjoyed it when her classmates followed her orders, even if she didn't understand what managing a class was really about, she just played at that role. But at least she was doing something at that time. She never stopped talking when she went out with her dad on the bus. I used to get quite annoyed with her and tried to stop her talking too much. Now, she won't speak a word even if you asked.

To be isolated in this community is a terrible thing for people; even harder for a child like her. People need to communicate with their friends, but my daughter is alone, she has only herself. What could we do for her? My husband and I tried to take on the role of a friend and chat with her from time to time, but she would never join in. When she got home her dad would say: "Yi Shi, come and sit next to me, let's chat," but she would walk into her room and close the door, like she doesn't care for us at all. She will stand up immediately and shut the door if I forget to close it after I leave her room. I really don't know how to deal with her. She just doesn't want to communicate with people anymore. When she is at home she just stays in her own room, listening to music, writing characters. She likes writing very much, she is always writing down words from books.

At the Sunshine Home She Could Engage with Society

Shi's mother: I discussed this with a teacher at the Sunshine Home and decided to send her there hoping to change her condition, being with classmates and chatting with them has to be a good thing for her. It wasn't a good experience for her staying at home for so long.

Q: When did she join the Sunshine Home?

Shi's mother: She's been there almost 3 years. The place isn't very close by; it takes her half an hour to walk there. She walks to the home by herself, I only went with her the first few days. Their class usually finishes around 3 p.m.; sometimes they can leave a bit earlier.

Q: How did you teach her to cross the road?

Shi's mother: It wasn't complicated for her; as we crossed the road together, I just explained what she had to do and showed her how to do it. I used the same method to teach her to how walk to the home by herself: I let her follow me all the way, told her where to turn, where to go straight, to be careful at the traffic lights and walk through on the right light. She needed a week, more or less, to learn this. The thing you have to remember is to be very patient with her. I don't worry about letting her walk to the home on her own. When she worked at the Sunshine Workshop, which was much farther away, she had to take a bus for five or six stops. If she could do that journey, walking to the home would not be difficult for her.

On the day we went to register, the teacher asked me if my daughter needed her parents to bring her or not, I said she will go to school by herself once I've taught her the route. It would have taken too much time to walk her to school every day, I wouldn't get enough time to do my housework at all, because they finish early.

Q: How long does she need to walk to the Sunshine Home?

Shi's mother: She's a slow walker, it's about a 20-min walk, more or less. From our place, there are two ways to walk from the community to the home; one way is shorter than the other but she has to cross a footbridge. She chooses her route at random, I don't mind which she takes and I think the walk is good exercise.

Q: Has anything ever happened to her during her journey that's made you worry?

Shi's mother: Not really. She had an old-fashioned mobile phone before, but she lost it. Later her dad bought her a new smart phone, but she doesn't like it, and she doesn't know how to use it either. The old one, a clamshell phone, was her favorite. These days, she doesn't use a phone anymore. But when she was working at the Sunshine Workshop, she had quite a lot of fun with her phone. She used to call me on her way back home to let me know she was on her way back, but she doesn't use her phone anymore, she never carries it with her.

Q: When she has to go to the Sunshine Home, does she get up by herself or wake up with you in the morning?

Shi's mother: It's probably half and half, but she gets up without my "morning call" these days. She might be a little bit lazier than normal from time to time, but she's been pretty good recently. She finishes her morning work before 8 a.m., and has her breakfast afterwards. I only need to cook her breakfast in the morning, nothing else. I have to remind her to leave home on time, because she doesn't have a good sense of time, and she can't read a clock. She's also a bit of a slow person.

She usually goes to bed around 9.30 to 10 p.m., but I have to start my "bedtime call reminder" from half past nine, and keep telling her: "Yi Shi, it's your bedtime, get on with it."

Q: What does she usually do at the Sunshine Home?

Shi's mother: The teachers get them to do all sorts of things, making boxes, making a cat-shaped phone case with beads, some children are really good at it; playing table tennis and baking. Sometimes she likes to bring back home the biscuits she made in class and wants me to try them. I'd ask her: "Did you make them?" and she'd reply: "Mom, the teacher taught me to make them." I wish I'd sent her to the Sunshine Home earlier! The teachers are very nice and they arrange all kinds of activities and events to create social opportunities for the children. It's quite important for these children, most of them are older than my daughter, but they can only stay at the home and don't have any other place to go.

Q: Do you have any of Yi Shi's handicrafts that she's made at the Sunshine Home?

Shi's mother: I don't keep many of them these days, but I used to keep quite a few. For example, I kept her early paintings when she'd just started to learn painting, but I stopped collecting them, there were so many. She had lots of balloons, but I threw them away after a while. I kept some of her handmade flowers. She said she made them by herself in the class, but they almost seem too pretty to be have been made by her. I guess her teacher helped her lots with these flowers. Even though she didn't

make them herself, they're still a special gift from my daughter, they made me very pleased. Yi Shi is a very caring child; she would make birthday cards for the family when she was a student. She used to make me a hand-drawn card and sing for me on Mother's Day. As her parent, I'm so pleased she's such a grateful person.

Q: Does Yi Shi receive a salary from the Sunshine Home?

Shi's mother: No she doesn't, but she had a salary in her first job.

Q: Was she very happy when she received the first month's pay?

Shi's mother: It was hard to tell, because she doesn't have the same concept of happiness like other people, she also doesn't understand the value of money, especially when they receive the salary on a bankcard.

We don't use her money; her dad saves all of it just in case she needs it one day. While she's living with us, she doesn't need money, she doesn't need to buy anything here, or at the Sunshine Home.

My daughter's sense of numbers was very poor, but it's getting better now. She only liked to use 1-yuan coins and she didn't want to use any notes. At least now, she understands what 10- and 20-yuan notes are, but if the note is bigger than that she won't use them, she can't understand their value. She won't know how much change she should get if you let her go shopping with a 100-yuan note.

Every child has his/her own characteristics; some like mathematics, some like my daughter are musical. I usually tell her which shop she needs to go to before I give her any money to buy things—all the local stores know us—they won't cheat my girl. Let me speak frankly, if there's an outsider in the community who isn't very nice, he would only give her 1 yuan of change after she bought a 1-yuan bottle of water with a 20-yuan note; my daughter wouldn't know she'd been cheated. I tried to teach her something about money a while ago, to recognize different currency by playing with different notes together. Now, she knows the notes, but she can't add up the numbers, so she still doesn't feel confident using a 100-yuan note. It took me quite some time to teach her, she just isn't sensitive to numbers at all, so I stopped when my patience ran out. might have to try again when she needs to deal with money more often.

Q: Does Yi Shi talk a lot at the Sunshine Home?

Shi's mother: No, she doesn't talk at all. She probably talks more at home than at the Sunshine Home, but I can't let her stay at home on her own anymore. She just sits there and doesn't talk to anybody even though I'm always telling her that she should communicate with the other students, talk more and try to make some friends. She usually says yes to me, but I know my advice doesn't work. I have to keep reminding her. It's not just my daughter, the other children are the same. They are not like their parents who are used to socializing with people and making conversation, these children find it hard to make conversation unless others talk to them in the first place.

I've been to their place and seen some very active children who don't look like they have any kind of intellectual problems. They look normal, good talkers and they have great abilities, but they only have learning difficulties. They're so different from my daughter, her face tells you everything. There's a boy in her class who has to do lots of housework every day, he has to mop the floor and hand wash summer clothes. One time, his mother told him: "You aren't allowed to go to the home until you finish the housework."

I volunteer for some Sunshine Home events from time to time; that’s how I got to know more about these children. There’s another boy who has a paralyzed mother to look after, he has to get up at six, sort out the house, and make breakfast for his mother before he leaves for the Sunshine Home. When he gets home, he has to do other things for his mother. What a difficult life! But he’s always positive and even knows quite a lot about healthy living; he told me when it’s the right time to have certain herbal teas. He looks exactly the same as a person without disability. People used to say poor children mature early, this boy is certainly one of them.

Last month, on the 17th, the Sunshine Home had a big event. Everybody was told to be there on time, but one child didn’t make it. The teacher told us his story afterwards. This boy has a paralyzed mother and a very ill father to look after. The family’s life isn’t easy at all, and the boy has to take responsibility for looking after his parents. Before the event, he asked the teacher for leave, because he had to stay at home and care for his parents. What a good boy, that would be impossible even for lots of ordinary children (see Fig. 2).

Q: Does your daughter like to go to the Sunshine Home?

Shi’s mother: She doesn’t have an opinion, but she would listen to you. I told her: “The teacher might criticize you if you don’t go to the home,” then she started to go there. It’s unusual for her to ask us what she should do except when she has a very strong interest in something. For example, she likes handwriting very much and she’ll ask her dad for paper, pen, and a notebook if she runs out. If she asks us to buy things she likes, we usually give her some coins and let her buy them in the shops herself. But she won’t ask for more than that.



Fig. 2 Yi Shi (front row left two) performing in the community

Q: Last time when I met her at the Sunshine Home, I asked her which she preferred between her own home and the Sunshine Home; she said she preferred to stay at home.

Shi's mother: No, it's not possible, I can't let her stay at home. When she was staying at home all the time, she just shut herself in her room and hardly went out. When she got used to that kind of lifestyle, she even had her meals in her room. She would shut the door all the time and never talk to anybody. My husband and I had to force her to stay in the living room with us, to write her characters in front of us, too. This isolated lifestyle wasn't good for her at all.

Q: What does Yi Shi usually do at home?

Shi's mother: She usually listens to music, dances a little bit if she's in the right mood, or just sits there, being lazy. She didn't do any activities and became worse after she put on a lot of weight. Now, she's become a short, fat girl (takes out some of Yi Shi's old pictures). She looks good in this picture, but she's already getting bigger, and now she's much bigger. We worry about her a lot. After school they don't need to do any homework or practice sports, they just eat and sleep.

A Dedicated Mother Who Becomes a Volunteer

Q: Did you get any help from the community?

Shi's mother: The community doesn't do very much, but the subdistrict office helps us more. In this subdistrict, there are five disabled people's associations: for intellectually disabled people, mentally ill, physically handicapped, blind, and deaf-mute people. I'm working for children with intellectual disabilities that live in the subdistrict. The official asked me to join their volunteer team and I thought it would be a good thing to do and joined them. Later, the official asked me to work with intellectually disabled children, those with the same condition as my daughter. I thought this would be a good way to encourage families to deal with the same problems together, so I said agreed to help.

Every year our association receives some funding from the subdistrict office and I usually arrange some events for the children every quarter based on the budget. Generally speaking, our group events are about singing, playing games, having parties, or doing puzzles together. At the end of the year, we have a group day trip as well, but it can't be anything too expensive or too far away because the budget is tight. Last time, I took the group on a day trip to Gongqing Forest Park. In December, some people from the Association of Persons with Psychiatric Disability and their Relatives joined us for a day trip; we visited Disney Town, not Disneyland Park because our budget wouldn't cover that. Here's the group pictures from that trip, I usually take some pictures of the children and print them out and give them to the children as a gift.

There are over 20 children in our group, the mildly disabled children came on the day trip alone but the parents of the severely disabled children would accompany them. I usually pay for the parents' tickets and buy a meal for everybody afterwards. We have to work out the best way to use our limited budget so the children and their

families feel our care and love. New Year is coming and I'm thinking about what kind of little gifts I could afford for them. This association work is on top of my busy housework and everyday life, I'm so busy. We will probably take the children out again next month; going away together is a great way to learn about the outside world. They are just poor children and I like to do these things to help them.

Q: Do you have any volunteers who go out with you?

Shi's mother: No, we don't have volunteers for the day trips, this is a "family tour," a time for parents to share with their children. To be honest, letting the parents come along to the events is a better way of looking after the children in the group. I can't take responsibility if any of the children get lost during the trip, so it's better for the parents to be there. Safety is very important.

Just this week, the district DPF office arranged a day trip for some of the children and their families, and all of the adults were terribly worried when a boy went missing. The parents looked everywhere for him. I was so anxious, and the leader of the organizers was so worried she cried. We called an emergency number for the police search group. They sent a big group and looked everywhere for him. We even used the social media, WeChat, to share missing information about the boy online.

Finally, around eight that evening, the boy was found at home. He's an interesting boy, he walked for over 4 h and arrived home with blisters on his feet. The only mistake he made was he didn't tell anybody, even his parents, where he was going. What a scary story! Every child is a special treasure for his or her family, no matter what kind of condition he or she is in, nobody can afford to lose them, especially when they're under your charge. Special children aren't safety conscious and need to be more careful, you never know what will happen, and any safety precaution is never too much.

A Happy Family Enjoying Life

Q: How old was Yi Shi when you quit your job?

Shi's mother: Actually, I didn't quit my job, I had a redundancy offer in 2005. I worked until the very last moment of my first pregnancy, it's difficult working when you're pregnant. After my daughter's birth, I didn't have anybody to help with babysitting, because of her condition. I had to ask my boss for leave. The boss approved because of the special family situation.

I never went back after that. In the beginning, I was suspended without pay until I was told to go back to work. I didn't want to take the redundancy offer at first, but one of my good friends, who was also a colleague told me this offer was a better deal. So, both of us took the same deal together. After that, I became a housewife and spent all my time looking after the family.

I started taking some part-time jobs from time to time after my children grew up, but I couldn't do this for long because the children usually finished school earlier than me. Especially my daughter, she would leave the special school and get home

around 3 p.m. I didn't dare give my daughter the house keys at her age, so somebody had to be home for her.

Now I don't need to worry about my daughter in the same way. Yi Shi has her own keys and she comes back anytime she needs to. To be honest, I sacrificed a lot for my daughter, but it's the only thing I could do.

She's my daughter and I have to take responsibility for her. My life's very hard especially after I had my son.

Q: What does your husband do?

Shi's mother: He worked at the Shanghai Oil Refinery until he was quite old, and then changed his job. Now he works in Hangzhou but only comes back home once a week.

Q: How about the relationship between Yi Shi and her dad?

Shi's mother: They're very close; she's really close to her dad. The first thing my husband does when he gets back home is gives my daughter a kiss. If you ask her who is your favorite parent, she will always tell you she likes both of us equally, but everybody can tell that she's much closer to her dad. My husband only comes back home once a week, but he usually spends his Sundays taking our daughter out somewhere. If he's going to a social event, like a group meal or afternoon tea, my daughter always goes with him. My son doesn't go to these events with him at all. She likes to go out with her dad as well, she enjoys the food and their company, and never disturbs him and his friends.

One time, on the way back home from the supermarket when we were passing a Cat Cafe, she told me she'd been there. I said to her: "No way, even I haven't been there yet." Later, I mentioned this to my husband and he said they had been to the cafe together when he had a business meeting there. He ordered a cake for her and let her sit next to him. You see, she has quite a happy life.

Actually, I love my daughter very much as well, but I can get loud when I'm angry and lose my temper; she probably finds me a bit frightening. When her dad gets back home, it's a completely different story, she likes to call him: "Dad, Dad..." all the time, she's very close to my husband. But she never kisses me! Sometimes, I make a joke with my husband: "Lucky you! I've had such a hard week and I don't get a kiss from my daughter." Even now, she never forgets to give her dad a good-bye kiss before he goes back to work. My son is closer to me.

Q: Do you ever disagree about the children's education with your husband?

Shi's mother: No, we never disagreed with each other about this issue; in fact, we always agree about children's issues. We're a happy family, we never argue with each other, especially my husband and me, and we never argue about the children. My husband is usually busy at work supporting the family, and I focus on caring for the family and children. If I'm ever concerned about our children I'll discuss it with him. My husband trusts me and lets me deal with all kinds of issues about the children whatever it is, family or school. He's never been to a parent's meeting since they were little.

Q: So your husband doesn't share the caring duties?

Shi's mother: No, he's too busy at work, the whole family lives on his income. It's understandable, isn't it? We share the family duties, he earns the money for the

family and I stay at home and look after them. I didn't have a choice, somebody had to make a sacrifice for the child.

She's our own child and we have a duty to look after her; whatever her condition is, I have to take care of her and raise her. My husband also says we shouldn't expect too much from her in the future, but let her enjoy her life.

Q: How many years older is Yi Shi than her brother?

Shi's mother: She's 3 years older.

Q: So you had to look after two children when Yi Shi was 3 years old—was there anything particular that you remember about that time?

Shi's mother: The biggest feeling from that time would be "busy." I never got my own free time, I was always very busy. It was very difficult. My daughter is different from normal children; she was completely helpless when she was 3 years old. I didn't get much help bringing them up, except for the time my mother-in-law helped me to look after my newborn son for a month. What an exhausting life!

When they were little, we lived in a one-bedroom room apartment. I had to close the doors and windows all the time just in case one of the children hurt themselves. There was a big bed and a cabinet in the room and if I had to cook or do housework, the only way to stop them crawling off the bed was to put lots of things around the edge. Bringing up my daughter is the best thing I've done in what's been a difficult life.

To be honest, having the second child was a good thing for us even though most families in our group are one-child families, although now I'm relieved that they've both grown up.

Q: What were your thoughts before you had a second child?

Shi's mother: My husband and I are healthy people—we aren't related in any way definitely—our families didn't live in the same area, one was in the Shanghai Railway Station area, the other came from Gaoqiao Town: how could we have had a disabled child? We thought about this again and again and then decided to have another child.

It might be even harder to look after two children, but who would we depend on when we got old if we only have our daughter? It's a serious problem. The one-child families in our group are worrying about who will care for them in their old age and for the future of their children. Their family problems are also a social problem, most of the one-child families choose not to have another child because they worry that the second child might also be unhealthy, and for some families who decided to have another child, this happened. There are two pairs of twins who are siblings who attended the same school as my daughter, all of them are disabled children. Their parents didn't dare to have any more children after that. When this kind of thing happens, parents are helpless and desperate.

Q: How do you communicate with your children?

Shi's mother: I don't communicate with them specifically; I just tell them what they should know and that depends on their different needs. I used to pay most attention to my son's study, but I didn't need to do the same thing for my daughter.

Q: How long did your children play together?

Shi's mother: They were quite close when they were little, but after my son went to nursery they played together less and less. Anyway, one is a boy and the other is a girl, they're different. We moved to this apartment with more rooms when my son started at the nursery; they were older and we could give them their own rooms. Since then, they haven't had very much to say to each other. The brother is different from his older sister, they can't really keep each other company, they like very different toys. You can't let a boy play with dolls.

Q: Does Yi Shi talk to her brother often?

Shi's mother: Very rarely, my son doesn't talk to her very much either. My husband said things might be different if our second child had been a daughter too, at least Yi Shi would have more things to talk about with her. But now, my children don't have anything to chat about together. My son usually stays in his room and reads or does something else when he's home. He isn't bad towards her, even though they don't talk very much. When we eat at home he always lets his sister have her favorite dish first.

Sometimes, when they were younger, if my daughter liked her brother's notebook, and she didn't dare ask him herself, she used to ask me to borrow it for her. My son would never say no if his sister wanted his stuff. When they were bigger, if my husband and I couldn't cook for them, my son would cook for my daughter and keep her company at home. But they really don't talk to each other very much.

My daughter has changed quite a lot. She has become more autistic; she shuts herself down and stops talking to people, not only with my son, but also with my husband and me. She might respond once if you speak to her ten times.

A couple of days ago, on the way to a district event, I tried really hard to make conversation with her. I kept asking: "Yi Shi, let's chat or why don't you tell me something," but she just kept silent. My husband and I have really tried everything we can to communicate with her, but she is still the same. I can't work out why she's so autistic, it looks like she can't find the words or she doesn't have anything to talk about. This is what she's like now.

Q: Does her brother have a girlfriend?

Shi's mother: No, my son hasn't reached that age yet, even though we encourage him to find a girlfriend. He isn't a mature boy.

Q: Do you take Yi Shi out at the weekend?

Shi's mother: Sure, sometimes, but we don't go on trips very often. We usually have a family holiday every year. Last year we went to Zhangjiajie. We can't take a holiday very often because of everybody's busy schedule. My husband has a full-time job, I'm very busy as well, and my son is in his last year at college and probably has more free time than before, so it isn't very easy for the family to go out somewhere together very often.

Now my daughter doesn't like to go out anymore, even though I'd like to take her somewhere. People tell me, you should take your daughter out more often, Japan is a good destination for her. I like the idea of going to Japan with Yi Shi, but I wouldn't like her as a companion. It would be a difficult experience; can you imagine a traveling partner never talking to you even at meal times? It doesn't motivate me!

Q: Where do you usually go with Yi Shi?

Shi's mother: We usually go to the park or the karaoke hall. When I go out with my friends from school, they usually ask me to bring along my daughter; she used to join us for meals or singing. Sometimes, if both of us were free, I'd take her to the Shanghai Song City KTV to have some fun. I've asked her to come with me again if we get a chance in the next week or so.

My daughter is a great singer and has several MP3 and MP4 players; now her dad just bought her a tablet. She keeps a lot of songs on the tablet, and she is always playing different songs at home; she even knows more songs than us, that's pretty good? She doesn't have any musical talent, but she really likes to sing. I have to say, it's her one big hobby and it's something that also interests me.

Q: What about her relationship with her paternal grandparents?

Shi's mother: Her grandpa passed away and her grandma is now in her eighties. My daughter and I visited her last week; she isn't very close to her grandma. Yi Shi doesn't have a deep affection for my mother-in-law because she has never lived with us since my daughter was born. My son is the same, he knows her, but there is no real affection.

Q: How is Yi Shi's relationship with her maternal grandparents, then?

Shi's mother: It's not bad. My parents live just downstairs, in the same building. We are on the sixteenth floor and they are on the ninth floor. I go to check on them every day because they're over 80 years old; I worry about them even though they have a nanny to look after them. I worry who's going to take care of them when the nanny goes home for spring festival.

Q: How many siblings do you have?

Shi's mother: I only have an older sister and Yi Shi's dad has two siblings but one of them passed away. We don't live together; everybody's busy and hardly have the time to meet up or talk to each other. When my daughter was young, she used to play with her paternal cousins and they were quite close, but now she's autistic she's stopped seeing them.

To be honest, the siblings aren't that helpful even when you need them. When my children were younger and we needed some help, my sister wasn't able to help me at all because she had to work and look after her own child. So, whatever I'd hoped for, I was always on my own. Both sets of parents couldn't help me raise either of the children.

Q: What is your daughter's attitude towards others?

Shi's mother: She doesn't care much about other people. When we eat out together, she's pretty relaxed, she never bothers other people, just concentrates on her food.

Q: Does your daughter ever show any concern for you; even though she doesn't communicate with you very much?

Shi's mother: Yes, she does, for example, when we have a meal together, she usually hands you a napkin, we never taught her to do this. Even though she doesn't always remember to hand you a napkin, she is mostly very good natured. My daughter's behavior is much nicer compared to some of today's self-centered children.

Q: What do you think is Yi Shi's best characteristic, or what would you say is her good side?

Shi's mother: My daughter is a very kind girl. Actually, all of the children like her. The children of the Sunshine Home are simple minded and nice. They never embarrass you, cheat or trick you, and they have a natural desire to help people. In this respect they can be better than many children without disabilities.

Q: Could you give me some examples?

Shi's mother: My daughter's classmates always help her with learning issues. Yi Shi doesn't talk to people very much and has a bad memory, so she can't or doesn't want to tell me about her homework or the next day's schedule.

But her classmates usually send me WeChat messages to remind me what she needs to take to school, what time she should be there, or let me know that she has notes that I have to read, or something else I should know. These children help my daughter a lot.

My daughter is a caring person, too. I had a knee joint fracture after I fell down in 2008; she was my carer during the time I had to lie down in bed, she would bring me water or clean the house, and she never complained. She also chatted with me, checked I was feeling okay, she helped with the pain and the pressure.

She looked after me for over a week until her teacher called to ask why she'd been absent for so long. The teacher was full of praise when I explained what had been happening. She said: "Yi Shi is great, she can even look after her mother now!" She also said she would come and see us, but I felt embarrassed about this and sent my daughter off to the home afterwards.

I was moved by her; she took on some difficult tasks that even normal children would be reluctant or refuse to do and she didn't have any complaints. Maybe one day she will be able to care for me when I'm very old. She isn't a troublemaker and very easy to look after at home, except she needs me to cook for her. She's pretty independent in other ways; she takes a shower or washes her hair on her own. Her only problems are that she doesn't have a good sense of value about money and she isn't good at cooking. Really, she isn't any bother at all.

More Social Tolerance and Better Policies

Q: Have you thought about her and marriage?

Shi's mother: No, we never think about this, she'll be with my husband and me wherever we go. If she's lucky and dies before us that will be fine, if it's the other way around, we'll have a plan for her. We don't worry about our son too much, one day we'll give him this apartment and let him live his own life.

Q: What's your plan for Yi Shi when you get old?

Shi's mother: We don't have a clear idea, because we don't have many choices; some parents, especially those with just a disabled child, are very anxious about this already. My husband and I are in a better situation because we also have our son. Most parents at the Sunshine Home only have one child; as well as looking after the child, they also have to look after their parents; nobody knows who will look after them or the child in the future.

I've heard there's a special care home for special children in Chuansha Town—it's quite far away from our place—a disabled institute that opened several years ago. In the beginning, they struggled to enroll a decent number of children, but now it's full and short of places. There are quite a number of people on the waiting list already, so we'll think about where she can go later; a nursing home is another choice.

In our family, I'm the one with a short temper who might criticize her from time to time, but her dad is very tolerant. He used to tell me: "We have to give her a happy life, try our best to be tolerant and protect her, even though we can't see what might happen in the future."

The government needs to set up more disabled people's nursing homes and provide places for all of these children for the time when their parents can't look after them anymore. But I'm reluctant to send my daughter to a place now, because that will mean the end of a productive life for her. These places don't provide teaching, social events, or better care services, but they get three meals a day.

If she stays with us, at least we can talk to her every day. Her dad bought her a book of *Three Hundred Tang Poems*, so she can read through the book and practice her handwriting in her own time, but who would think about this kind of thing for her if she went to live in a nursing home? When the government sets up new disabled nursing homes, they have to develop the facilities, offer a higher quality service, and give more attention to the children's development.

There are some poor children who are suffering from both intellectual and physical disabilities who have no life skills of any kind. There's a boy I know in this situation, he's a very big boy, his dad has to carry him to his wheelchair and put him in before he goes to work. The child has to stay in his wheelchair all day, every day. The family had an hourly paid maid to go and clean up his room and do the housework. She'd buy him some steamed bread if they didn't have anything to eat at home. He can't look after himself at all, but at least he can speak, so when his mom came home, he asked her to pay the maid for the steamed bread. What can you do if you have a child like this? Of course, everybody wants a healthy child, but things can go wrong. These children could have a very miserable future.

Q: Do these children receive some kind of allowance or service from the government?

Shi's mother: Only unemployed children receive an allowance. If some mildly disabled children have a job, then they won't get any money. But 2 months ago, Shanghai implemented a new policy to let all disabled people receive a 150-yuan benefit every month. In addition, if they go to a park or tourist attractions with an admission charge—some of them can be quite pricey—with a disabled card, they will let these children in for free. It's a kind of benefit as well.

Q: What are your future plans for the family?

Shi's mother: We don't expect too much, we just want our children to be healthy, for our son to do well, and one day for our daughter to enjoy her life. For me, a happy, safe and harmonious family life is the most important thing.

Q: Do you have any advice for other Down syndrome children and their families?

Shi's mother: I would say to these parents, please treat your children well and don't look down on them, because they have lives just like you and me. The truth is

you mustn't expect too much from these children. I said the same thing to my son; he has to treat his sister well, especially because she is the reason I brought him into the world. If my daughter was a child without disability, the one-child policy wouldn't allow us to have had him.

These days I meet so many nice volunteers through some events. There's a friend who volunteered for one of our events; he is also the classmate of Pubajia, both of them graduated from Shenyang Conservatory of Music. We have a pretty good relationship. He would say to me, please let me know if Yi Shi needs my help, I'll try my best to help her. These days, there are more kind people than in the past when some people would discriminate against them. Now, most people are more open and have more sympathy towards these children. Let's be honest, none of these children chose to be disabled, everybody wants to be a healthy and able person, but fate decided against them and they have never had any choice. I urge other people to be tolerant and understanding towards them.

Q: It's the end of the interview, and I'd like to ask if we can use Yi Shi's name in the article or would you prefer her to be anonymous?

Shi's mother: I have no problem with you using her real name, that's fine. After all these years we don't care about other people's attitude towards us anymore; we are comfortable with who my daughter is.

My daughter is good at sign language dancing—would you like her to perform *A Grateful Heart* for you? Yi Shi, could you perform it for us?

(Yi Shi remembers the lyrics very well and she's singing alone with the music. Her performance is very delicate and fluent. There is a sweet smile on her face all the time throughout the show.)

Q: Thank you very much for the interview, let's end it here.

Interview with Miss Yi Shi's Younger Brother

Interviewees: Yi Shi's mother and Yi Shi's brother

Interviewer and writer: Mengying Yang

Interview date: October 27, 2016

Interview place: Yi Shi's home

Q: How do you and your sister get on?

Shi's brother: I don't talk to her very much, it's kind of mutual. If I think about, we definitely haven't spoken more than ten sentences to each other, maybe even less than five, for some time. I won't try to make conversation with her, and she doesn't talk to me either. It would be unusual if we spoke more than a couple of times. I want to communicate with my sister, but it never works, I guess because we don't have enough things in common to talk about.

I don't have anything to say when someone talks about my sister's condition, probably because we grew up together.

Q: Do your classmates and friends know your sister?

Shi's brother: My current classmates don't know about her and I'm not sure if my high school classmates knew or not, but my middle classmates definitely knew, some of them even mentioned her to me. I don't know how they knew about our family.

Shi's mother: His classmates knew Yi Shi because some of them came to our place to play with my son quite often. Both of my son's primary and middle schools were close to home, and his old classmates used to come to our place.

Q: Are you worried about what their attitude might be towards your sister?

Shi's brother: I was when I was young, but not now. In the past, perhaps, but it doesn't bother me anymore.

Shi's mother: He can deal with the situation because they grew up together. I won't let him look after his sister in future because he has his own life to live. Yi Shi is my husband's and my responsibility; I won't force this responsibility on him. If my son was a girl, he might take care of Yi Shi, but one day he'll get married and his wife's attitude towards my daughter could be problematic. For a brother to look after a disabled sister, his wife would need to be a kind and caring person.

So, Yi Shi will live with us wherever we go in the future. During the National Day holiday, my husband and I bought two big apartments on the same floor in Haimen Town. We'll move there when we're old. I don't worry about my son very much, we'll give him this apartment and let him get on with his own life. Maybe one day we'll move to a nursing home with my daughter, we're not sure yet.

Q: Do you ever hang out with your sister?

Shi's mother: That's not possible, on the one hand they don't communicate with each other; on the other, my son is always busy. It's more likely that my daughter and I will go out together.

Interview with Miss Yi Shi's Teacher

Interviewee: Yi Shi's teacher at the Sunshine Home

Interviewer and writer: Mengying Yang

Interview date: October 16, 2016

Interview place: The Sunshine Home in Shanghai

(The teacher is interviewed while the other teacher, Ms. Lu shows the children how to make things with beads.)

Shi's Teacher: Teacher Lu teaches two students at a time, hand by hand, step by step, she only calls for the next pair of students when they have learned the skills properly. The two students who are being taught by teacher Lu are pretty good and can already do some things on their own. Yi Shi has the ability to make some good things with the beads, she just doesn't want to do it.

Q: When did Yi Shi come here?

Shi's Teacher: Around the end of 2013 and the beginning of 2014. She was no different to today, silent, wouldn't talk, and wouldn't answer other people's questions. She just shakes her head and nods to communicate with other people and she isn't very willing to speak to the teachers either.

Q: Can Yi Shi work with beads?

Shi's Teacher: Yes, she can do a little bit, but her poor eyesight makes it difficult for her. She stops after she makes too many mistakes. She isn't a sociable person; she doesn't like to speak to her classmates and teachers. We asked her mother about her behavior at home and she said Yi Shi hardly talks to her family. Yi Shi always closes the door of her room when she gets back home and stays inside by herself all the time. She can't understand the teachers' words properly; for example, if you ask her: "How are you doing?" She won't understand the question, and if she answers it doesn't mean very much, she might just say something in response to your question.

This child is so difficult to communicate with, I really can't understand why. Yi Shi isn't like most of her classmates who like to chat with the teachers. When the teacher says something, the other students usually get quite excited, but she is different. It seems she lives in another world. Sometimes, she sits there and giggles for no reason. We realized that her behavior was different after she had been here for a while and we guessed she might have a problem hearing imaginary voices, she thought somebody was talking to her. But if this is true, her problem is more profound than an intellectual disability.

At the same time, Yi Shi has strong interests, she loves singing and dancing. Even when the teacher gives her a chance to sing or dance, sometimes she won't join in the group performances; but at other times she looks very excited and willing to join in the performance. Her behavior is based on her own free will; the teachers can't control her mood or responses.

Q: Teacher Wu just told me that Yi Shi hasn't been doing well recently.

Shi's Teacher: You're right. She went to the hospital with her mother, it seems she has some auditory hallucinations or some symptoms of this kind. (A student walks into the room and the interviewee starts to talk about him.) He just learned the bead-making skills from Teacher Lu as well and was Yi Shi's classmate in the past. Compared with Yi Shi's, this boy's condition is much better.

Q: Yi Shi's mother said after she's had been at home for 2 years she became unwilling to talk to other people.

Shi's Teacher: I don't know very much about this, and I don't know much about her condition either. The Sunshine Home Project only started 10 years ago. We have some students who are older than Yi Shi, in their mid-thirties now, who have been at the home even longer than her, but they don't have the same problems. This cohort of students were in their twenties when the Sunshine Homes were set up. They started primary school at six. After the 9-year compulsory education, they were 15 more or less; they then had to spend 3 years at a vocational school and were 18 years old by the end of that. After that, they had to stay at home until they were 25, more or less, before they came to a Sunshine Home, but none of them that I know had a problem like Yi Shi. The student I just mentioned, Yi Shi's old classmate, he joined the Sunshine Home later than her and he's doing very well. I can't even tell what kind of problems she has; it's definitely an individual problem, not a common phenomenon.

We don't know Yi Shi's past history very well; all of that information comes from her mother. She said her daughter was a very active and open child, but it's very hard for us to imagine what she used to be like from her present condition. None of our

teachers had seen her before, we feel so sorry for her. Some of our students rarely talk at home, but after they join us, they become more willing to communicate with the teachers. But Yi Shi is totally another story.

Q: How many students do you have?

Shi's Teacher: We have 25 students with all kinds of intellectual disabilities. Some of them are the same as Yi Shi, Down syndrome children, some were born prematurely, some have a low IQ. But almost all of them are in the mildly disabled category. Some children have a more serious condition that might be considered as moderate to severe, grade III, or disability.

Q: It's great that the Sunshine Home provides these children with a place to stay after they leave school.

Shi's Teacher: You're right, the Sunshine Home provides some rehabilitation training classes and events to help with their self-development; also, it's a place where they can keep in touch with the world and it stops them being dumped by society. We have all kinds of activities and events; we also invite volunteers to come and deliver special classes and training; bead-making is one of our skilled training classes.

Our children only develop their skills, we don't have a way to sell what they make and very few people know about or buy their DIY products. But promotion isn't part of the Sunshine Home's duty. Basically, we're an NGO group and can't carry out commercial transactions. Also, we don't teach the students skills for making money, but create practical and learning opportunities for them; for example, the bead-making work isn't only good for their eyes, but also for their coordination.

We also have music, drawing, and culture classes and Special Olympics related sports classes. Additionally, we have an open class for them as well; in this class, if anybody wants to share something with his/her classmates, then they can do it here. After the applicant has submitted their topic and material to the teacher, he/she will receive a special tutorial to help him/her to work out how to make and deliver the presentation. After the class, the teacher will also do a presentation and discuss this with the student, giving him/her some feedback about the quality and delivery of their presentation, and how to develop their public speaking skills. It's a good way to develop social skills and help them to build their self-confidence.

The children feel care and love from society through our external volunteers who come here to help with some activities. Usually, before these volunteers leave, our children will give them some of their handmade gifts as a mark of gratitude. The reason we let them to do this is we want them to think that a disabled person's gifts, like other people's, are a natural expression of gratitude. Nothing is taken for granted. They have to try to do something for society and other people while they receive care and love from other people.

Q: Do you have any other classes?

Shi's Teacher: We have five main classes in our teaching curriculum. From Monday to Friday, we have an open class, music, artistic expression, bead-making, and an integrated class. The integrated class includes handicraft, drawing, and cooking. The drawing is a part of an ongoing module after we finish the teaching schedule. We have handwriting classes on Monday and Wednesday afternoon, Special Olympics related

sports on Tuesday afternoon, and games time on Thursday afternoon. Games time is their free time, allowing them to play games and rest after the highly structured studying schedule.

Friday afternoon is clearing-up time; we let them clean up the classroom on their own, it's also a way to cultivate life skills. The same afternoon, there is also an hours safety education from 2 to 3 p.m. The teachers believe this aspect of education is very important for the children. We use this time to teach them some basic safety awareness, what they should be aware of when they go outside, how to deal with a call from a stranger, how to deal with a change in the weather, and so on. It's a good way to prepare them for the weekends.

Q: In which classes does Yi Shi perform better?

Shi's Teacher: She usually likes to practice her handwriting, but she doesn't play any games with her classmates. She won't refuse to join the cleaning group if you ask her to do something. She seems to like the dancing class more than music. She doesn't like to be a part of the open class or bead-making; she isn't very active in the drawing class. But she likes the artistic expression class because it includes percussion and dancing.

Q: Does she interact with her classmates?

Shi's Teacher: No, not at all. It's why we feel so sorry for her. Her mother said at home she always locks herself in her room and doesn't communicate with her parents either. I don't want to blame her parents, but for a child in this situation, the parents have to act as soon as possible and shouldn't be taking 2 years to do something. We are just her teachers and don't know her very well. When she arrived here, nobody knew her condition and background, and we couldn't communicate with her very well at all. And still, after such a long time, she hasn't improved.

We've looked for reasons and we've tried to sort out any mistakes that we could have made trying to communicate with her, like our method of communication, or our style of communication, or our speaking style. But we couldn't find anything that we could have done better. We have tried several different ways to approach communicating with Yi Shi.

We've tried approaching her through her hobbies, letting her be the principal dancer of our show at the National Day Disabled Person's performance, but that didn't work. Another time, a teacher let her participate in an ad-libbing show, dancing to the song *Wahaha* at a district event, but she hasn't changed at all.

We also talked to her parents about this problem, asked them to pay more attention to their daughter; on the one hand she only spends some of the day at the home, as her teachers, we aren't able to get to know her any better; on the another hand, there are many students here and everybody needs attention, we have to treat them equally. Her mother told to us, they are concerned about her condition all the time, but she always locks everybody out of her room, and doesn't want to be with the family. There aren't many more things they can do.

In the office, some teachers have discussed her case privately; firstly, the parents should have sent her here earlier, right at the beginning when they first saw signs of problems. Secondly, they should have paid more attention to her problem in the early stages; for a child like her, they need to make more effort than with their normal

child. One day, their normal child will be independent but Yi Shi won't be; her entire life depends on her parents. Personally, I think her parents could do better than this.

Q: Thank you for the interview.

Interview with Miss Yi Shi

Interviewee: Yi Shi

Interviewer and writer: Mengying Yang

Interview date: October 16, 2016

Interview place: The Sunshine Home in Shanghai

(Yi Shi doesn't like to talk, she doesn't have any friends at the Sunshine Home either. She sits alone. For the interviewer's questions, she only replies with body language, nodding her head or shaking her head, or she answers with some simple words like "Yes" or "No" or "I don't know." Yi Shi seems to live in her own world except for answering questions or occasional eye contact with the interviewer.)

Q: Hi, do you remember me? I've been to your home before.

Shi: Erm...

Q: Do you remember anything about the time when you studied at the special school in the Pudong New Area?

(She shakes her head.)

Q: Did you have any friends when you were a student?

Shi: No.

Q: Have any of your classmates ever visited you?

Shi: No.

Q: Your mom told me some of your old classmates used to come around to your home because your place was nearby. Once, one of your classmates stole your mom's purse, is that true?

Shi: Yes.

Q: Do you remember what happened afterwards?

Shi: I don't remember anymore.

Q: Which grade were you when this happened?

Shi: I don't remember.

Q: What was your favorite class at school? Music class?

Shi: Erm.

Q: I saw the picture of you when you were the presenter of a school show, when I visited you last time. Is that right?

Shi: Erm.

Q: Can you remember what that show was?

Shi: I can't remember.

Q: Your mother told me that you were very open and active; you liked to chat with people. You used to give the teacher kisses and hugs every school day, didn't you?

Shi: Erm.

Q: When did you stop talking to people? Did it happen after being at home for 2 years?

Shi: Erm.

Q: Why, is it because you don't see other people very much anymore, and don't like talking to people?

Shi: Erm.

Q: Except for the teachers, classmates, friends and parents, do you see any other people?

Shi: Erm.

Q: Do you remember the Special Olympics Game?

Shi: Erm.

Q: I saw your pictures, the ones of you and the *My Hero* singers taken at the television station. Do you remember this?

Shi: Erm.

Q: Do you remember who you took pictures with?

Shi: I don't remember.

Q: Were you happy being part of Special Olympics?

Shi: I was happy.

Q: Do you remember when you first came here?

Shi: I don't remember.

Q: Were you nervous when you went to the Sunshine Home for the first time?

Shi: ...

Q: Did you come with your mom?

Shi: Erm.

Q: I heard you could walk to the home on your own after she taught you how to find your own way?

Shi: Erm.

Q: How did your mom teach you to remember the route from your home to here?

Shi: I don't remember.

Q: Didn't you need to cross the road on the way here?

Shi: Erm.

Q: Were you worried when you walked to the home by yourself for the first time?

Shi: I wasn't worried.

Q: You were very brave. Were you nervous when you came to the Sunshine Home on the first day?

Shi: A little bit.

Q: Do you remember what you did on that first day?

Shi: I don't remember.

Q: Do you need your mom to wake you up in the morning?

Shi: I get up by myself.

Q: Do you need an alarm?

Shi: No, I don't.

Q: Your mom told me you're quite an independent girl; you can take a shower by yourself and wash your own clothes as well. Is that right?

Shi: Erm.

Q: Do you remember when you learned these skills?

Shi: I don't remember.

Q: Do you remember how to hand wash clothes? What do you usually do?

Shi: I don't remember.

Q: Do you need your mom to remind you when to go to school: "Yi Shi, it's time to go to the Sunshine Home"? Or do you just go when the time is right?

Shi: Mom.

Q: What does your mom put in your bag before you go out?

Shi: The keys and some paper tissues.

Q: Do you prefer coming to the Sunshine Home or the school where you were before?

Shi: I like them both.

Q: What do you like to do at the Sunshine Home?

Shi: ...

Q: Do you like listening to music?

Shi: I like that.

Q: Do you like anything else apart from music?

Shi: I like dancing.

Q: Do you have any favorite teachers?

Shi: ...

Q: What's your favorite class?

Shi: Music.

Q: Do you do things in any other classes apart from the music and dancing? Do you like the drawing class?

Shi: I like that.

Q: What do you like drawing?

Shi: Animals.

Q: What kind of animals?

Shi: Birds.

Q: Do you like the pottery class? I saw the mugs you made, quite pretty.

Shi: No, I don't like it.

Q: Are there any other handicraft classes you don't like?

Shi: Erm.

Q: Do you like to go and chat with your classmates?

Shi: I don't do that.

Q: Do you just sit here alone?

Shi: ...

Q: You don't like to chat with other people?

Shi: Erm.

Q: Do you prefer to come here or to stay at home?

Shi: I like to stay at home.

Q: Do you like to be alone?

Shi: Erm.

Q: Do you like other people talking to you?

Shi: I like that.

Q: So, you do like other people talking to you?

Shi: Erm.

Q: But why don't you talk to other people? Is it because you don't know what to say to them?

Shi: Erm.

Q: Do you talk about how you feel to your mom?

(She shakes her head.)

Q: Your teacher told me you haven't been great recently. I remember you were pretty good when I visited last time and you also performed for us. What happened?

Shi: ...

Q: Why don't you make beads? You don't like that?

Shi: I can't do it.

Q: Didn't Teacher Lu teach you how to make beads?

Shi: Erm.

Q: Could you make things with beads after the teacher taught you?

Shi: I could a little bit.

Q: So, you don't like making beads, right?

Shi: Erm.

Q: You just had a bead-making class recently, can you still do that?

(She shakes her head.)

Q (asks Yi Shi's classmates who are sitting around): Does Yi Shi chat with you often?

Classmate: She's always on her own, no classmates, no friends.

Q (asks Yi Shi's classmates who are sitting around): Has she been like this since she joined the class?

Classmate: Yes, she just likes to be alone.

Q: Your mom said you worked for a while, right?

Shi: Erm.

Q: What did you do?

(She shakes her head.)

Shi: ...

Q: Your mom said you like listening to music at home?

Shi: I like writing.

Q: Anything else you like doing at home? I remember you did some handwriting for us when I visited you last time; your handwriting is very beautiful. Do you like doing anything else apart from listening to music and writing?

Shi: ...

Q: I remember your mom said your main subject at the vocational school was cooking, do you cook for your family at home?

Shi: I do.

Q: What dishes can you cook? Fried tomato and egg?

Shi: Vegetables.

Q: You can cook vegetable dishes, have you cooked it for your parents?

Shi: No.

Q: Do you remember how to cook vegetable dishes?

Shi: I don't remember.

Q: Do you go out with your parents when you have free time?

Shi: No.

Q: Do you like to go out to the park with your mom and classmates?

Shi: I like that.

Q: Do you remember where you went last time?

Shi: I don't remember.

Q: Where do you prefer to go?

Shi: Park.

Q: What do you usually play in the park?

Shi: ...

Q: Who do you go to the park with more often, your mom or your classmates?

S Shi: Mom.

Q: Last Friday you went to a meeting with your mom, what did you do there? Did you have a happy time?

Shi: I was happy.

Q: What did you go there for, an event?

Shi: Yes.

Q: Do you remember the name of the event?

Shi: ...

Q: How do you get on with your brother?

Shi: Good.

Q: Does your brother treat you well?

Shi: Erm.

Q: Do you talk to your brother often?

Shi: Not very often.

Q: Do you and your brother just do your own things at home?

Shi: Erm.

Q: Do you talk with your mom often?

Shi: Not very much.

Q: Last time, your mom said your dad doesn't come home very often, but you're usually very happy when he does, you like to give him hugs as well. Do you like your dad?

Shi: Erm.

Q: Who do you like more, Dad or Mom?

Shi: Dad.

Q: Why's that?

Shi: ...

Observation of Miss Yi Shi at the Sunshine Home

Observation date: December 16, 2016

Observation place: The Sunshine Home in Shanghai

Observer and writer: Mengying Yang
 (The Sunshine Home's timetable had been changed and the observation only went for half a day.)

Time	Content	Observed activities
9:13	Yi Shi arrives	
9:14	A classmate asks Yi Shi to sign in	
9:15	Practicing the eighth setting-up exercises and the dance <i>Most Dazzling Folk Style</i>	Yi Shi remembers all the movements. Her performance is fluent compared with her classmates, she's pretty good
9:30	The bead-making class starts. It's one and a half hour simple handicraft class The students use beads to make phone cases and animals. The aim is to develop their hand-eye coordination	Yi Shi and the other students have been taught by Teacher Lu before, so this time she and another student sit at another desk while the teacher is teaching somebody else
9:35	Making beads	Through the class, until the end, Yi Shi sits alone and doesn't do anything or move while the other students are working with beads
11:00	The class is finished, then it's lunch time	A teacher brings the meals to the room, but Yi Shi doesn't leave her seat, so a classmate fetches her lunch for her
11:00–13:30	Break time	Yi Shi and her classmates are having lunch in the classroom

*Translated by Huili Meng
 Edited by Russell Murray*

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A Glimmer of Hope for Three Generations of People Living with Disability



Shuo Cheng

Interview with the Grandfather of Miss F

F, female, only child, born in 1997. Mild intellectual disability. In 2015, after graduating from a special education school—Sunshine School in Huangpu District, Shanghai, she was enrolled in the Junior Vocational Technical School for special education students in Changning District, Shanghai. In 2017, she was admitted into a spare-time university for ordinary people in Shanghai, majoring in hotel management.

Interviewee: Grandfather of Miss F

Interviewer and writer: Shuo Cheng

Interview dates: November 17, 2016 and May 7, 2017

Interview place: Miss F's home

Grandfather and Grandmother Got Married

Q: Nice to meet you. Could you please tell me how you met your wife?

Grandfather: We were introduced by one of our managers. We worked in the same toy factory, where I was at the main workshop of the factory, and she at a subordinate “Happy Toy Production Team” in the subdistrict, working on tasks assigned by our factory.

Q: Did you live in the same area?

Grandfather: Yes. We're both locals here. We originally came from Nanshi District. Later, according to the new division of the district, she lived in Huangpu District, while my house was in Pudong District.

Q: When was Miss F's mother born?

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Grandfather: My daughter was born in 1979, a beautiful baby back then. But it wasn't until she began school that we found out about her disabilities in learning.

Q: Did you and your wife consult a doctor?

Grandfather: Of course. We went to a lot of hospitals. Actually, this has something to do with my wife. She hid her condition of mild epilepsy from me before our marriage and took pills in secret while pregnant. It wasn't until the child was born and she went through a seizure that I learned about it. We called the disease "Yang Dian Feng" back then in Shanghai, literally "sheep-vesania-craziness" and now "epilepsy."

Q: How did you feel when you found out about it?

Grandfather: There wasn't any advanced technology. I knew nothing about genetics, either. So, I didn't think much about it. I was simply determined to raise my daughter well, without thinking about getting a divorce.

Q: Has your wife's condition improved over time?

Grandfather: She still has epilepsy, and it got even worse after the birth of my daughter.

Q: Was she able to continue working?

Grandfather: Yes. After a short while when the seizure episode was over, she was back to her normal self and could carry on working.

Q: Have you always been working at the toy factory?

Grandfather: Yes, we were there until retirement.

Q: When did you retire?

Grandfather: Both of us retired at 50.

Q: When did your wife pass away?

Grandfather: She wasn't in a good shape because of her epilepsy. She passed away in January 2011. It never rains, but pours. After her death, there were tragic events one after another.

The Mom Who Loves to Run Away

Q: What was it like when your daughter was born?

Grandfather: She was perfectly normal at birth. She was lively, smart, and naughty, just like any other kid.

Q: Did she go to a kindergarten?

Grandfather: Yes. It was in the neighborhood.

Q: Did you notice anything different about her at that time?

Grandfather: No, we didn't notice anything until she was in primary school.

Q: How old was she when she went to primary school?

Grandfather: Seven years old. Everything was normal during the first one and half years. But then, by the second semester of the second grade, her teacher told us that she had trouble catching up with the rest of the class, for she had difficulties in reading and memorizing even the simplest things. Considering she was quite naughty, we assumed that she had ADHD. We sought for a treatment everywhere for nearly a year, but it was all in vain.

By the third grade, her teacher suggested that she should drop out, saying that there was no use for her to stay in school. I would never let this happen whatever the situation was, so I continued to seek medical treatments. We first went to the Huadong Hospital. A professor from East China Normal University also ran a test on her. The result indicated mental deficiency. But still, I couldn't get a clear picture after all these efforts. Anyway, since the school refused to allow her to attend classes, I could only go to the educational bureau to file a complaint. If my daughter's condition was confirmed, she could be transferred accordingly with help or even to school for children with intellectual disabilities. But like anyone else, she should never be deprived of the right to education.

In response to my complaints, the education bureau allowed her to attend classes without having to repeat a year. She just went to the school every morning and came back home after school. In the meantime, we continued to seek a cure. Later, we consulted an ADHD specialist in the Maternal and Child Care Service Center in Nanshi District. The doctor went through our family history and concluded that her condition was genetic, stemming from her mother's side. It was further compounded by the medication for epilepsy. It was then that I realized the extremely detrimental effects of these pills on children.

By the fifth grade, she couldn't catch up with her classmates anymore. As she grew older, she often went out and wouldn't come back home. I frequented the police station, but the police couldn't find her, either. Every time, she came back on her own. Alas...

Q: When did she start running away?

Grandfather: After she stopped going to school. Maybe in her teenage years.

Q: How often was it? How long would she stay away?

Grandfather: Quite frequently. In the end, even the police stopped trying. We all knew that she would return eventually. She would stay away for long, sometimes even for months.

Q: You must have been very worried about her.

Grandfather: Indeed, but there's no use in worrying. She wanted to leave. There was nothing we could do. In some cases, we asked her to clean the spittoon at the required spot outside the house, while she would leave it outside the door and run away. In another case, we told her not to run away again during the gathering of relatives and friends in the Spring Festival. She made a promise, but disappeared a moment later. It seemed as if it was out of her control.

Q: Would she tell you what happened to her when she was away?

Grandfather: No. She would do whatever she wanted once she ran away. If caught by the police, she would give them our address so that I could pick her up.

Q: What were usually the reasons for her arrest?

Grandfather: Mainly her involvement with men. Society was quite chaotic back then. Not knowing her condition, some bad guys would trick her into having relations with them by buying her food and things. Of course, there were also good people who brought her home.

Q: When things like this happened, was it often found out by the police?

Grandfather: Some were reported by others, some were discovered by the police, and some were reported by herself.

Q: She knew she should go to the police?

Grandfather: Yes, as she grew older, she knew.

Q: Have you taken any measures to address the result of her possible relations with other men?

Grandfather: At that time, we were quite ignorant. There were fewer contraceptive measures too.

Q: As far as I know, some families choose surgeries, like sterilization, to prevent pregnancies. What's your view on that?

Grandfather: She was too young to undergo that surgery (voice raised, looked more vigilant). She wasn't even fully developed physically. Previously, she wouldn't get pregnant even if she had sexual relations. We never thought about contraceptives. But when she was 18, she came back once after a couple of months with a big belly, already 6–7 months into her pregnancy. By then, abortion was obviously not an option. She had to give birth to the child, who is my granddaughter.

Q: Did your daughter know that she was pregnant? Did she provide any information on the father?

Grandfather: Of course, she knew. That's why she came back, but she had no idea who the father was.

Q: Did your daughter take care of the baby after she gave birth?

Grandfather: Basically, it was me and my wife. My daughter was incapable of that. Nonetheless, my granddaughter was very close to her mother. Despite the birth of a child, my daughter still couldn't control herself. She would run away just like before, sometimes for months on end. This way, she couldn't take good care of the child at all.

I even thought about asking the police to lock her in jail for 3 years so that she can finally "settle" down, but there were no legitimate grounds for them to do so. Once, she was caught stealing money from schoolbags in a university by the police, but they could only ask me to take her home without sentence after learning about her condition.

Q: Did the stealing stop afterwards?

Grandfather: Yes. Knowing that she might be sentenced, she didn't dare steal again, but she still knew nothing about chastity. She just led a free life when she wandered around. I've done my utmost to regulate her and prevent her from making a mess outside, but to no avail. Locking or tying her up would be breaking the law. In the end, we could only let her be. Alas...I lost all hope. She would run away when we were still having lunch and talking. The entire family would worry to death; our relatives and friends would also report to the police and look for her. At last, even the police were out of solutions. We had to give up as well.

Q: What would she normally do at home?

Grandfather: She would just eat and play. There was nothing that she could do. No proper business, basically.

Q: Did she often talk to you?

Grandfather: Yes, but it was not like what it is today. We were quite busy, so we just tried to talk her into staying at home and stopping wandering outside, etc. Although she said yes, she still couldn't control herself.

Q: Did she understand all that was told to her?

Grandfather: Yes, she understood, but she was illiterate. She didn't know how to write her own name. She could understand what you said, and she could speak to you, but she would be confused if the conversation was extended. In her thirties, she got sick while she was away and passed away after unsuccessful treatment.

Q: What did she die of?

Grandfather: Tuberculosis.

Q: When did she pass away?

Grandfather: September of 2009.

Being Registered for Hukou at Age of Eight

Q: Could you please tell me more about the situation when your granddaughter was born?

Grandfather: At that time, we lived in a shanty town with poor living conditions. My daughter came back pregnant, but she couldn't be blamed. It was already too late for induced labor. Fortunately, she gave birth to baby F smoothly in December of 1997 thanks to her good health. The whole process was short. I remembered the surgery could cost over 3,000 yuan. I only paid 1,000 yuan and got her discharged as we weren't well off.

Q: Did they find something wrong with Miss F in her physical examinations?

Grandfather: Absolutely nothing. She was an adorable baby, and as pretty as her mom. We didn't find anything wrong with her.

Q: Was she healthy?

Grandfather: Generally speaking, she was healthy without any serious diseases. She received all the vaccinations required at school, but she did tend to have a fever. When she was 2 years old, she had a high fever. One doctor said this was pneumonia and an X-ray was needed. Feeling that I was being fooled, I took her to another hospital, where she was diagnosed with only a virulent cold. She recovered after taking some medications.

Q: Who brought her up mainly?

Grandfather: It was me. Her mother was not around most of the time. Her grandmother was weak and received little education; she couldn't take care of a baby.

Q: Did Miss F go to a kindergarten?

Grandfather: No. We didn't know about her father, so she couldn't be registered as a permanent resident.

Q: Did it affect her in other ways?

Grandfather: No. She hadn't started school yet. I was basically with her all the time, feeding her, playing with her, taking her around, and sometimes teaching her basic things such as simple songs and numbers.

When she was 9 years old,¹ there was a new policy whereby anyone could apply for a household registration regardless of the circumstances. This way, she could be accepted by the schools. To get it done, I prepared all the documents, and went through all the administrative procedures in the education bureau and municipal authorities, etc. In the end, I succeeded.

Q: You went through all the procedures as required by the policy?

Grandfather: Yes, totally. I had neither resources nor connections.

Q: Did you learn about this policy yourself or did someone else tell you about it?

Grandfather: Someone told me, but I also knew a little about it. Everyone knew, as word got around.

Q: Do you remember which policy it was specifically?

Grandfather: I remember that it allowed a child to be registered in the household record of direct relatives, either those from the mother's side or the father's side.² F is registered in her maternal grandmother's household. The policy remains the same now, I think.

Adored by Teachers and Classmates Alike

Q: When did Miss F start primary school?

Grandfather: When she was nine,³ when the household registration was done. I applied for the Guangming Primary School, but after the interview, the dean of students suggested that my girl might need an IQ test. A special education school might be an option if the result indicated the need for it.

So, we went to the No. 6 People's Hospital. Upon learning about the test results, I could hardly remain standing. My heart sank. Just like her mother, she also suffered from an intellectual disability. Though she was slightly better than her mother, it didn't make me feel any better. I knew she wouldn't be able to attend a normal school. Later, she was enrolled into the Sunshine School for intellectually disabled students on Beijing West Road. It was far from home. I had to drive her there in the morning and pick her up after school in my mobility car for the disabled while carrying on with my own business. Sometimes, her mother would also pick her up, but her grandmother couldn't.

Q: Was everything okay when her mom came to pick her up?

¹Nominal age. The actual age should be eight.

²According to Article 8, Chap. 2 of the *Regulations of Shanghai on Management of Registered Permanent Residence*, implemented since July 1, 2005, "The birth of a newborn baby can be registered in his or her father's or mother's household registration record in this municipality as a non-agricultural permanent resident".

³Actual age.

Grandfather: It was okay. Despite her intellectual disability, she was good at finding her way around town. She might not know the name of the road, but she remembered clearly the routes and knew which bus to take and how to transfer.

Q: How long did it take to bring Miss F to school and back?

Grandfather: About 2 h.

Q: When was she able to go to school without your company?

Grandfather: Since her second grade. At that time, a teacher surnamed Xie, the teacher in charge of her class, also lived nearby in Pudong. So, the teacher would take my granddaughter to school and take her home after work. I'll always remember the teacher's kindness.

Q: How was it when she was in primary school?

Grandfather: She was pretty good. Her teachers all liked her.

Q: What courses did she take?

Grandfather: The curriculum for different grades was different. Basic courses such as Chinese, math, and IT were all offered. A very good school, actually. I remembered she said she learned how to use the computer at school. At first, I didn't buy it. Later, it turned out she was pretty good at it after I bought one for her.

She learned many things at school, and was good at some subjects, apart from singing. Dancing and sports are her strengths. I remembered that she put on an amazing performance at a dancing show organized by her school in a square on Nanjing Road. The audience was deeply moved; some journalists even came to interview her. This was surprising to me.

In terms of academic courses, however, she barely matched normal students. Her math was particularly weak. Other students could do multiplication and reduction, while she could only do the basic one-digit calculations and had a hard time learning multiplication. As a child, she couldn't go out grocery shopping simply because she couldn't do the math.

She was not bad at Chinese. She could even draft her own speeches. Orally, she could understand basic conversations, but found it hard to discuss things in depth. Still, she was so much better than her mom. Sometimes, I think she's even smarter than me. She's a quick self-learner with phones and computers, while I am not.

Q: How did she get along with her teachers and classmates?

Grandfather: They got along quite well. Younger students would call her sister. All the students from the first grade to the ninth knew about her and adored her. She also assisted the teachers in a lot of things.

Q: How long did she study in the special education school?

Grandfather: Nine years, as required by the policy of 9-year compulsory education.

Q: Did she assume any role in her class?

Grandfather: Yes, such as the Young Pioneer Group Chief, flag raiser, and class monitor.

Q: How was she admitted into the Junior Vocational Technical School after graduation from primary school?

Grandfather: She applied for it and passed the interview. In fact, she was already known to the school officials during their meetings. Her excellent performance at school and the prizes she won had already caught their attention.

Not Afraid of Hardship in Her Training for Special Olympics

Grandfather: F performed pretty well at school, especially during the 2007 Special Olympics.

In a sense, she was much luckier than if she continued her studies at a normal school. In the Sunshine School, she learned quickly, and was very capable. Good opportunities always came to her first. Once, for example, she participated in a competition as a substitute. The school noticed that she became champion or runner-up in many competitions, showing strong stamina. That was how, in the following year, she was selected to receive training in roller skating in Heilongjiang Province for the 2007 Special Olympics. Finally, she won a silver medal. She also competed in swimming. From then on, I started to have more confidence in her and see a glimmer of hope. I was happy for her (see Fig. 1).

Q: How old was she when she went to Heilongjiang Province?

Grandfather: About 11 years old.

Q: Was she afraid of being so far away from home?

Grandfather: No. This was good. Also, I would contact her regularly through mobile phone at that time.

Q: You said that she was good at a variety of sports. Did she receive any special training for that when she was little?

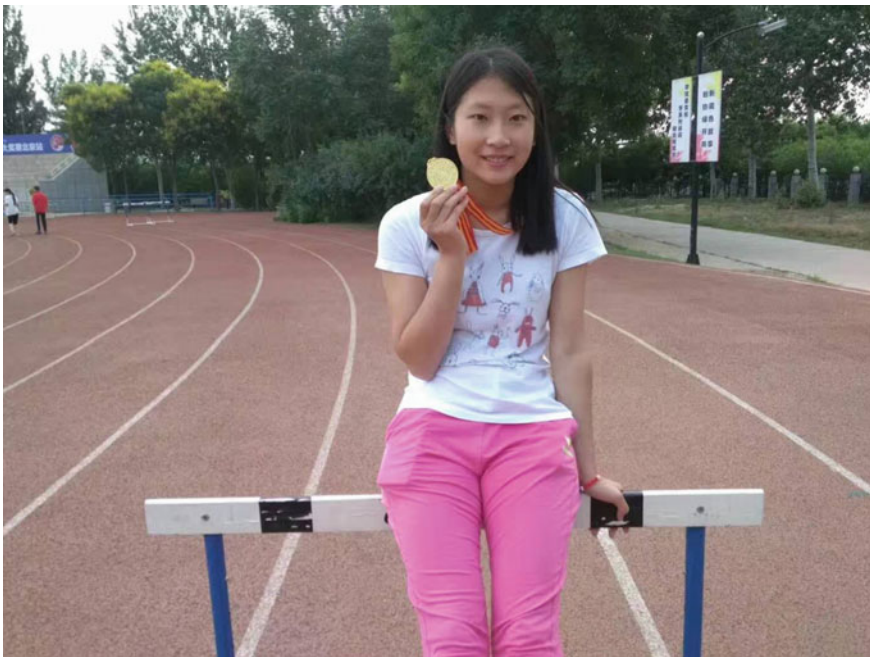


Fig. 1 Miss F on the school playground with her medal

Grandfather: No, she learned them later on.

Q: I imagine these achievements were no easy feat?

Grandfather: Indeed. She took swimming classes at school. A professional swimming pool was also rented for practice. So, swimming became one of her strong suits as well. She competed a lot, and won a lot of medals.

Q: Did she practice every day while learning to swim?

Grandfather: Basically, every day. I remember the intensive training were all organized at Tera Wellness Club on Henan South Road, a well-equipped center. The training was hard, but she was willing to make the effort. Sometimes, she had to travel across the country for such training. Physical exercises, such as stair running and push-ups, made everyone sweat all over. F would never complain about the hardship as everyone else did, but said, "I love sports. I'm willing to do this." I guess this was probably the reason why the teachers liked her.

Q: Apart from extracurricular training, did she have daily training on campus?

Grandfather: No. At school, she just attended the lessons.

Q: Have you noticed any difference in Miss F since her participation in sports?

Grandfather: She became more confident and healthier. She tended to have colds and fevers, but now she seldom falls ill. This is the benefit of exercises. The only thing is that she still has rhinitis.

Q: What's the impact of Special Olympics on Miss F?

Grandfather: It had a huge, huge influence. Otherwise, she couldn't have become so joyful; she wouldn't have reached what she has today. More importantly, Special Olympics allows her to do what she loves. She has always been diligent and tenacious. She gains confidence and courage through the game. This is the key.

Q: Did you raise her to be this tenacious?

Grandfather: To be frank, we didn't do much. I myself received only basic education. I'm not in the best position to teach her. She may have become tenacious for two reasons: her interest in and passion for sports, and her commitment to our family. She wants to create a better life for everyone. Aside from the encouragement from the school and society, she was also inspired by the theme of Special Olympics—I know I can! F is becoming more mature. She strives for the honor of her school, which wins her admiration from all of her teachers. What we have given her is simply encouragement and support.

Become Independent at a Young Age, Sticking Together with Grandad

Q: She must have learned how to take care of herself at a very young age, such as getting dressed and feeding herself, didn't she?

Grandfather: Yes. We didn't have to teach her. She was quite independent. She would wake up in the morning and go to school on her own. She loved learning, which was good. Take going to school as an example. She had to get up really early,

take Bus No. 451, and then transfer at the People's square. The journey took over 2 h, but she never complained and never needed us to wake her up or urge her to go to school.

Q: When did she learn to do housework?

Grandfather: I was not the best example in this aspect. I spoiled her a bit and didn't ask her to do anything when she was young, since she's my only granddaughter and also suffers from an intellectual disability. By the fifth grade, she was able to help around the house, washing vegetables, sweeping the floor, going grocery shopping, and so on. She got better by then. By the time she was in middle school in her teenage years, she could put what she learned at school into practice and prepared meals for us.

Q: It seems that she is really independent. Did you teach her to be this way?

Grandfather: Not intentionally, but I am really happy that she understood what I said about how to be a responsible person. Now that she has grown up, she knows that I don't have an easy life. She does what she can to help me, such as learning how to cook and prepare for simple meals, and taking care of the family. She's very thoughtful.

She never gets me to worry too much. She tells me about her daily life, like where she is, at school or on the way back home, what she is doing, when her class finishes, and she'll go to swimming training at 4:30, etc. This morning, she was in Chongming. She also sent me a message asking if I've had my breakfast and if I wanted to have a video chat with her.

Q: Do you miss her, as she is not home most of the time?

Grandfather: Of course, but now with the mobile phone, we can call each other, or have a video call. I'm happy with that.

Missing Mom on Mother's Day

Q: Apart from housework, does she have heart-to-heart talks with you?

Grandfather: I don't know if she has something on her mind, but I can feel that she's down occasionally. She knew she had no father and her mother has gone. She was particularly sad and not willing to talk on Mother's Day.

Q: Have you ever talked to her about her parents?

Grandfather: Yes. She knew something about it. Her mom was still alive when she was in primary school, so she knew about her mother's life, personalities, disease, and death.

Q: Does she know anything about her dad?

Grandfather: No, because he was never in her life.

Q: Has she ever asked about him?

Grandfather: Yes. I explained to her that it was due to her mother's condition.

Q: Could she understand?

Grandfather: Yes, she could. I told her there was no point in finding out who was to blame. She understood it. However, I could still feel that she was a bit sad, particularly

when she was in primary school. She would cry and get emotional on Mother's Day, or whenever the word "mother" was mentioned or appeared in textbooks. It was a sore spot for her. Now she can handle it better. In contrast, she wasn't as emotional at the idea of father, as she never knew her father, and her grandad is like a father to her.

Q: Have you tried to get through to her?

Grandfather: Sometimes I will, but some things are just too difficult to explain, and she can be really stubborn.

Q: What was she stubborn about?

Grandfather: Knowing that I was quite tight with money, she wouldn't ask for any money unless it was absolutely necessary. Sometimes, depending on her needs, I would give her more and tell her how to control the spending. Emotionally, she mainly felt bad on the topic of her parents, which was understandable. It was a rebellious stage during her adolescence. She became quick-tempered and worked off her anger on teachers and family if she couldn't figure out something. Teachers knew this. They would also talk to me about concerns over her mental health.

Q: So, you talked to the teachers?

Grandfather: Yes. Mr. Shao, her teacher in charge, once came to me. He was kind-hearted. He cared about her, while kept in touch with us, informing us of her performance at school. When F got into trouble in her rebellious years, I would communicate with Mr. Shao. He showed great understanding and helped her through that phase.

I think it's more challenging to be a teacher in special education schools than in normal ones. Teachers in normal schools can focus on teaching. Talks with disobedient students can make them behave. But in special education schools, teachers have to be responsible for a whole range of issues from students' intellectual disabilities to emotions. Once, in the primary school, a student in F's class approached a teacher with a knife. When attempting to stop the student, she accidentally got hurt and was immediately sent to the hospital.

Q: How did you feel about this incident?

Grandfather: I didn't take it seriously, nor did I argue with the school or the teacher. I believe teachers and parents should be complementary to each other. In this way, teachers can become more confident in their work. It's meaningless and unnecessary to blame teachers for risks of security or disfigurement. Helping the teachers is helping your child. To be honest, families of children with intellectual disability are under immense pressure. No one wants to have a child like this. It's important to put yourself in other's shoes. As for teachers, their work is already challenging as it is, we can't put extra pressure on them.

Q: Was there any cause to her rebellious period?

Grandfather: Deep down, I believe it was probably due to her parents. Though she wouldn't say it out loud or admitted that she was unhappy, she would feel wronged and upset if I brought it up. She could be very stubborn. She has a personality.

Q: How long did it last?

Grandfather: Only half a month. She was about 17 at that time. She would ignore you for no reason. Sometimes, she would cry and throw a tantrum. If a teacher blamed

her, she would talk back. Of course, she knew she was wrong afterwards and would greet the teacher when they met again. This is just normal for a growing teenager.

Mobile Phone and Friends

Q: Apart from sports and study, does she have other hobbies in her spare time, such as reading, and watching movies?

Grandfather: She doesn't watch movies. She enjoys listening to music, watching animations, and surfing the Internet on her phone. At home, she loves to do housework, like washing the dishes and cooking.

When she was little, she would pester me to take her outside for a walk or to the supermarket. Now as she grows older, she prefers staying at home. Sometimes, I urge her to go hang out with friends and talk to them, but she won't. However, if there is a sports event, she becomes energetic again. She will go to training and never complain about the difficulties.

Q: Does she have any friends?

Grandfather: Yes, she often hangs out with an orphan girl who will also take the college entrance examination. I heard that the girl can go work for KFC, but she doesn't want to. They receive training together, and have parties celebrating birthdays and graduation. They have developed their own circle of friends.

Grandfather's Foot Impairment and Hardship in Life

Q: What is the mobility car that you just mentioned?

Grandfather: It's a car specifically designed for the disabled. We paid for the car and the government would give us the license plate. I can't remember exactly the year, but the government suddenly didn't allow these cars to be used for business purposes on the road, claiming that too many of them affected the traffic. The government recycled all of them at the original price. After that, the Shanghai Disabled Persons' Federation (DPF) designed a new model according to its integrated planning. The total subsidy from the government for this was 6,000 yuan. You could either get your own car recycled by the government and receive 6,000 yuan, or if you still wanted to drive it, you could buy one from the DPF at the price of 5,000 yuan, for example, and receive the rest of the money, 1,000 yuan.

Q: You also have disabilities?

Grandfather: Yes, I have trouble walking because of my feet problems.

Q: Could you please tell me more about doing business with the mobility cars for the disabled?

Grandfather: Back then, people looked for business opportunities everywhere. The Shiliupu Pier on the Bund was famous. It was accessible to major ports in

Ningbo City, Zhejiang Province and Jiangsu Province, etc. Since there weren't high-speed trains, ships were the means of transportation. The ships would be anchored at the passenger terminal with a fixed time schedule. We would be there waiting for people, like the cart drivers in the old days. Then we negotiated the price with our passenger, like 10 yuan for City God Temple. If the price was agreed, we would take them to their destination. The whole market was not properly regulated. Even people without a disability certificate could drive around in cars for the disabled, looking for business. Later, the government ruled that vehicles for persons with disability shall only be used for facilitating mobility, not for business purposes. Only people with lower-limb disabilities could drive the cars to make their life easier. The government confiscated the cars without proper documentation and restored order to the road.

My car was a good one. It cost 5,000 yuan. I got it recycled by the government for 6,000 yuan, after it was banned from being used for business.

Q: What kind of car was it?

Grandfather: It was three-wheeled and petrol-driven, and it could be started easily just like a motorcycle. Now I regret that I didn't buy a new one at that time.

Q: Why?

Grandfather: It's convenient for travelling. As long as you do nothing illegal, this type of car, with a petrol subsidy from the government, is allowed on the roads across the whole country. One can drive it across the Huangpu River or even to Beijing. This is because relevant polices exist to protect the rights of persons with disabilities.

Q: Do you usually go out for a change of mood?

Grandfather: Yes, I often talk with my friends about life over dinners, but I would leave at the mention of housing. This is my biggest disappointment and regret. I used to have an apartment, but when we were relocated by the government, I chose the compensation of cash, instead of an apartment. The amount was less than 100,000 yuan. We also planned to buy a house with it, but didn't act immediately, assuming the housing price wouldn't go up. Surprisingly, the price skyrocketed simply within a few months and never decreased. It became totally unaffordable. I regret my choice back then. It's miserable for a family without a house nowadays.

Q: Why did you choose to take the money?

Grandfather: It happened that my wife and my daughter were sick at that time. I needed the money for their treatment, which really cost a lot.

Q: Did you find this current apartment by yourself?

Grandfather: Yes. The monthly rent is only 1,000 yuan currently, but its total area is only more than 70 m², and the transportation is not convenient. Now the rent in this area has risen to 2,000 yuan. I have to negotiate with the landlord on an acceptable increase before our 3-year agreement expires. Apartments around here are originally low-cost housing for people relocated from Hongkou District and Yangpu District.

Q: Is it big enough for the two of you?

Grandfather: It is okay after a simple renovation.

Q: You have a nice home here. Did your wife also live here?

Grandfather: Yes, but she passed away many years ago. Now, it's only F and me.

Q: Did you go to the local authorities regarding the housing issue?

Grandfather: No, there's no use. There's nothing they can do about it, either. If F is registered in my household, we can apply for low-income housing, but then again, it costs a lot. The payment and mortgage are complicated as well. In the end, we still have to rely on ourselves. Another possibility is that F may be assigned an apartment if the residents in the area of her household registration are to be relocated. In that way, our situation might improve.

Q: Do you feel any other pressure in life except for housing?

Grandfather: Of course, apart from the 1,000 yuan for the rent, we still need money for F's transportation, meals, and other daily necessities.

Q: What is your major source of income?

Grandfather: I've got a pension and subsistence allowance, and F has subsidies for persons with disabilities, as well as the subsistence allowance.

Q: Does she get paid for her participation in these competitions?

Grandfather: She used to. She could receive more than 1,000 yuan as a bonus and training fee apart from the accommodation and meals covered by the government. Now, these additional subsidies are gone. She only gets a reward for her participation as a token of encouragement. It's kind of like charity, trying to attract public attention to them. Besides, she can receive an annual scholarship of 200 yuan since primary school.

Q: Do you give her some pocket money? How does she spend it?

Grandfather: Yes, I do give her some. She knows we're not well off, so she tries to save money. Of course, certain expenditures, such as transportation fees, cannot be cut back. Sometimes, I give her more to ensure she won't feel short of money and get embarrassed. For example, I gave her some money when she went to Macao, and she brought back some local delicacies for me, like others did. Though I thought it was unnecessary, I didn't blame her since I knew it came from a good place.

Hope for a Better Future

Q: Have you changed much throughout her growth?

Grandfather: Her growth felt like a roller coaster ride to me. I was happy that she was a perfectly normal baby, but was later devastated by her diagnosis before primary school. Now, I feel elated that she went to school, and went on to win many competitions. There were gloomy days of course, but now there is hope and happiness. Compared with her mother, I am relieved to see how far she has reached. Sometimes, I would think to myself if F had been a child without disability, she might not have had so many opportunities and achievements, and I wouldn't be so happy now. Once a staff member from the education bureau told me that, since F was an athlete leader of Special Olympics, she could do what she was good at in the future, such as a journalist, or a coach. There is a bright future for her.

Q: Do you think she will get into college?

Grandfather: I think there is chance for her because she is quite good at Chinese. In her spare time, she can write speeches, while I can help her with the delivery and

expression. This may seem easy, but good delivery of a speech requires certain skills such as how to control pace and rhythm. When introducing ourselves, we should be able to enunciate, articulate, and keep a good pace. I will help her if she encounters any unfamiliar characters.

Q: Miss F works really hard. This is my second interview with you, and I've heard she has already been admitted into college.⁴ Do you support her further studies?

Grandfather: Certainly. It is her wish to go to college, I'll be supportive as always. I don't know what will happen next, but I'll do my utmost to help and support her. I am grateful that the government is doing the same.

Q: Do you have any expectations for her future?

Grandfather: I don't want to put any pressure on her. Her future depends on her choices and actions. I just hope that society and college can give her more opportunities so that it won't be so difficult for her. Before I die, I wish to see that she can live a happy life with good health and a steady job. My concerns now are just her job and marriage. She has to consider these after all. I want to see her get married and be happy.

Q: Society is changing for the better and Miss F is an exceptional and hard-working person. I'm sure all your wishes will come true.

Interview with Miss F's Head Teacher

Interviewee: Mr. Shao

Interviewer and writer: Shuo Cheng

Interview date: March 9, 2017

Interview place: Junior Vocational Technical School in Changning District, Shanghai

Witnessing Her Grow into an Outgoing and Thoughtful Girl

Q: Mr. Shao, it's a great pleasure to have this interview with you and talk to you about Miss F.

Teacher: It's alright. This is what I should do as the teacher in charge.

Q: Have you always been the teacher in charge of Miss F's class since she started school here?

Teacher: Yes, I took over her class when she entered the school until her graduation. I know her quite well.

Q: What do you think of her?

⁴This part of the conversation was undertaken during the second interview, when F has already been admitted into a college.

Teacher: Generally speaking, she is thoughtful and careful, and more capable compared with other students. We like students like her.

Q: How has she changed over the past 3 years in the school?

Teacher: She has become much more mature. At first, she had trouble fitting in and was very uptight. Gradually, as she had more interactions with teachers, students, and the management, she became more outgoing, talkative, and capable. Because of her abilities, she was elected as one of the class representatives. She made huge progress while undertaking this role. Her general state is really good.

Q: Now that she fits in well, could she have been a good student if she had studied at a normal school?

Teacher: Children like Miss F do not suffer from severe intellectual disabilities, so they can perform well in our school. But as you know, normal schools focus a lot on academic performance; Miss F is simply no match for students there. The fact that she's been studying in special education schools makes it even harder for her to study in a normal one.

From a different perspective, a normal school is not necessarily the best option for her. Her weaknesses would have been heightened, costing her many opportunities for her better growth. And she couldn't have had the chance to know about Special Olympics, let alone become an athlete leader. The huge support for her would have been impossible. Her current opportunities and achievements are essential for her future development. It's fair to say that the special education school is the best place for her.

Q: I agree with you. Could you elaborate on her difficulties in learning?

Teacher: Generally, her performance has been satisfactory. She is relatively good at Chinese, but not at math. She can only do simple addition and subtraction, but finds it difficult to deal with multiplication and division.

Q: For her, it is more important to be able to put things she learned into use, isn't it?

Teacher: Yes, the ability to apply what she has learned in life would suffice. With mobile phones and calculators, we don't need to force her to learn multiplication or division, but it is still good for her cognitive development to know the basics of math.

Give Full Play to Her Strength and Live to the Fullest

Q: Does her strength in sports compensate for her weakness in academic performance?

Teacher: You can say that. Compared with academic learning, her strength lies in sports. This gives her more chances to succeed. She started to participate in Special Olympics training and the Special Olympics World Games from a very young age, travelling home and abroad for competitions. This allowed her not only to give full play to her strengths, but also to broaden her horizons, meet more people, and have more experiences as she grew up. For Miss F and her family, this is something to be proud of. I am also proud of being a witness to her success.

Q: Do you support her in her further development in sports?

Teacher: I always encourage Miss F to pursue what she is good at and interested in. If she intends to take part in certain types of sports, our school will look for the opportunities and resources to support her professional training to pave her way to success. As an athlete leader of Special Olympics, she often gives speeches now. I'll teach her some techniques, and guide her on how to draft a speech, so now she has become quite articulate.

Q: What kind of guidance have you given her?

Teacher: In terms of language abilities, practice makes perfect. It's also important to know how to properly express oneself. So, in practice, I would focus on training her to be more articulate.

Q: Is she able to fit in at school?

Teacher: Yes, she gets along very well with teachers and classmates. With her rich experience in competitions, she now regularly participates in activities and competitions on behalf of our class and our school. She performs very well on stage.

Q: Does she normally take the initiative to talk to you?

Teacher: She would talk to me if something was wrong. But there are things she would keep to herself, which is normal, given that she was going through puberty.

Q: I also heard that she went through a rebellious phase.

Teacher: Yes, there was a short period when she didn't talk much and became very headstrong. But then again, people all go through a mood swing every once in a while. It's the same for people without disabilities.

Q: How did you help her through that phase? Any special measures?

Teacher: Nothing special. I just noticed that something was wrong, so I talked with her to understand what was going on. After some period of adjustment, she was herself again without anybody's help.

Q: How was she doing during the preparation for the college entrance examination?

Teacher: During that period, she studied and reviewed her lessons very hard, taking classes every day. There was great pressure, actually.

Q: Did she encounter any obstacles during the preparation?

Teacher: Math was difficult for her. Although the math test was designed to be much easier, basic concepts were still hard for her.

Q: Do you have any thoughts on or any expectations for her future development?

Teacher: She is really good. She got herself into college on her own. It may not be a major university, but it is a huge success for her. In the future, I hope she can seize every opportunity to play to her strengths and live her life to the fullest. This is our shared hope for her.

Q: Thank you for your best wishes. I also hope that she will continue to be a contributing member of society.

Interview with Miss F

Interviewee: Miss F

Interviewer and writer: Shuo Cheng

Interview date: March 9, 2017

Interview place: Junior Vocational Technical School in Changning District, Shanghai

My Teachers and Classmates

Q: Hello, Miss F. It's a great pleasure to meet you.

F: Nice to meet you, too. Can I call you sister?

Q: Of course, you can call me sister Cheng.

F: Sister Cheng, you look young. Where do you work?

Q: I am still a college student.

F: Where are you studying?

Q: I am studying at the Huadong Normal University. I am on campus in Putuo District. Have you ever been there?

F: No, I've never been there, but I've heard of it. Mr. Li, my gardening teacher, used to be a student there.

Q: Really? Could you tell me something about this teacher?

F: Em... (thinking for a while) My gardening teacher is Mr. Li. He is very kind to me and cares a lot about me. Besides gardening, he also taught me math. He even tutored me in math when I prepared for the college entrance examination. He is an amazing person. He knows so many things and teaches me so much about gardening, like this pot plant (taking the interviewer to a potted plant while talking). He taught me how to remove the weeds and replace flowerpots.

Q: How do you do it exactly?

F: We use a special little shovel to remove the weeds and turn the soil over. Mr. Li told me that there were dos and don'ts. You can't just do whatever you want. You see... (demonstrating while explaining) there are plenty of weeds in this pot. I need to remove them all at their roots so that they won't grow back. These are particularly difficult to get rid of, because they are really thin, and some are deep-rooted. We need to dig deep to take out their roots and not leave any remnants in the soil.

Q: You really know a lot!

F: I learned from the best. He is quite knowledgeable. I still have so much to learn (a little shy). Also, don't forget to replace the flowerpot after getting rid of the weeds.

Q: Really? Why is that?

F: You see that the soil in this pot is kind of whitish, which means it lacks nutrients. We need to flip the soil. If the soil becomes entirely white, then we need to replace it with a special type of soil rich in nutrients.

Q: What kind of soil is the best?

F: Soil that is black and damp. This means it is rich in nutrients and water, which helps a plant grow.

Q: How do we flip it?

F: You should be careful not to cut off the roots of the plant. Just turn the soil slowly and gently from the side, layer by layer. You see just like this (demonstrating). When the surface layer has been overturned entirely, use the shovel to press it down a little bit to make it flatter. And that's it.

Q: You are quite an expert!

F: Thank you! I am not as good as Mr. Li actually. He takes care of all the plants and flowers here (taking the interviewer on a tour of the gardening area). He comes here every day to water the plants, remove weeds, and turn over the soil. He is quite meticulous. There is still so much to learn from him!

Q: When did you start to take gardening classes with Mr. Li?

F: Ever since I came to this school. It's been a long time and I've forgotten some of the things that I've learned, but I can always turn to Mr. Li for help. He is always patient with me.

Q: How do you get along with other teachers?

F: They are all kind to me. Mr. Shao has been the teacher in charge of my class ever since I got here. He is kind, patient, and careful. He cares a lot about me.

Q: Can you give me an example?

F: I can't think of an example at the moment. There are so many. Anyway, he's just very kind to me. Sometimes, he would ask me about my family. If I was in trouble, he would lend me a helping hand. In terms of studies, he encourages me and helps me with math. I am delighted that I can help him and other teachers too, such as managing the class.

Q: So, you're one of the class representatives, aren't you?

F: Yes, I've always been the class monitor.

Q: What does it entail?

F: I am responsible for the discipline, homework, and other tasks assigned by the teachers, such as sending out notices, and attending events on behalf of our class.

Q: I figure you must be quite busy.

F: Sometimes, but I take pleasure in helping teachers. Besides, it gives me an opportunity to improve myself, which is good for me.

Q: That's really positive thinking.

F: I think that all the teachers are nice to me, so I should do something in return, helping them as much as I can.

Q: Do you take the initiative to talk to Mr. Shao?

F: Sometimes I would tell him something and he would also ask me about how my grandad and I are doing, and what's going on in my family. I also tell him about my classmates and things that I experience outside of school. I find it interesting talking to him.

Q: So, you enjoy talking with teachers?

F: Yes, I love it. Mr. Shao is kind-hearted and thoughtful, so I am not afraid of him at all. I can share everything with him.

Q: Do you have many interactions with other teachers?

F: Of course, I get on well with all the teachers. They all like me.

Q: Do you enjoy attending their lessons? Do you have a favorite subject?

F: I enjoy them a lot. They are good teachers. I've learned so much. My favorite subject is... (hesitant) I don't know. I like them all. If I had to choose, I think I enjoy baking the most, because I get to make delicious and beautiful cookies.

Q: Really? I remember that you want to become a pastry chef, don't you?

F: I have thought about it, but I've just begun with the learning process. I am not sure if I am going to be good at it, but I'll give it my best.

Q: I believe you! What do you learn in baking lessons?

F: We've learned to make many things, including cookies and cakes. There are many things in the textbooks that I'm not able to make. There is still so much to learn (see Fig. 2)

Q: So now you know how to make all of these things? Do you usually practice at home?

F: Almost, but some are particularly difficult. I cook at home, but not so often. I only go back home once a week, since my grandad lives far away. So, I don't have much time.

Q: Do you live on campus except for the weekends?

F: No, I live with the sister of my grandmother. She lives closer to my school, near the City God Temple. It's walking distance to school and more convenient than going back home.

Q: Are you used to living with her? Do you miss your grandad?

F: Yes, I am used to it. I've been living here for a long time. They are all nice to me. I miss my grandad sometimes, but I can always have a video chat with him or send him a message, which helps a lot.

Q: Do you often hang out with your friends?

F: Sometimes, but not often. They have their own things, so it's hard to get together.

Q: Could you tell me something about your friends?

F: I don't have many friends, only a few close ones. They are friendly, and I am really happy spending time with them.

Q: What about your classmates? What do you normally do together?

F: There aren't many classmates. I got to know my friends mostly from training. We watch TV, chat, and sometimes go shopping and play games. It is wonderful.

Q: Do you go out a lot?

F: Not often. I just stay at home after school or on weekends. I'm quite comfortable at home. I would go out if I feel bored.

Q: I also enjoy staying at home, being alone and quiet. Apart from baking, what else do you learn at school?

F: I have specialized courses, including baking, services, and gardening, and also Chinese, math, and English.

Q: Are you happy every day at school?

F: Yes, because I can learn many useful things and all the teachers are kind to me. I can also help them with many things. My life is full.

Q: What about your classmates? How do you get along with them?



Fig. 2 Miss F in cooking class

F: My classmates are also friendly, but some of them are disobedient. Some tend to disregard discipline during classes, making it very difficult for teachers.

Q: Do you usually talk to them or play with them?

F: Not often. There's not that much time. During breaks, I may assist teachers and sometimes I sit at my seat and talk to some of my classmates.

Q: Can you communicate well with your classmates?

F: Basically okay. I think it's fine to chat with them, but there is not much to talk about. Also, the break is short.

Going to College

Q: You are going to graduate soon, aren't you?

F: Yes. I'll graduate this June. I was admitted into a 3-year college and now I'm taking relevant courses.

Q: Which college?

F: A spare-time university on Shuicheng Road.

Q: Did you get in through the college entrance examination?

F: Yes. The college entrance examination for adults.

Q: What subjects were there in this examination?

F: Mainly Chinese, math, and English.

Q: Did you find it difficult?

F: I was under a lot of pressure at that time. English and math are pretty difficult for me.

Q: How did you prepare for the examination?

F: I attended exam review classes organized at our school.

Q: Who were your teachers?

F: Mr. Li was my math teacher, Ms. Liu was my English teacher, and Ms. Yan was my Chinese teacher. They were all from my school. There were many students attending these kinds of courses.

Q: How did you overcome the difficulties in math?

F: Teachers would show me how to do it step by step. If I still couldn't understand, they would ask me to write it down.

Q: Did you receive any additional tutoring?

F: No.

Q: Did your teacher in charge give you a lot of encouragement?

F: Yes. He told me to prepare well. In fact, before the exam, I had the option of going to a forum in America or sitting for the college entrance examination. I chose the latter.

Q: What is your major in college? What courses do you have?

F: I major in hotel management. I have taken a lot of courses such as management science, politics, and so on. I don't remember the titles. On Monday morning, I have Marxism and Xiaoping Deng Theory. In the afternoon, I need to go back to attend courses at the Junior Vocational Technical School. The courses for hotel management

are scheduled on Friday mornings and I can go back home in the afternoon. From Tuesday to Thursday, I attend specialized courses at the Junior Vocational Technical School.

Q: You mean you have to take courses at two schools?

F: Yes. I have to go to two schools because I haven't graduated yet.

Q: Why do you have classes now? Doesn't the school start in September?

F: Actually, it started in March. I have to learn beforehand just like other students.

Q: So, you are quite busy. Do you have any trouble with your studies?

F: I don't think it is easy. I don't understand some of the things I've read, but teachers will explain things in class. I take notes and read them over afterwards. I think it's much more difficult than what I am learning now.

Q: Ha ha, it is indeed more difficult in college, but I believe that if you try your best, you can do it. I believe you!

F: Thank you for your encouragement. I will do my best!

Observation of Miss F at School

Observation date: March 9, 2017

Observation place: Junior Vocational Technical School in Changning District, Shanghai

Observer and writer: Shuo Cheng

Time	Activities	Performance of Miss F	Notes
8:20–9:00	Horticulture class. Learning <i>Basic Botany</i> , such as photosynthesis and respiration	Miss F was well prepared and waited quietly for the teacher to start. During the lesson, she was very attentive, with her eyes always focused on the teacher and presentations, and would take notes when important points were mentioned. She could also have simple interactions with the teacher, asking and answering questions	This is a preparatory course for a 3-year college

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Time	Activities	Performance of Miss F	Notes
9:10–11:35	<p>Baking class with visitors from other schools. Under the teacher’s guidance, Miss F helped prepare the ingredients, including sugar and flour. Then, Miss F, other classmates, and teachers were divided into groups of three people. The teacher first explained and demonstrated how to make cookies. Since the basics have already been covered before, he focused on demonstrating the difficult part and details. Afterwards, while Miss F and her classmates were putting what they had learned into practice, the teachers answered their questions and corrected any mistakes</p>	<p>The ingredients need to be weighed accurately. When preparing the ingredients, Miss F was focused and adjusted the amount meticulously. The teacher was pleased that she could immediately understand any guidance provided, and then make necessary changes. During the demonstration by the baking teachers, she was attentive and would raise questions when she didn’t understand. During practice, we could see that Miss F was not only skillful and well practiced, but also well organized in that she always cleaned up the table after each step. She also interacted with the teacher, discussing proper techniques, and making necessary corrections under the guidance of the teacher. From her eyes and movements, I could see that she was committed and focused. The teacher gave her a lot of praise and encouragement during the class</p>	<p>The morning baking lessons were held instead due to visits from other schools. In addition, a bakery competition was to be held in May of 2017 by a food processing company. One of the sections would invite people with intellectual disabilities to do the baking. So, they are currently receiving training for that</p>

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Time	Activities	Performance of Miss F	Notes
11:35–12:45	Lunch and lunch break. Lunch was in the classroom. During the break, a team of students led by Miss F inspected the work undertaken by students, such as the sanitation in staircases, hallways, classrooms, and teachers’ offices in the Happiness Building and the Harmonious Building. Then, after a summary of their performance, a star student was recommended	Miss F chewed her food slowly, and didn’t look around while eating. The table was also kept clean. After she finished, she put her meal box back into the designated slot and also helped the teachers arranging the meal boxes. She also brought meals to teachers, and politely said “Please enjoy your meal.” During inspection, she explained to her classmates, with patience and through examples, how to inspect the sanitary conditions and how to make comments. It showcased her language skills and clear line of thinking. If students failed to do a good job, she pointed it out and showed them how to do it properly. She was responsible and efficient the entire time and had communicated well with her classmates. Her classmates all think highly of her	As an inspector in her school, Miss F is in charge of overseeing the work done by students. Now that she is going to graduate, she needs to help the students who will take over the job familiarize themselves with the process

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Time	Activities	Performance of Miss F	Notes
12:45–13:25	Psychology class. The teacher checked their homework and started a new lesson	As the teacher was checking their homework, Miss F found that she didn't finish all of it, so she started to answer the rest of the questions. By the time the teacher came to her, she had already finished and showed it to the teacher who, upon inspection, was pleased with her work and asked her to continue checking if there were any mistakes. Sitting in her chair, Miss F seemed a bit bored, playing with her pens or arranging her books. After a while, she leaned back on her chair, lost in thought. When the teacher returned to the podium, ready to start the lesson, Miss F shook herself up and paid attention to what the teacher was saying while finding the corresponding content in her textbook	

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Time	Activities	Performance of Miss F	Notes
13:25–13:35	Break	Miss F sat in her seat most of the time, either having a rest on her desk or arranging her textbooks. As requested by the teacher, she went to fetch something from another teacher. After she returned, she had a little chat with her classmates before sitting down, observing, and keeping her fellow students in order. For example, having noticed a student was running and jumping around in their classroom, she stepped up and stopped them	
13:35–14:20	Chinese class. Dictation exercise. Read an article from the textbook— <i>Road Safety</i>	During dictation, Miss F listened very carefully to what the teacher was saying and was able to quickly write down the correct answers. Afterwards, she helped the teacher collect the answer books. When she read a text out loud, she was focused, fluent, and accurate. She was able to enunciate and project her voice. The teacher then raised a question. Miss F was very eager to answer, but would also give other students opportunities and wait for her turn if others provided the wrong answer. Miss F was energetic throughout the whole class	

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Time	Activities	Performance of Miss F	Notes
14:30–15:10	Gardening class. Exercise in replacing the flowerpot and removing weeds	Miss F was the only student in today's gardening class, so she had a one-on-one opportunity to learn from Mr. Li about how to replace the flowerpot and remove weeds. They had smooth interaction and communication, with occasional jokes thrown in. Mr. Li had a good sense of humor and made her laugh sometimes. The general atmosphere was relaxing. As observed, Miss F was well practiced, and able to adjust her techniques per instruction. By the end of the class, she has already finished two pot plants	Gardening is an individualized optional course provided by this school, which Miss F has chosen for this semester
15:20–16:00	Indoor exercises and activities. Play flying chess	While playing flying chess, Miss F showed good teamwork with her classmates. She was patient and waited for others to finish their moves. If they didn't know their next move, she would give them tips and assistance. When she took a break from the game, she walked around the classroom, took in what others were doing, and made occasional inquiries. She was polite and didn't cause any disruptions	

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Time	Activities	Performance of Miss F	Notes
After school.	She collected her stuff and said goodbye to her teacher	Miss F put her stationery and textbooks back in order and tidied up her desk and drawers. She was well organized. She looked around the classroom, waited for a while after everyone had gone, and asked the teacher if any assistance was needed. After saying her goodbyes, she walked towards the school gate	

Translated by Min Cui

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