

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 1

Overview

Economy and Social Inclusion

Creating a Society for All

Series Editor

Akihiko Matsui, Tokyo, Japan

This series provides a forum for theoretical, empirical, historical, and experimental analysis of issues related to economy and social inclusion and exclusion. Included are the interconnected problems of alienation, deprivation, discrimination, economic inequality, polarization, and prejudices caused by or related to abusive behavior, aging, depopulation, disability, the educational gap, the gender gap, natural disaster, poverty, rare diseases, war, and various other economic and social factors.

The common theme of the series is to examine how we can create an inclusive society that accommodates as many people as possible and promotes their welfare. We believe this should be the main goal of economics as a discipline. Society need not passively observe its inequality, social exclusion, and decline. Policy, institutions, and our actions matter. The series aims to enrich academic discourse, influence economic and social policy, and enlighten a global readership.

Methodologies adopted in this series are mainly economic theory, game theory, econometrics, statistical analysis, economic experiments, and disability studies. Psychology, sociology, legal studies, and medical sciences, among other disciplines, are also considered important related fields of study.

The interdisciplinary research taken up in the series utilizes these existing methodologies for the common goal of creating a society for all. Furthermore, progress in such interdisciplinary studies will contribute new insights to the development of economic studies. The major geographical targets of the series are Japan and other Asian countries but are not restricted to those areas. At the same time, however, the goal is to amplify the findings therein to universally applicable insights and knowledge.

Editorial Board:

William P. Alford (Vice Dean for the Graduate Program and International Legal Studies, Jerome A. and Joan L. Cohen Professor of East Asian Legal Studies, Harvard Law School)

In-Koo Cho (Professor, University of Illinois, USA)

Partha Sarathi Dasgupta (Frank Ramsey Professor Emeritus of Economics at the University of Cambridge, UK)

Hidehiko Ichimura (Professor, The University of Tokyo, Japan)

Daiji Kawaguchi (Professor, The University of Tokyo, Japan)

Osamu Nagase (Visiting Professor, Ritsumeikan University, Japan)

Yasuyuki Sawada (Chief Economist, Asian Development Bank, Philippines; Professor, The University of Tokyo, Japan)

Tomomi Tanaka (Senior Economist, The World Bank)

More information about this series at <http://www.springer.com/series/13899>

William P. Alford · Mei Liao · Fengming Cui
Editors

An Oral History of the Special Olympics in China Volume 1

Overview

 Springer Open

Editors

William P. Alford
Harvard Law School
Harvard University
Cambridge, MA, USA

Mei Liao
Shanghai, China

Fengming Cui
Harvard Law School
Harvard University
Cambridge, MA, USA



ISSN 2509-4270

Economy and Social Inclusion

ISBN 978-981-15-5131-4

<https://doi.org/10.1007/978-981-15-5132-1>

ISSN 2509-4289 (electronic)

ISBN 978-981-15-5132-1 (eBook)

© The Editor(s) (if applicable) and The Author(s) 2020. This book is an open access publication.

Open Access This book is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits any noncommercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if you modified the licensed material. You do not have permission under this license to share adapted material derived from this book or parts of it.

The images or other third party material in this book are included in the book's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the book's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

This work is subject to copyright. All commercial rights are reserved by the author(s), whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed. Regarding these commercial rights a non-exclusive license has been granted to the publisher.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Singapore Pte Ltd. The registered company address is: 152 Beach Road, #21-01/04 Gateway East, Singapore 189721, Singapore

This is the first volume of three Open Access books that commemorate the 50th Anniversary of the Special Olympics 1968–2018. The three volumes are:

- *An Oral History of Special Olympics in China Volume 1—Overview*
- *An Oral History of the Special Olympics in China Volume 2—The Movement*
- *An Oral History of the Special Olympics in China Volume 3—Finding and Keeping a Job*

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.

Foreword by Timothy Shriver

Fifty years ago, a movement was born. The first International Special Olympics were held in Soldier Field in Chicago, Illinois, USA, on 20 July 1968 with 1,000 athletes from the USA and Canada. Today, more than 108,000 games and competitions are happening with more than 5 million athletes every day around the world.

The history of Special Olympics is vast and deep, made up of millions of individual stories of how we grew to be in 172 countries. Personal accounts of transformation that capture how families went from shame to pride, how athletes who once faced injustice have found justice through joy. Stories of hearing “you can’t” and then showing the world “I can!”

Our collective stories woven together create a beautiful tapestry of inclusion.

Special Olympics China was our first program to reach 1 million athletes and continues to be our largest program worldwide. The stories of the people throughout the country account for incredible work to open the doors of opportunity for persons with intellectual disabilities. May these game changers inspire a new generation—a unified generation—to continue to build upon this history.

Washington, D.C., USA

Timothy P. Shriver, Ph.D.
Chairman
Special Olympics International

Foreword by Mary Gu

It was in 1999 that for the first time I worked with Special Olympics, when Special Olympics International (SOI), the Ministry of Civil Administration of the People's Republic of China, and the Shanghai Municipal Civil Administration then jointly planned for a grand publicity event. The event successively called on leaders and people of all walks of life within society to support Special Olympic games and persons with intellectual disability, while also pledging to increase the registered Special Olympics athletes from 50,000 to 500,000. I had the greatest honor to receive an invitation from Dr. Derong Shi, then Director of the Shanghai Municipal Civil Administration, to serve as a volunteer planner for a fund-raising campaign in Shanghai. Over the past 19 years, like a flash, I have been closely bound to Special Olympics, growing from at first being a volunteer, then to being a key participant in planning the opening ceremony, fundraising for the World Summer Games, and organizing the Global Torch Run for the World Games at the Organizing Committee for the 2007 Shanghai Summer Special Olympic Games. I eventually became a full-time SOI member in 2011, as Regional President of SOI East Asia. These jobs were challenging yet rewarding, but more so, I had the experience to share a very different perspective from family members of Special Olympics athletes on what an endeavor it was for them to have an ordinary life as a student, employee, and ultimately a person who should also be treated with respect and dignity.

Whether as a social participant or full-time staff, I must say that the Chinese government across different levels, as well as the core social force, are earnest supporters of Special Olympics movement, and all understand the importance of the social inclusion for persons with intellectual disabilities.

With the support from the government, over the past two decades the number of Special Olympics athletes has now soared to nearly 1.2 million, from just 50,000 in the beginning. A considerable number of these athletes are participants in Special Olympic games and competitions at different levels, while a small number of them take part in the national and international games.

During my tenure of office as the Regional President, and thanks to the support from specialists in academia and the China Disabled Persons Federation, Special Olympics was introduced to nearly 2,000 special educational schools nationwide as part of their physical education curriculum. It once again gave these athletes in schools an opportunity to demonstrate their gifts and talents through sports to society.

As most Asian Countries have either an elite or rigorous education program, we realized through the process that there is a practical challenge for schools to implement an inclusive education system to give a fair chance to students with intellectual disabilities to be fully included. We worked with educators who believe in and were passionate about this subject to pilot a Unified School program between prestigious mainstream and special education schools. We wanted the students from special schools to have an opportunity to form friendships with their peers from different social environments and we want young elites from mainstream schools to take on a societal leadership role to accept people with differences.

The success of the World Summer Special Olympic Games in 2007 has brought the public awareness of the Special Olympics movement to an unprecedented level, but the journey towards acceptance, respect, and equality remains uncertain for the Special Olympics family members and teachers of special education. The daily lives of persons with intellectual disabilities are still filled with challenges, and parents of athletes often felt helpless. I was very much inspired and excited when Chinese historian Dr. Mei Liao suggested compiling a series of nuncupative history of Special Olympics movement in celebration of its 50th anniversary. With some limitations of their own, persons with intellectual disabilities often have difficulty in making their voices heard. Their guardians, parents, teachers, friends, and colleagues are unable to find additional channels to share their reflections and experiences. The records of the movement mainly source from official statistics and news reports prior to the publication of this book. With nuncupative history and the project of Special Olympics oral history for the very first time, there is a version of history that comes from the source of Special Olympics athletes and the stakeholders within the movement. The book dates back to 50 years ago when Mrs. Eunice Kennedy Shriver founded the movement with the vision to show the world the great potential of persons with intellectual disabilities like her own sister Rosemary who should have deserved the same respect and acceptance by society like any of her other successful family members. It is also our hope that after half a century, this book not only serves as a record of facts and stories on how Special Olympics movement progressed in China, but also as a testimonial to the society: like anyone in the society, persons with intellectual disabilities also deserves acknowledgment in history.

In the early stage of the preparation of this book, I was privileged to participate in some interviews. I was once again inspired by the amazing family members of Special Olympics athletes. I was ceaselessly impressed by the tireless efforts from

so many people for their commitment and dedication to support the movement. I trust this book is not just an overview of the history, but will also open a new chapter of the movement.

I wish Special Olympics continued success! My heartfelt gratitude to those who have included me in this amazing journey!

Shanghai, China

Mary Gu
Former Regional President
Special Olympics International
(SOI) East Asia
Edited by Chongshun Bai

Foreword by William P. Alford

Professor Mei Liao deserves enormous credit for the inspired idea of inviting a range of Chinese citizens whose lives have been touched by intellectual disability to speak for themselves. *An Oral History of Special Olympics in China* is a multi-volume collection of interviews with persons with an intellectual disability, and their family members, teachers, co-workers, and others. But that hardly begins to describe what a wonderful and powerful accomplishment it represents.

The interviews, conducted with skill and compassion by Prof. Liao and the students she recruited from Fudan University and the East China Normal University (both leading academic institutions located in Shanghai), have tremendous emotional resonance and are brimming with information about issues concerning disability in China's most cosmopolitan city. The first-hand accounts by 34 persons with an intellectual disability are, at times, heartrending, as some talk about the bullying and isolation they have experienced, including even physical abuse, at the hands of classmates or others who typically did not understand the human consequences of their meanness. So, too, is the anguish of parents who recount valiant efforts to overcome the stigma expressed, even in some instances by relatives, and who worry, as only parents can, about who will care for their child after they have passed away.

Yet, for all the hardship the oral histories capture and convey, the far more compelling and far more important message that emerges is one of courage, determination, ingenuity, love, and gratitude. This is most significantly evident in the accounts by the 34 individuals who are the principal focus of this oral history of their schooling, work experience, participation in Special Olympics, and so much more from their lives. What comes through, again and again, is a challenge encountered—be it regarding social exclusion or trying financial circumstances—and a challenge bravely engaged through talent, perseverance, and the support of caring family, friends, and colleagues. What also comes through is the pride that these 34 interviewees have taken in their considerable accomplishments in the classroom, at work, and in the sporting and other activities made available through

Special Olympics. It is crucial that we not lose sight of how much opportunities for expression, participation, and camaraderie that many of us may take for granted mean for individuals who may have been marginalized by society.

Beyond their individual force, these accounts have much to tell us about the ways in which the world around them has changed. Problems persist, as their accounts so vividly evidence, but it is also vital to take the full measure of important ways in which change is afoot. More employers are giving persons with disabilities the opportunity both to earn a living and to experience the sense of self-worth and inclusion that comes from being part of a work unit while also helping disabuse the larger world of stereotypes about persons with a disability. The Chinese government, through increased efforts at inclusive education and through the establishment of so-called Sunshine Houses (centers at which adults with an intellectual disability might congregate) and other programs, is increasingly committed to providing more opportunity. And, as so many of the accounts indicate, Special Olympics has been an extraordinary gift—bringing athletic and other programs to more than 1.325 million citizens of the PRC, providing outlets for physical, social, emotional, and intellectual growth, and creating among families a deep sense of community and shared purpose. For more on Special Olympics in China, please see <https://www.specialolympics.org/programs/east-asia/china>.

A final few words on the editing of the volume. First, this initial shorter volume represents a sampling of the interviews contained in full in volumes two and three. We hope you will find it engaging enough that you will delve into the other, fuller volumes. Second, in the interest of authenticity, the translators of the interviews have used English wording that they believe best captures the original Chinese. Some of those terms are inartful, and rightly falling out of use, but, after some debate, we thought it is best to convey those as it is, in the interest of accuracy as to what was said. And, third, the editors want to thank Alonzo Emery, Associate Director of Harvard Law School's East Asian Legal Studies program, for his thoughtful and careful work in bringing this publication to fruition.

Again, my thanks to Prof. Mei Liao not only for having the idea that animates these volumes but also for addressing so artfully the many challenges that such a novel project raises.

Cambridge, USA

William P. Alford
 Vice Dean for the Graduate Program
 and International Legal Studies
 Jerome A. and Joan L. Cohen Professor
 of East Asian Legal Studies
 Director of East Asian Legal Studies
 Chair of the Harvard Law School Project on Disability
 Harvard Law School

Preface

I.

In 1941, 23-year-old Rosemary suddenly disappeared from home.

None of her siblings knew where she went. For more than two decades, she became virtually non-existent.

Rosemary was the third child of Joseph Kennedy and Rose Kennedy, and the younger sister of John Kennedy, the 35th President of the United States. Lack of oxygen at birth led to her intellectual disability and, in 1941, she was sent to a Catholic convent in Wisconsin where she received private care. Her father never paid her a single visit.

In the 1960s, Mrs. Eunice Shriver, Rosemary's younger sister, started Camp Shriver in her own backyard to engage children with intellectual disabilities (hereafter referred to as "with ID") in various sporting activities. She wanted to bring Rosemary back to the Kennedy family and to bring millions of people like Rosemary back to American society. Separating persons with ID from society was almost like racial segregation, and Mrs. Shriver wanted to end it.

This is a family story recounted by Dr. Timothy Shriver, Chairman of Special Olympics International, in his book *Fully Alive*. By the time Timothy was born, Rosemary had become a regular guest at the Shriver house where she played poker, swam, and took walks with the Shriver family. "There, she finally became seen in her family and seen in her country as well."

Having persons with ID be seen and inviting them and their families on to the stage to share their life stories and experiences with readers is the purpose of these *Special Olympics Oral History* books.

II.

Modern oral history started in the USA in 1948. Currently, on a global scale, the oral history of people is very well developed for two groups: the elite and the disadvantaged.

The most distinguishing characteristic of oral history is its subjectivity, meaning that the world depicted is the world seen by the narrator, who is also the subject.

Participants in the elite group are often involved in major historical events. Their oral history not only documents personal history and thoughts, but also supplements details of major events and activities of well-known people. Because memories can be faulty, histories, as told by the elite group, must be validated by existing documentation, or other people's oral histories. As a result, in traditional political and economic history, oral history has its own limitations as secondary historical sources.

Oral history of the ordinary citizens and the disadvantaged became popular in Britain and the USA after World War II. Under the influence of the trend of social history and the civil rights movement, scholars started to turn their focus to marginalized groups and the disadvantaged, including farmers, factory workers, women, and minorities. The goal of the research is no longer to supplement documentation of major events but to understand disadvantaged groups and to imprint undocumented groups on human memory. Therefore, oral history is also known as "people's history" and is seen as a movement for the pursuit of civil rights. The subjectivity of oral history reflects exactly the need (or purpose) to conduct research on disadvantaged groups—to truthfully reveal their lived experience and subjective understanding of the external world around them. In other words, oral history is the medium disadvantaged groups need in order to be seen and to be heard.

Building upon existing news coverage and promotional short films, *Special Olympics Oral History* documents not only highlights from the Special Olympics movement but also the long life journeys and unique feelings of persons with ID so as to present a comprehensive picture of their lives. To weave the Special Olympics movement into the intricacy of personal lives is to help the public better evaluate the Special Olympics movement, as well as the influence and impact of public policies and historical events.

III.

Friends and families of persons with ID, Special Olympics movement organizers, volunteers, sponsors, and reporters, as well as professionals, who have relocated from remote cities to Beijing to work with persons with disabilities—they all know, to varying degrees, how persons with ID live their lives and what challenges they face. Experts and scholars engaged in related research have more in-depth interpretations of the struggles of persons with ID and predictions for their future.

The majority of the general public, however, have had no chance to get to know anyone with ID. Segregation might lead to a vicious cycle. Because persons without ID seldom encounter persons with ID, once they do meet in public, persons without ID tend to give them curious, fearful, or even loathing glances. Such unfriendly glances compel some parents of children with ID to keep their children hidden at home.

But the fact is that a lot of people will lend a helping hand once they have some understanding of the situation that persons with ID and their families face. For example, there was a parent who tried to register her child for a swimming class in order to learn physical coordination but was turned down, and the swimming coach who witnessed it offered the child free swimming lessons. And a bus driver and a conductor, whose names were never disclosed, saved seats for a mother taking her child everywhere for doctor visits or allowed them to ride on the bus for free. Every family that includes a person with ID can probably tell a story or two like that.

Ignorance spawns fear and discrimination, whereas communication leads to understanding and inclusion.

When families of persons with ID tell society, in a straightforward manner, their struggles, sorrow, and laughter, it will help others empathize with them and drive communication between persons with and without ID so they can better help each other.

What can families of persons with ID bring to society? They can bring perseverance, commitment, and love. There are world records for sports events. If there were also world records for the emotional world of mankind, the record holders would be families of persons with ID and other disabilities. The long-term pain endured by many families is likely to have tested human limits. Their stories have taught persons without disabilities that human beings have a strong spiritual world, endurance that defies all boundaries, iron will, and love that asks for no return and that never runs dry. They are role models who encourage other people by quoting Mrs. Shriver, "Let me win. If I cannot win, let me be brave in the attempt." They have expanded the possibilities of mankind's emotional world and marked the ultimate height of human emotions. Their emotional journey is a valuable spiritual asset for mankind.

Families of persons with ID help others discover their own virtues and complete self-improvement. Mencius believed that human nature is good. According to him, we were born with four seeds that are the beginnings of goodness, namely, compassion, shame, respect, and the knowledge of right and wrong. If we cultivate these seeds, they will develop into moral qualities, whereas they will be lost if we ignore them. The self-cultivation and enlightenment that the Confucian School has been pursuing ever since is, in essence, nurturing these four seeds into qualities all human beings should possess. The opposite example is to uproot these sources of goodness and become shameful as a result. Persons with ID give other people the chance to discover their own virtues and to nurture the goodness in human nature to become humane even in modern society with its tough competition.

Families of persons with ID help instill in other people the spirit of equality and tolerance. A middle-school teacher learned from her own child with intellectual

disabilities that not every student has a high IQ. Therefore, she never discriminated against students who were lagging behind and eventually transformed a problematic class into an outstanding team in the district. All of us face obstacles: some have trouble learning English, some don't do well at math, some shy away from socializing. Everyone has some "difficulties" that are hard to overcome. In some sense, perhaps these disabilities are not so much weaknesses as another form of being. The question is: are these difficulties to be hidden or accepted, discriminated against or tolerated? We have learned from physics that energy is balanced and will not disappear. It just transfers from one object to another or from one form to another. The way we treat persons with ID is very likely to become a social trend which will eventually become how other people treat our own weaknesses. Families of persons with ID teach us to put ourselves in other people's shoes and to commit ourselves to the pursuit of equality, diversity, and tolerance.

Families of persons with ID and persons with disabilities drive society to pay more attention to individual welfare and propel the continuous advancement of human welfare as an industry. Persons with disabilities often need more physical and psychological care. Endeavors on the behalf of persons with disabilities serve only people and voluminous studies of human beings have been accumulated. With the development of science and technology, simple labor is gradually replaced by artificial intelligence and a lot of traditional jobs have disappeared. On the one hand, machines have liberated manpower, so that human beings can afford the time for self-development. On the other hand, machines have taken jobs away from human beings and forced them to develop new jobs. And these new jobs are most likely to be developed in order to meet the increasingly diversified needs for individual growth. Therefore, in the future, human welfare as an industry will become a mainstream industry for human beings, and endeavors on the behalf of persons with disabilities will become the undisputed pioneering and leading force because of the dedication to individual welfare.

What can society bring to families of persons with ID while benefiting from them? Encouragement, support, and development, undoubtedly. Once persons without ID have an understanding of the life stories and special needs of families of persons with ID, they will learn how to communicate with them and how to help them with clear objectives in mind. The so-called targeted efforts refer to this: overindulgence will hinder the self-growth of persons with ID, and the best help that can be offered to them is to improve their quality of life while driving the development of their own abilities. For example, with training, persons with ID can enhance cognition and small motor skills, therefore, volunteers and charity organizations can host activities for this particular purpose; persons with ID need encouragement and interaction with society, therefore, organizations and schools can invite persons with ID in the same community to perform at their annual meetings and celebrations; persons with ID can engage in simple labor, therefore, hopefully, more and more enterprises will set aside simple jobs for employees with ID.

We live on the same planet, and we build our homes on the planet by staying together with each other in order to promote mutual understanding so that we can nurture and embrace each other as we move forward. This is the second objective of *Special Olympics Oral History*.

IV.

Special Olympics Oral History was launched in June 2016. The plan is to publish, over a span of 3–4 years, nine books, including *Finding and Keeping a Job*, *Special Olympics Movement*, *Special Olympics World Games Athletes*, *Athlete Leaders*, *Family Leaders*, *Home Care*, *Athletic Coaches*, *Principals of Special Education Schools*, and *Volunteers*. The protagonists in *Special Olympics Movement*, *Special Olympics World Games Athletes*, *Athlete Leaders*, and *Family Leaders* are all families actively participating in the Special Olympics movement. *Finding and Keeping a Job* and *Home Care* may be less directly linked to the Special Olympics movement and some of the protagonists may even be strangers to Special Olympics, but the books feature two sub-groups of persons with ID. The former sub-group has, on the whole, been included into the social life of persons without ID and developed as best as can be expected of persons with ID; whereas the latter stays home in isolation from society and is the least included sub-group of persons with ID. So we have devoted two books to those two sub-groups in the hope that we can present the most comprehensive picture of persons with ID. The protagonists in *Athletic Coaches* and *Principals of Special Education Schools* are professionals involved with the Special Olympics movement. The coaches and principals spend long hours with children with ID and have first-hand knowledge of the growing pains of students with ID and Special Olympics athletes. Therefore, they will be able to help the readers look at the development of the Special Olympics movement in China and changes and improvements of relevant government policies from the relatively macro perspective of primary-level educators and managers. Volunteers in the *Volunteers* book are neither family members of persons with ID nor professionals working with persons with ID. They all have day jobs, as well as ideals and a big heart, which constitutes the main reason why they are participating in the Special Olympics movement in their spare time. It reflects the progress we have made in civilization as a society.

Each oral history case comprises two parts: interviews and observations. The interview part includes interviews with parents, as well as individuals with ID themselves and their teachers and co-workers. The observation part is an objective documentation of one day in the life of persons with ID. Interviews with professionals working with persons with ID include interviews with these professionals and their co-workers and students, while the observation part is an objective documentation of their activities during certain times of the day.

Instead of being a first-person narration, oral history is in the Q&A format for the maximum revelation of the interview scenes.

Text in () documents the observed expressions and actions of the interviewees whereas text in [] is added by the editor at a later time.

We use either real names or initials of interviewees and parents according to their preferences.

The oral history volumes are arranged in a descending order of the interviewees' ages so as to show how the social status of persons with ID has changed and how government policies have improved over time.

All of the main interviews have been reviewed by the interviewees. Some contents, although in the opinion of the interviewers are true reflections of the current status of persons with ID, have been excluded from the books to show respect to interviewed parents who are unwilling to publicize them.

We would like to thank all of the families and interviewers who participated in this *Special Olympics Oral History* project. We would also like to thank the schools, companies, and organizations that have supported this project. We would not have been able to launch these books without the teamwork and contributions from everyone.

We would like to thank members of the *Special Olympics Oral History* team. They are Mary Gu, former President of Special Olympics East Asia, Daisy Cao, Rebecca Liu, and Cora Shen. They have been invaluable in organizing and running this project. Daisy Cao, in particular, has been amazing in effectively coordinating all parties involved throughout the project and readily providing consultation, in both Chinese and English.

We would like to thank Dr. Fengming Cui, Director of China Program under the Harvard Law School Project on Disability, for professional guidance in both Chinese and English.

We would like to thank Mr. Weisong Wang, Editor-in-Chief of Shanghai People's Publishing House. When we expressed the wish to publish an oral history by families of persons with ID, he immediately granted our wish without asking for details. His decisiveness, trust, and support encouraged us to produce a high-quality work in *Special Olympics Oral History*. We would also like to thank editors Chong Shao and Yuhan Zhang for their down-to-earth and meticulous work.

We hope that more organizations and groups will join the oral history endeavor for the disadvantaged group. Once we have collected a sufficient number of oral history samples, we will be able to build a database on the lives of persons with ID in China. If we continue to conduct oral history projects for people with other disability categories, such as those with visual, physical, hearing, speech and mental disabilities and their families, we will be able to build a categorized oral history database and eventually develop a comprehensive database of the lives of persons with disabilities in China. This will contribute to a very good qualitative supplement to the government's digitalized database of persons with disabilities and will definitely facilitate the inclusion of persons with disabilities into society. If

databases on the lives of persons with disabilities are built in other countries and regions, people can exchange success stories and learn from each other on a global platform of collaboration, and work together to drive efforts for persons with disabilities to build a more civil world. This is truly exciting to envision.

Shanghai, China

Mei Liao

Translated by Cissy Zhao

Edited by Andy Boreham and Zijian Chen

Contents

Getting Involved in Society	1
Xiangmeng Huang	
I Will Raise Him Up	27
Zhuojun Zhang	
Once a Supermarket Cashier	59
Yi Zhang	
Find the Courage to Face the World	99
Mei Liao and Zian Li	
A Compilation of Aid Policies for Persons with Intellectual Disabilities in Shanghai City	133
Mei Liao	

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. Professor Alford's 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 the 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.

Fengming Cui serves as the director of China Program at Harvard Law School Project on Disability. She is also an adjunct professor at China Renmin University School of Law, an honorary professor at the Nanjing Normal University of Special Education in China, and a senior fellow of China Renmin University Disability Law Clinic. Her main scholarly interests, academic, and public interest work focus on issues of comparative disability rights studies, disability laws, and policies in China; rights in inclusive education, employment, and community for persons with disabilities; family involvement and system support; and the development of civil society for equal participation and general social development. She is an editor for *Legal Rights for Persons with Disabilities in China: A Guide Book* (China Renmin University Press, 2016, both in Chinese and English, with JianFei Li et al.). Her book chapters and journal articles cover topics concerning inclusive education, equal participation of disabled persons' organizations and parent organizations, and rights in employment for persons with disabilities in China. She holds an Ed.M. in higher education from Nanjing University in China and an Ed.D. in special education from Boston University in the United States.

Getting Involved in Society



Xiangmeng Huang

Self-realization Through Work—Interview with Mr. ZL¹

ZL, male, born in 1982. The only child in the family. Grade IV intellectual disability. Graduated from a special education school. Now working at Shanghai Papa John's.

Interviewee: ZL

Interviewer and writer: Xiangmeng Huang

Interview dates: September 25 and October 16, 2016

Interview place: The restaurant where he works.

Lisp not Taken Seriously, Optimal Treatment Time Missed

Q: The purpose for today's talk is to know something about your daily life, chronologically from your childhood first. Just tell me what you remember. It doesn't matter if you can't remember, so take it easy.

ZL: Okay, so from childhood?

Q: Yes. What is the year of your birth?

ZL: 1982.

Q: Are you Shanghainese?

ZL: No, I'm from Jiangsu.

Q: When did you come to Shanghai?

¹ZL's father indicated that he had no time for the interview because he was busy between work and caring for his 90-year-old father. He believed that ZL's communication ability was good enough for him to be interviewed independently. So his family series only includes interviews with ZL himself and his colleagues, as well as observation of his work.

X. Huang (✉)
Fudan University, 220 Handan Ro, Shanghai, China 200433

ZL: To Shanghai, I came to Shanghai when I was 7 years old.

Q: Seven years old, with Mom and Dad?

ZL: Yes.

Q: Did your mom and dad come over here for work?

ZL: My parents worked in Shanghai, and they had no time to take care of me. So I was taken back to my grandparents in my hometown.

Q: Oh, you were brought up by your grandparents?

ZL: Yes. Then I was brought back to Shanghai for schooling when I was seven.

Q: Did you go to kindergarten in Jiangsu?

ZL: I went to kindergarten in Puxi, in Minhang District.

Q: Minhang District, so that means you went to kindergarten after you came to Shanghai?

ZL: Yeah.

Q: That's after you turned seven.

ZL: Yes, after I turned 7 years old.

Q: When did you stay at kindergarten 'til?

ZL: I can't remember that.

Q: Do you still remember when you went to elementary school?

ZL: If I remember correctly it was when I was about 8 years old.²

Q: You spent your childhood with your grandparents, so do you remember some impressive stories from your hometown? Something interesting, or sad, or anything.

ZL: My grandparents also took care of me here in Shanghai, and they did very well. However, my grandpa was not used to living in Shanghai, so in the end they went back to their hometown.

Q: Oh, I see. What kind of jobs did your parents do?

ZL: My mom used to do cleaning work and my dad worked as sales rep of a machine packaging business in Puxi, Minhang District.

Q: Oh, your father was a sales re— (before the interviewer had finished, ZL gave the answer in a very eager manner)

ZL: —and my mother did cleaning work.

Q: Do you still have any memories about things that happened in kindergarten?

ZL: No memories, that was a long time ago.

Q: What about your elementary school?

ZL: Little memory about my elementary school, either.

Q: When was it detected that your intelligence might be flawed?

ZL: For that, it seemed to be when I was 10 years old, or 4, or 5, or 7 years old? Should be at the age of ten. I used to be good, except for my lisp, good in all aspects, and I was talkative, too.

Q: Okay, you were good in all other aspects, except for the lisp.

ZL: Yes, all good.

Q: This problem was noticed when you were 10 years old, right?

²ZL cannot remember his age of entry into elementary school, so there's a discrepancy in his answers on this point, but based on his answers, we can roughly conclude that he stayed at kindergarten for 1 year at about seven, and then started elementary school at about eight.

ZL: Yes, but it was already too late due to my parents' negligence, in the end it was too late.

Q: Were you then taken to the hospital for a check-up to find out the cause of your lisp?

ZL: No.

Q: Did your mom and dad take you to treatment for your lisp?

ZL: No. They would take me to see a doctor when I felt sick and uncomfortable.

Q: Just for common illnesses?

ZL: Common illnesses, cough, cold, and so on.

Q: Why didn't your parents take you to treat your lisp then?

ZL: Because it was late, really late.

Q: Have you ever been taken to the hospital to confirm if there was hope of a cure? Or did your parents think it was already too late?

ZL: It was confirmed, too late.

Q: Oh, already confirmed, and the doctor told you it was too late?

ZL: Yes, the doctor said it was too late.

Q: Did you do an IQ test then, in the end, to confirm it was a defect in your intelligence?

ZL: Yes, it was done when I was in junior high school or senior high school, identified in school, and I was given a certificate of disability.

Q: Could you recall if it was in junior high school or senior high school?

ZL: I can't remember, it was a long time ago.

Q: When your lisp was identified, and some issues were confirmed, how did your parents respond to that? Any big fluctuations in their moods?

ZL: No, because it was too late by the time it was identified.

Q: Did your parents show any sign of sadness?

ZL: No, no.

Q: Was this condition told to your relatives?

ZL: Our relatives all live in our hometown, and we only go back when something comes up; otherwise, no.

Q: So it was only you and your parents living in Shanghai?

ZL: Yeah. My grandparents also live in our hometown, and they don't come over here.

Excelling at Study and Enjoying Activities at Special School

Q: Did you get to school yourself or were you taken by your parents?

ZL: My parents took me to school when I was 7 or 8 years old, and then I went to school by myself after I turned eleven.

Q: Would your parents supervise your study? Say, check your homework?

ZL: No, there was no need for that.

Q: Do you remember how long you studied at elementary school? Was it 6 years?

ZL: Nine years, because ours was a special school, from 1991 to 2003, 2002 or 2003, I don't remember, anyway, a total of 9 years.³

Q: You studied at a special school directly?

ZL: Yeah, Lujiazui Special School, and I've never been to a general school.

Q: You went directly to a special school for special children?

ZL: Right.

Q: Just now, you said your lisp was not noted until you were 10 years old, then why were you sent to a special school directly, but not a general elementary school first?

ZL: No, I used to study at a general school, then I was transferred there.

Q: Oh, you were transferred there later.

ZL: Yes, transferred, to that special school.

Q: How long had you been studying in that general elementary school?

ZL: For 2 or 3 years, then I couldn't go any further, so I was transferred to the special school.

Q: Oh, so you mean, it's not that you've never been to a general elementary school. You actually studied there for 2 or 3 years, and then it was found that you could hardly keep up with the class in that kind of school because of your difficulties in expressing yourself, so you were transferred to the special school, right?

ZL: Right.

Q: During the 2 years at the general elementary school, did you find the lessons too hard for you to keep up?

ZL: No, it was just the lisp.

Q: Did you make any good friends at that time?

ZL: All of us kids played together, and I have very good memories of that.

Q: Did you have any good friends during the 9 years at the special school?

ZL: Yes, some classmates went out for fun together, something like that.

Q: Are you still in touch with them now?

ZL: Not anymore, not after I went to work.

Q: What were the main courses taught at the special school?

ZL: All kinds of courses: Chinese language, mathematics, sports, and cooking, too, you name it. We had classes Monday through Friday, and art class as well.

Q: Compared with general elementary schools, what additional courses were offered to you? You just mentioned cooking. Were there any other courses similar to that?

ZL: Yes, cooking, I completed a cooking course, and I have a cooking certificate. Our school specifically taught us how to cook.

Q: You even have a cooking certificate! You must have learned it very well.

ZL (Hearing compliments, ZL was slightly shy): I might have forgotten what I learned a long time ago—apart from cooking some simple dishes at home, I probably forgot everything about the other dishes.

³In ZL's answers, what was consistent was 9 years at the special school, so here ZL might be wrong about the exact number of years, or he might have included in the first 2 or 3 years in the general elementary school.

Q: Were there any other special courses in addition to cooking?

ZL: I think there were no more, only cooking.

Q: Did your school organize some activities for you? For example, taking you to shows and things like that?

ZL: No, but we had sports games, and I participated in many sports programs.

Q: What was your favorite course?

ZL: I like both mathematics and PE, and I was good at them. I wasn't good at Chinese language, though.

Q: You were very active at sports games?

ZL: Yes. By the way, we also had labor skill class. I was very active in those classes, too. I was also active in activity classes. However, the details I've long forgotten, and I haven't been back to the school ever since.

Q: Were there any organized outings in spring and fall?

ZL: Yes there were, in both spring and fall.

Q: Where have you been?

ZL: We've been to Jinjiang Amusement Park three times and Shanghai Zoo several times. There are some other places, but I can't remember. Also, we sometimes went out for fun ourselves.

Q: Did you have any favorite teachers?

ZL: Too many of them: one was our class teacher, and another one was an art teacher. My mathematics teacher was one of my favorites too, according to my memory.

Q: What did the class teacher teach?

ZL: Chinese language. There was also a math teacher and a music teacher, both of whom are very good.

Q: Why did you like them?

ZL: Because they were nice, and their lectures were also very good.

Q: What were your grades like?

ZL: Well, my grades were below 90, about 80ish.

Q: How did you get along with your classmates? Were you on good terms with them?

ZL: We were like cats and dogs, but on the whole, we got along all right. We were all similar kinds of people.

Q: Oh, the students were mostly similar to you, so easy to get along with?

ZL: Right.

Q: Were the teachers strict with you?

ZL: The teachers were not very strict with us, as long as we studied hard.

Self-reliant, Diligent, and Proactive, Taking Initiatives on the Job Market

Q: When did you start working?

ZL: Work? You mean here or somewhere else?

Q: Your first job.

ZL: If I remember correctly, I got my first job in 2004, oh no, it was the job in a factory in 2001.

Q: Was it a fast food restaurant, too?

ZL: No, no, I started working at Papa John's in 2006. I worked in a factory at first, and later I also worked in Carrefour as well as Lotus Supercenter.

Q: What did you do in the factory?

ZL: What the factory produced was mineral water, called Sparkling,⁴ and my job was to deliver water to customers. I can't remember the address of the first factory. It was relocated later, so I don't remember.

Q: So the first job was delivering water?

ZL: Yes, I worked 3 years delivering water, then our factory moved. Since I lived in Pudong, it was inconvenient to go there, so I quit.

Q: What about the jobs after that? How long did you work for them?

ZL: I worked at Carrefour for 2 years, and at Lotus for a year.

Q: What were your duties at the supermarket?

ZL: Goods handler.

Q: For both supermarkets?

ZL: Yeah, goods handler for both supermarkets.

Q: Did the special school teach you some professional skills?

ZL: No, they didn't, I got the skills myself.

Q: So you started working directly after graduation from the special school, without going to any vocational schools?

ZL: Right.

Q: Was there any period of time when you stayed at home without working?

ZL: No, I don't want to sit idle at home, which is so meaningless. I don't like it.

Q: Did you just look for jobs based on job recruitment information?

ZL: The first job was recommended by the Disabled Persons' Federation, but I got the next two at supermarkets on my own.

Q: How did you find the jobs at the supermarket on your own?

ZL: I went to an employment agency, found the job positions and went for the interviews.

Q: Oh, you went to the employment agency yourself, saw the employment information of the supermarkets, and then you went to the supermarkets for interviews on your own?

ZL: Yes.

Q: Later did you get the job at Papa John's on your own, too?

ZL: It was on my own.

Q: Through which channels did you find it on your own?

⁴A drinking water brand.

ZL: No, no, I got this job myself—I just got it at Papa John’s Dongchang Restaurant on my own. I went to the restaurant for the interview, and then started working. I got it on my own.⁵

Q: You went straight to the restaurant?

ZL: Yes, I went to the restaurant.

Q: Then you asked them if they were recruiting employees there?

ZL: Yes.

Q: Have you been working only at this fast food restaurant in Pudong?

ZL: No, no, I first worked in the restaurant on Dongchang Road for 2 years, then worked on Huacheng Road until it was closed in 2015, and then I came here. I was transferred over here.

Q: Which job do you like better?

ZL: Papa John’s. Actually, the others weren’t bad, either.

Q: All of them were not bad? What are your main duties at Papa John’s? Did you have the same duties at all the restaurants?

ZL: Exactly the same, the water bar, delivery, and all other things.

Q: What is the water bar for?

ZL: It’s just over there (showing the interviewer by pointing at it), making drinks.

Q: I see. Do you make snacks in the kitchen?

ZL: Yes. Sometimes when we are understaffed, I will go to help out making snacks.

Q: It seems that you worked in many different positions. You would help out wherever hands are needed, right?

ZL: Right.

Q: Was there any professional training when you first came on board at the fast food restaurant?

ZL: Yes, at the first restaurant, I received training about how to make snacks, about the water bar, but not for delivery, since I already knew how to deliver goods.

Q: Do you think the training was too hard? Did you learn fast?

ZL: Not very hard, and I learned pretty fast.

Q: You took the initiative to look for the job, and you weren’t urged by your parents?

ZL: Right. My parents would be happy as long as I have work to do. I myself didn’t want to stay at home, because it was so boring.

Q: What was your personality like in your childhood, introverted or outgoing?

ZL: I was a very lively person.

Q: Always lively since childhood? Or did you become so after you grew up and started working?

ZL: That’s not something I could choose—I was driven to be like that by work.

Q: Does that mean there are changes in your personality?

ZL: Yes, after I started working, I became very open.

Q: Oh, after you started working, you became a more cheerful person?

⁵Here ZL might have mistaken “through which channels” for “through personal relationships”, so he emphasized repeatedly that he found the job on his own.

ZL: Cheerful, working happily, very cheerful, talking and laughing. I get busy when my colleagues are busy, and when we are not so busy, we make some jokes.

Q: Why were you not so cheerful at school?

ZL: Because I was under the control of my school teachers.

Q: Do you have a pretty good relationship with your colleagues?

ZL: Pretty good, but sometimes we might argue about work.

Q: Argue about what?

ZL: There may be an argument when there's a mistake, not a big argument, though.

Q: Have you ever thought about changing your job?

ZL: No, I don't want to—I've been working here for 6 or 7 years. I can't pretend that I don't love Papa John's. There is a bond, really.

Shy but Longing for Love, Hard to Find Mrs. Right Through Matchmaking

Q: Have you ever dated a girl?

ZL: Yes, but they were not a good match, too tall.

Q: Are you too tall or are they too tall?

ZL: I am too tall.

Q: Oh, not a good match, but who made the match?

ZL: My mother, or someone from my hometown or my auntie. Anyway, I am too tall.

Q: Oh, so you are too tall. What kind of girlfriend are you looking for?

ZL: No idea.

Q: Do you want to find a girlfriend?

ZL: Yes, of course. But I haven't found anyone suitable.

Q: Not found up until now?

ZL: Right.

Q: Have you ever dated a girl?

ZL: Yes, I dated a couple of girls, but we broke up in the end, and neither of them had jobs, which means I had to support them.

Q: Those girls you dated were all arranged by matchmakers?

ZL: Yes, by matchmakers. Because I had no ... I was a very lively boy, but my mother said I was very introverted and inarticulate.

Q: Okay, according to your mother, you are introverted. And as an introverted person, you don't know how to talk to girls, so girls broke up with you.

ZL: It's possible.

Q: What kind of girls was introduced to you by matchmakers?

ZL: All kinds of girls.

Q: Including girls without disability, who broke up with you later because you weren't suitable for each other?

ZL: Right.

Q: What are your parents' opinions on your frustration in the pursuit for love?

ZL: They have no opinion.

Q: (Laughing): No opinion?

ZL: It's meaningless thinking about it, and my parents told me to first work hard here and be happy with my work.

Q: You are working hard, aren't you?

ZL: I was delivering takeout orders when you came, and I just came back.

Q: Any possibility you could get lost when you deliver orders?

ZL: What?

Q: Do you know your way all the time?

ZL: Yes, how could I not know my way? When an order is taken, there's always an address, very simple, I never get lost. I know my way very, very well.

Q: When you deliver the orders to the customers, how do you communicate with them?

ZL: This is very simple, so here is the delivery order, and there's a mobile phone number on it. I would say, "Hello, this is Papa John's delivery, I'm on the first floor, please come down for it." Or I'll press the doorbell and say "hello". The customer will answer, and then I will say, "Miss, this is Papa John's delivery, please open the door."

Q: Okay, sounds good.

ZL: Yes, as easy as ABC.

Q: When the order is delivered, is it still hot?

ZL: Yes, it is hot—hot and delicious.

Q: Will you tell this to the customers?

ZL: Yes, I will say to them, "Madam or sir or miss, this is your delivery. Please enjoy it while it's hot. Bon appétit!"

Q: If you can do a good job, you can always find a girlfriend. What about your classmates and friends? Have any of them found their love or got married?

ZL: I already stopped hanging around with them. Why? Some of them don't work. They would simply come to play with me, but I do not want to hang out with them.

Q: Classmates from which school?

ZL: Elementary school.

Q: Do you have brothers or sisters?

ZL: No, only me.

Q: What are your interests and hobbies?

ZL: Too many of them. I love watching soccer and reading newspapers. I love every aspect of sports. I love watching the World Cup and the America's Cup, as well as the Olympic Games and the Paralympic Games. I watch all sports programs.

Q: You also watched the Paralympics?

ZL: Yes.

Q: Did you take part in Special Olympics in your school?

ZL: No, I didn't.

Q: You work hard and have a wide range of hobbies. I'm sure you'll be able to find your love.

ZL (Sighed): Hey, but reality is reality.

*Translated by Si Zheng
 Edited by Andy Boreham and Zijian Chen*

The Internet Broadens My World—Interview with Mr. D⁶

D, male, born in 1987. The only child in the family. Grade IV intellectual disability. Graduated from a special education school – Shanghai Primary Vocational and Technical School. Now working at Shanghai Papa John's.

Interviewee: Mr. D

Interviewer and writer: Xiangmeng Huang

Interview dates: September 25 and October 16, 2016

Interview place: Restaurant where he works.

Lifelong Pity After Falling Down the Stairs

Q: First of all, please give us a brief introduction about yourself. How old are you this year?

D: I am thirty-one this year, or thirty.

Q: In which year were you born?

D: 1987.

Q: Are you Shanghainese?

D: My hometown is Wuxi, so although my father grew up in Shanghai, my origin is Wuxi.

Q: Did you grow up in Shanghai as well?

D: Yeah.

Q: Are you the only child in your family?

D: Yes.

Q: Your parents know about this interview, right?

D: Yeah, they do.

Q: Why don't they want to be interviewed?

D: They are busy with family matters, so they don't have time.

Q: I'll ask you some questions mainly in chronological order, from your childhood to...

(The interviewer began to cough because of a cold, and D kindly expressed concern).

⁶D's mother indicated that she had no time for an interview because she was too busy with work. She believed that D's communication ability was good enough for him to be interviewed independently. So his family series includes only interviews with D and his colleagues, as well as observation of his work. Since D and ZL work in the same restaurant, interviews of their colleagues and observations of their work are combined and are placed after ZL's interview.

D: Drink some water first.

Q: Thank you. Please answer as much as you can remember, just like an everyday chat. You were diagnosed with...

D: No, it happened when a neighbor was babysitting me. At that time, I was a little child just learning to walk, then I fell down from the sixth floor to the fifth floor, rolling down the stairs.

Q: And something was detected after the fall?

D: Yes.

Q: It's not congenital?

D: Not congenital.

Q: How old were you, approximately, at the time?

D: About a year old; anyway, it was when I had just learned to walk.

Q: How did your parents negotiate with the neighbor later?

D: At the time I didn't get checked up. I slept a few hours after the fall, and no problem was noticed at the time.

Q: When did you go to the hospital for a check-up?

D: There were no CT or X-rays in the 1980s, and no one knew about them. I did some physical examinations when I was a child, but everything was normal, except for brain response... poor coordination, but nothing serious.

In the 1990s, when things became more developed, my parents consulted doctors everywhere about my condition, but they all said it was nothing serious. Then we stopped bothering about it. After I went to school, however, they said my IQ was not high.

Q: You have a certificate of disability, right? It is a proof of disability check.

D: No, no, we didn't do the check.

Q: You didn't do the check? Then how could they determine that something is wrong with your intelligence?

D: When I was in elementary school, I did very poorly in my study. I could hardly keep up with my classmates. Because of that, I did an intelligence test, the score of which was very low. Later, when I was in the third grade, I failed in the exam so I was held back a year. After I finished the fifth grade, which was the last year of elementary school study, my mom was concerned that I might go astray in high school, so she sent me to a special school for persons with ID. Since all fifth-graders had to take an intelligence test for enrolment into secondary schools, we got a certificate then.

Q: So the certificate of disability was given by the special school?

D: Yeah.

Q: What are your parents' occupations?

D: My mother is retired now, but still working part time for others; my father is a driver.

Q: What about before, when you were born?

D: The same. My father has always been a driver, and my mother was an accountant before.

Q: Do you know who gave you your name?

D: My name? Before my sister was born, I was the sixth kid in our family, and the number “six” means “happy”, as “six” in Shanghai dialect sounds like “happy”, right?

Q: You must be the sixth kid in the extended family, right? Those who were born before you are your cousins, aren't they?

D: Yes, cousins, and “six” sounds similar to “happy” in Shanghai dialect.

Q: How many cousins do you have?

D: If I remember correctly, I have one maternal cousin, one paternal cousin, lots of older female cousins, and two younger female cousins, plus one paternal and one maternal.

Q: Many older female cousins? How many of them?

D: Lots—I'm not sure of the exact number.

Q: Among these relatives, who are you on good terms with?

D: I'm on better terms with my older female cousin.

Q: Do you often drop by her place?

D: I often sing karaoke and go to the movies with my elder female cousins.

Bittersweet Schooling Years

Q: Who mainly took care of you when you were a young child?

D: It was mainly my auntie, since my parents were pretty busy.

Q: Did you go to kindergarten or just stay at home?

D: I went to the nursery first, and then kindergarten.

Q: How old were you when you went to kindergarten?

D: Normally it would be, you know, about four as a child... I can't remember very clearly, because it was a long time ago.

Q: So you went to kindergarten at the normal age, right?

D: Yeah.

Q: How old were you when you started elementary school?

D: I had a critical disease when I was young, so I probably started elementary school at 8 years old, eight or nine.

Q: What are your impressions of your childhood? For example, was there anything that made you particularly happy or sad?

D: Happy things include going out with classmates singing, playing, and the best memory would have to be hanging out with a bunch of buddies who have been very good friends of mine ever since childhood; the bad moments were basically when my parents beat me.

Q: Why did your parents beat you? For being naughty?

D: For not being serious with my homework—my parents were usually informed by my teachers, or something like that.

Q: You were held back for a year in grade three?

D: Students like me could join Learning in Regular Classroom (LRC) in those days,⁷ and I hated one of my teachers, because that teacher didn't have a good impression of me.

Q: A teacher of what subject?

D: Mathematics. The relationship between the Chinese language teacher and my parents was also, um, well... (the interviewee did not speak clearly here). Later it turned out not good, so I was held back for a year.

Q: The Chinese language teacher did not have a good relationship with your parents, either?

D: No, their relationship was good, but the math teacher did not agree, because our class was a key class.

Q: At that time the class teacher was that math teacher?

D: No, it was the Chinese language teacher, but the math teacher was the deputy associate class teacher.

Q: He thought you could not keep up with the class, and wanted you to be held back for a year?

D: Yeah.

Q: And your parents communicated with him at the time and then agreed?

D: Right.

Q: What subjects were your favorites, and what subjects were hard for you when you were in elementary school?

D: When I was in elementary school, my math was good but my English wasn't. In the 1990s, I just started English when I was in grade three, so basically I wasn't good at all. I think I was better at science and other subjects.

Q: A little bit partial to the sciences?

D: No, no, what we learned in our time was different from what you would have learned, it was math and that... I can't remember clearly. Our textbooks were not the same as yours. We had H version and S version,⁸ with slightly different content. You can search online for more information. S version was relatively easier while H version was more difficult, and at that time we used H version.

Q: So it was not easy for you to keep up with the class, right?

D: Our class was a key class, and our teachers gave us more homework than others. Sometimes I couldn't turn in my homework, and when our Chinese language teacher learned about that, he gave me a telling-off over it.

Q: So, the content was difficult to learn, plus the workload was too much?

⁷Learning in regular classroom (LRC) refers to a policy of allowing some children with special needs, like those with physical disabilities, mild mental disabilities, amblyopia and hearing impairment and other disabilities, to learn in mainstream classrooms.

⁸⁸In the mid-1980s, the Chinese government allowed the implementation of a "multi-syllabus and multi-course books" or "one syllabus with multi-course books" policy for some disciplines in some regions; that is, either multiple syllabuses or a single syllabus could be adopted, on which basis a variety of course books could be developed. In Shanghai, two series of Chinese language textbooks were published as an endeavor of the curriculum reform. H version was developed by East China Normal University and the Education Bureau of Xuhui District, while S version was developed by the Shanghai Petrochemical and Education Bureau of Zhabei District.

D: Right.

Q: When we were young, we had a course called natural sciences. Did you have that course?

D: Yes, I was better at natural sciences.

Q: Oh, so you were better at natural sciences and math?

D: Right.

Q: Then why didn't you have a good relationship with the math teacher?

D: Because the math teacher was more demanding, and I was the second worst student in the class, so he did not want me to drag down such a good class.

Q: Was your elementary school for 5 years?

D: Yeah.

Q: So you were held back for a year and then you continued into your fifth grade?

D: When I was in the fifth grade, I remember we graduated from elementary school in 2000, but I can't remember clearly. After graduating from elementary school, I continued to study at a special school for the students with ID for several years, and then after that we were recommended to a vocational school, where we studied for 4 years and then graduated in 2004.

Q: How long did you study in the special school?

D: I can't remember clearly, a couple of years, probably 3 or 4 years, it must have been 3 or 4 years, I can't remember clearly.

Q: After graduating from the special school, you went to the vocational school, right?

D: Yes.

Q: What were the differences between special schools and general schools?

D: What we learned was very easy, but now I have forgotten everything. Mathematics was very easy. We just learned addition, subtraction, multiplication, division, approximation, and so on, all pretty easy.

Q: What were the other courses offered?

D: Just Chinese language, mathematics and art. There was no English. Pretty much the same as the general schools, but the content of learning was relatively easy.

Q: Was there a course like crafts offered to you?

D: At that time no, but I guess it is offered now. We were among the first ones to go to that school.

Q: What kind of extracurricular activities did you have at the special school?

D: There were classes to develop your skills or hobbies, such as computer, painting, and sports, etc.

Q: Did you choose them yourself?

D: Yeah.

Q: Out of elementary school, special school, and vocational school, which was your favorite?

D: Vocational school, we learned more skills there.

Q: Oh, it made you happy to learn more skills, so what kind of skills did you learn at the vocational school?

D: Baking.

Q: Did you learn any other skills?

D: As for other skills, well, I also did some reading and writing. There were reading classes at the vocational school, too, but we didn't take them very seriously.

Q: Did you choose to learn baking yourself?

D: We were divided into different classes, such as cooking and baking. I had no idea why I was assigned to that class.

Q: It was a random assignment, not your own choice?

D: Right.

Q: Were there any extracurricular classes in your vocational school?

D: Our vocational school always had confidence in me, so I was given opportunities to take part in many activities. Basically, I was included in almost all activities.

Q: What were the activities that your school took you to?

D: I remember before Special Olympics there was the countdown moment, so the school organized a group of people to go out for that event. Liu Xiang and other celebrities were present, and Han Zheng⁹ came for a meeting. We were told to welcome him and shake hands with him. It was held at Hongqiao Airport, and the whole activity lasted 2 or 3 days, I remember.

Q: You had the opportunity to shake hands with the mayor?

D: Yes. After a period of time, that is, when we were approaching graduation, there was the opening ceremony of a certain exhibition, and I was told to hold the school sign in the front.

Q: Oh, holding the school sign. Did you also participate in any performances?

D: No performances, though.

Q: Did your vocational school organize any other activities, like outings in spring or fall?

D: There were some for sure, but I can't remember those long-past activities very well. We had a spring outing, just for fun, and we did not have many places to go to, so it was either the forest park or somewhere else, just some places like that.

Q: No deep impression?

D: No deep impression.

Social Life and Brotherhood

Q: I saw some photos of your elementary school classmate reunion in your WeChat¹⁰ moments.

D: Photos taken at a reunion a long time ago, in the 2000s.

Q: Is it that long? Are you still in touch with your classmates from elementary school now?

D: Basically yes, because we were a bunch of very good friends, pretty close.

⁹The mayor of Shanghai at that time.

¹⁰WeChat: A popular multi-function social media app in China.

Q: Chatting with you so far, I think your overall condition is relatively good, and your intelligence grade and communication skills are also good. Did you have any difficulties getting along with your classmates simply because of intellectual problems when you were young?

D: No.

Q: Normal social life?

D: Yes, because they had no idea of my condition when we were young. They didn't know until I went to the special school, and we've always been close, like brothers.

Q: So your problem was mainly that you had difficulty with exams and study? No other issues except that? And nothing was noticed in your social life?

D: Right, no one noticed.

Q: When your intelligence test result turned out to be not as high as that of other children, how did your parents respond to that?

D: My parents didn't care. They didn't take it seriously. My parents' concern was that I might go astray in junior high school or senior high school, so I was sent to the special school, and I didn't care much about it. Study at the special school was relatively easy, with not much pressure, so I just followed my parents' decision.

Q: Did they show any sadness or frustration?

D: Nah.

Q: They were both very calm?

D: Yep.

Q: How about your interpersonal relationships with classmates, since childhood...

D: We were like brothers, so the relationship with my friends was pretty good.

Q: Are there any friends you are still in touch with?

D: Yes, there are.

Q: Were you ever been bullied or isolated at school?

D: Yes, I was bullied when I was young, but our class was united like one, and no matter who was bullied, we would come out to fight for him or to settle with a duel, and that's all.

Q: Oh, classmates would help you fight? Were you bullied because of your grade of intelligence? Or was it simply some kids fooling around?

D: Just kids fooling around, like my pencil box being stolen by someone from another class, and boys of our class would go look for him to cause trouble.

Smooth Work After Entering Workforce

Q: When did you start to work? As soon as you graduated from the vocational school?

D: After graduation from the vocational school, I was assigned to a hotel for an internship, and after about half a year, I was assigned to another hotel for another internship, then I started working there. A year later, I quit the job because of frequent overtime without much pay.

Q: So you often worked overtime but didn't get much pay?

D: Too tiresome.

Q: Did you get the job at Papa John's yourself?

D: No. After I quit at the hotel, I went to a training center. After being trained for about 2 months, I went to another hotel through referral by my mom's friend. After working there for a while, I came back to the training center, where I found out that Papa John's was recruiting, so I registered, and then an interviewer came to interview us.

Q: So after you went to the training center, you went to work at another hotel through recommendation by your mom's friend?

D: Right. That job was also rather tiresome, so I quit and went back to the center. Just then Papa John's came to interview candidates, I registered, and then they picked me at first sight.

Q: Picked at first sight. That's impressive. What did you do when you worked previously at the hotels?

D: I worked in different departments. In both of the hotels where I worked as an intern, I had the experience of working in the laundry. Later, I was also assigned to the kitchen for butchering.

Q: You were assigned to different departments and then you learned the job requirements along the way?

D: Right.

Q: What job did you like most, in general?

D: I still think it's more comfortable to work in a hotel.

Q: Didn't you say that it was very tiresome just now?

D: Mainly because I was used to hotel work. After I came to Papa John's, I think it is very comfortable working here as well.

Q: So, what are your main duties here?

D: Making snacks, and just now you saw me busy making snacks over there, right?

Q: Yes, I did. Only making snacks? Nothing else?

D: Right.

Q: What are your working hours now?

D: Usually nine to six, sometimes ten to seven.

Q: Basically 8 h.

D: Right. From Monday through Friday. Sometimes when it's busy, I'll be asked to come and help out for half a day on Saturdays and Sundays, for about 3 to 4 h.

Q: Have you worked at any other stores of Papa John's before?

D: Yes, I have. Actually, I was transferred over here from another store, so in total I have been working here for almost... um, more than 2 years roughly.

Q: How long had you worked at the previous store?

D: Half a year there before I came here. I was transferred here because more hands were needed at this store.

Q: What do you think of the work environment and atmosphere here?

D: For our team here, and “team” is the word we use, cooperation and relationships are all very good.

Q: All very good, and you are all getting along very well with each other?

D: Very well, like brothers.

Q: Are there any recreational activities with colleagues?

D: No, we are always very busy here. Sometimes we have dinner together at night, like a dinner party, but very rarely.

(Then the interviewer coughed again, and D expressed concern one more time)

D: You’d better take some medicine.

Q: Okay, thank you. I’ll take some when I go back home.

Strict Parents and Harmonious Family

Q: Your parents have been strict with you since you were a child, right?

D: Yes, they have, always.

Q: Both Mom and Dad are very strict?

D: Yeah.

Q: When you could not keep up with your study, did your parents show any impatience with your education?

D: No, they are just fine. My parents’ temperaments are not bad, though they are strict and demanding.

Q: Would they stay with you or supervise you when you did your homework?

D: Sometimes they would, and sometimes when they were busy, it would be up to me to have self-discipline. If I couldn’t control myself, they would stay and supervise me.

Q: They beat you mainly because you didn’t behave?

D: Yes. Boys are more mischievous, you know, and girls are relatively quiet. Boys tend to be troublemakers when they are young.

Q: I believe your father and mother are always busy with their work, aren’t they?

D: Yes.

Q: Did they often take you out for fun when you were young?

D: My parents were so busy with work that they didn’t have much free time, so it was my relatives and friends who would take me out.

Q: Who usually took you out?

D: My auntie and others. Whenever she was free, my auntie would take me to travel, to places nearby, for example Wuzhen.

Q: Generally speaking, what was your personality like when you were young?

D: Very ordinary, nothing special. I think my personality is very common, that’s it.

Q: Are you introverted or outgoing?

D: I don't know.

Q: Do you think that falling down the stairs would have affected your personality in some way?

D: Well, I don't think there's been any major impact as a result of that.

Q: Did you feel any change in your personality when you grew up, shifting from school life to work?

D: Nothing special, I'm still the same person.

Q: When your grade of intelligence turned out a little bit low as shown by the test, did you tell your relatives about that?

D: No, my relatives didn't care, so nothing to tell them about.

Q: Did your parents ever mention this to them?

D: They didn't mention it because nothing was noticeable in me when I was young.

Q: What about now? Do they know it?

D: No, things just remain the same as before.

Q: Oh. There's no need to talk about it specifically because nothing is shown, right?

D: Right.

Q: Have you ever experienced a rebellious period, having constant conflicts with your parents?

D: There was nothing serious about my rebellious period, just refusing to do homework, refusing to listen to my parents, not giving them things when they demanded, coming home late, hanging out with friends and staying very late, things like that.

Q: That was when you studied at the elementary school?

D: It was at the special school. When there were extracurricular activities, I would be back home half an hour late.

Q: Do you now live by yourself or with your parents?

D: With my parents.

Q: Do you keep the money you make or give it to them?

D: I give all the money I make to my parents.

Q: All to your parents, and your parents will give you some pocket money?

D: Sometimes yes, sometimes no.

Q: What if you want to go out to have some fun?

D: I will tell my parents in advance.

Q: What do you usually talk about with your family?

D: Generally, we just talk about what work is like. Nothing in particular. Usually we watch some TV after dinner. That's all.

Q: Do you live far from here?

D: It's okay, not too far. It takes me a little more than half an hour to come here.

Q: You have no difficulty finding your way here, right?

D: Right, no problem.

Wide Range of Interests Including Internet Surfing

Q: What do you usually do in addition to work? When I read your WeChat Moments with friends, it seems that you like to go to a variety of exhibitions, to the movies, to CJ,¹¹ etc.

D: Because I quite like to hang out with my friends, for instance going to play tabletop games.

Q: What kind of friends do you like to hang out with when you are free?

D: There's a group of tabletop game players online, and they organize activities every Saturday. I go out with them.

Q: Oh, a group of tabletop game players. How did you join this group?

D: I saw it accidentally via a mobile QQ group, and was interested in contacting them.

Q: Do you hang out with your former classmates?

D: Rarely with classmates now, because most classmates from elementary school are already married. We occasionally chat on QQ, but we rarely meet.

Q: What are your hobbies?

D: I have a wide range of interests: tabletop games, anime and comics, movies, listening to music, games, surfing the Internet, watching basketball, hanging out and having dinner with friends, singing karaoke, etc.

Q: What kind of people would comment or like your WeChat Moments?

D: Just a bunch of friends. I don't care about that.

Q: Are they mainly friends and former classmates, or online friends?

D: Friends. Some of them are former classmates, and some are online friends.

Q: In addition to the tabletop game group, have you joined any other groups online?

D: The game group when I played games before, online game group and a group of YY¹² friends. We chat every day from morning till night.

Q: What kind of friends?

D: Friends that I previously came to know through YY, who I would chat and play games with, like Truth or Dare and Tricky Brains, in addition to singing and chatting. I would chat with them until it was time for sleep, because there was nothing to do in the summer vacation.

Q: Summer vacation? That was when you were still in school?

D: When I was in the vocational school.

Q: Are you still playing online games now?

¹¹ Abbreviation of China Digital Entertainment Expo & Conference (nickname: ChinaJoy), one of the world's most influential digital interactive entertainment events, held in Shanghai in July each year.

¹² YY Voice was the first software providing voice communication to game teams. It has now developed into integrated instant messaging software with team voice, friend chat, video chat, application games, and other functions.

D: Much less than before. I usually play on Saturday and Sunday, except for the weekends when I end up working. Then I won't play online games, just mobile games.

Q: How easily do you accept new things? For example, how easy is it for you to learn new skills?

D: It's fine. I learn new things fast, and I'm a handyman. It's just that my memory is not so good.

Q: What do you think you are good at doing? And what are you not so good at?

D: I don't know what I'm not good at, and I've never tried to find out.

Longing for Love with Ups and Downs in Reality

Q: Have you ever dated any girls?

D: I've experienced a lot of romantic frustrations. I met my first love in 2007, and it lasted over 2 months before we broke up. People basically treat me like a person without disability. As long as the girl I like doesn't mind that I am a fat guy, I'll be happy. I'm a dedicated person.

Q: Where was that girlfriend in 2007 from?

D: Shanghai, a high school student, and I was 20 years old then. We met each other online.

Q: Oh, you met online, not through a go-between. You are impressive, able to find a girlfriend online.

D: I might not like a girl who's arranged by a go-between. I've dated about four or five girls, but my parents were not aware of them, because at the time I was still in school. Now I just want to find a girlfriend that I can get married with.

Q: So you met online and you dated offline?

D: Right.

Q: With all of the four or five girls?

D: Yeah.

Q: You met all of them first online?

D: Yep.

Q: How long did the longest one last?

D: Usually less than 2 months, the longest one about 6 months.

Q: What were the reasons for breaking up?

D: I'm a simple-minded person, too simple and too dedicated, just trying to keep her close to me, then she said that she wanted some space, and then we broke up.

Q: Did those girls know which school you were in?

D: They didn't know, and they didn't even ask. I would say that I graduated from a vocational school. Our school offers a technical secondary school diploma—I think I'm no different than other people.

Q: Were those girls high school students or already at work? Or a bit of both?

D: Both. A little while ago I met a girl from our school who's younger than me. I think she's good, and we are dating now.

Q: You met her online, too?

D: No, she is also a student at the special school. She is a little bit slow, but still like a person without disability—it's not obvious. Besides, she's a nice person.

Q: You are dating now?

D: Yes. I don't want to tell my parents about my romance, because parents are so annoying. They will keep asking me when I'm going to bring her back for them to check her out. I think parents can be summed up in one word: trouble.

Q: Do your parents know about your ex-girlfriends?

D: Why tell them? I just let my female cousins know.

Q: Oh, you only shared the news with your cousins?

D: Yeah. If I tell my parents, they'd just say, "What do you want a girlfriend for? Can you even support yourself with what you're making?" I think they're afraid that someone might take advantage of me or cheat me. They're afraid that I might run into some problems with romance.

Q: Some parents would love to be matchmakers for their children.

D: I don't like that. I don't want my parents to be matchmakers, and I will let them know when we are ready. After all, dedication is the most important thing in love and I don't care that much about appearance, as long as the girl is between 1.50 and 1.60 m tall and doesn't mind the fact that I'm fat. Her level of education doesn't matter much, either, high school graduate, middle school graduate, it's all okay. What I value is not the outside appearance, but inner beauty. As long as she is an honest person, a person with whom I can live my everyday life with, why bother scrutinizing so much?

Q: So that's why you don't want your mom and dad to do matchmaking for you?

D: Exactly.

Q: Have your mom and dad ever suggested they find someone for you?

D: They have, but I think love is something you make your own decisions in. Well, after having been fooled many times, I don't think too much about love.

Q: Can you explain how you got fooled?

D: I met someone online, then we decided to date offline. When we met in person, however, this someone turned out to be a man. I was so duped.

Q: Oh, you've even run into that kind of thing!

D: Later, we turned out to be good buddies.

Q: (Laughing) Oh, you became good buddies?

D: Yeah.

Q: What about now? Are you still in touch now?

D: Not now. After all, he's someone like me and younger than me. He pretended to be his younger sister when we first chatted online.

Q: He pretended to be his younger sister?

D: Yes. And I didn't know he was a man until we met in person later.

Q: Your experience was quite dramatic.

D: I believe dedication is the most important factor in love. People will come to understand each other anyway. That's why now I think a long-distance relationship is also fine for me. My family is not wealthy. We live in an old house, and I don't

have enough money. My wage is too low, you know, so girls may not be interested in me.

Q: So you have your own ideas in your quest for love?

D: Yes. Unlike ZL who loves soccer or something, my hobby is computing, sports, online games, and stuff like that. And I usually like to watch NBA.

Q: You are now dating a girlfriend, right?

D: Yes.

Q: Will you go to the movies with her when you are off work?

D: Her parents are strict with her, so we can only date and chat occasionally. I don't want to date too often, as you need money for dating, right? You've got to be very realistic now, have to, you know. Who wants to be with you if you have no money?

Translated by Si Zheng

Edited by Andy Boreham and Zijian Chen

Interview with a Colleague of D and ZL (I)

Interviewees: Store manager and kitchen staff

Interviewer and writer: Xiangmeng Huang

Interview date: September 25, 2016

Interview place: Restaurant where they work.

Q: What do D and ZL usually do in the restaurant?

Manager: D mainly makes snacks. From that window (pointing to the window between the kitchen and the dining area) you should be able to see him. ZL is mainly responsible for making drinks at the water bar and delivery. That's why he is not in the restaurant now, because he's out for delivery.

Q: Oh, how's their performance at work?

Manager: Pretty good. Both of them are quite serious with their work.

Q: Would they make any mistakes?

Manager: Occasionally they will, but not many. Everyone is capable of having a subpar performance if they're not careful enough, for instance using the wrong ingredient when they're too busy taking care of too many customers.

Q: Will you criticize them under such circumstances?

Manager: I will point it out to them, and tell them to be more careful next time. I won't give them harsh criticism, just remind them of their mistakes instead.

Q: What do you think of their personalities?

Manager: I think they are quite happy every day, and will join others if there is a chat. There is no big problem with D, and even if there is, it isn't obvious at all. The only problem with ZL is his lisp, but he has a straightforward and cheerful personality. Both of them are quite good guys and they are almost no different from us. They also work very hard.

Q: Oh, they will chat with others. Do they have frequent social interactions with other colleagues as well?

Manager: Um, we will chat together when we take a break, but for private interaction, I don't know much about it.

Q: Are they on good terms with others?

Manager: Yes, they get along with others quite well.

Q: Will colleagues ignore them because they have disabilities?

Manager: No no, we all have good relationships with each other.

Interview with a Colleague of D and ZL (II)

Interviewees: Kitchen staff

Interviewer and writer: Xiangmeng Huang

Interview date: September 25, 2016

Interview place: Restaurant where they work.

Q: How long have you been working here?

Co-worker: For 2 or 3 years.

Q: So you have known D and ZL for quite some time, right?

Co-worker: Right.

Q: Do you usually chat with them?

Co-worker: Yes, chatting, joking, that kind of thing.

Q: What do you usually talk about?

Co-worker: Just small talk about daily life, but I can't remember what exactly. Sometimes, for example, we may chat about a sports match we've just watched.

Q: Do you think they are easy to get along with?

Co-worker: Yeah, they're quite easy to get along with—we're like buddies. Sometimes we would play some jokes and pranks on each other. We are all very happy.

Q: Oh, what do you think of D's and ZL's job performance?

Co-worker: Both are okay. They are quite serious with their work.

Q: Just now ZL said that sometimes there might be an argument over work?

Co-worker: It's not an argument really. It's just that we would talk at a louder volume on things like what ingredients have been missed and that kind of thing.

Q: Will you organize some activities together and take part in them?

Co-worker: We have very few organized activities, almost none.

Q: Will you play mobile games etc. during break time?

Co-worker: Yes, we will. The atmosphere here is quite relaxed and pleasant.

Observation of D and ZL at Work

Observation date: 11:00–16:00, September 25, 2016

Observation place: The restaurant where they work

Observer and writer: Xiangmeng Huang.

Time	What D and ZL did	Remarks
11:00	The observer enters the restaurant; he sits in the seat facing the window of the kitchen	ZL is not in the restaurant at the moment; he is out doing deliveries
11:07	D starts to make the pizzas ordered by customers at the window of the kitchen. He puts various ingredients of the pizza on the base, and at the same time takes a new bag of ingredients from the fridge, carefully opens it and puts its ingredients on top of the base	These are routine procedures for making pizzas
11:10	D completes the pizza, which is then served by another employee from the window to the customer	In the process of making pizzas, D looks up a few times from his work and gently nods at the observer who's facing the window
11:19	ZL comes back to the restaurant, walking rather fast; then he takes new orders from the manager in the kitchen, helps colleagues to pack the snacks to be delivered, nods to the observer and says "hello" before going out immediately to deliver again	
11:27	D wipes the tabletop in the kitchen and sorts out the plates	
11:32	D takes out a bag of ingredients, opens the bag and puts the ingredients into the ingredient box	
11:46	Customers order new snacks, and D begins to work, the process of which is basically the same as before	At this point of time, he also makes eye contact with the observer
11:58	ZL comes back to the restaurant from delivery, and there are no orders to deliver, so ZL goes to the water bar and prepares two drinks for the customers who have ordered them	
12:07	D squats down, sorting and cleaning up the food ingredients beneath the table as well as the tabletop in the kitchen	
12:19	Before ZL goes out for delivery again, he passes food ingredients to his colleagues, helping them finish the unfinished snack together, and greets the observer again as he goes out of the restaurant	Communicates with colleagues about what he needs to do at this point
12:29	D continues cleaning up the tabletop, and puts the ingredients from the cooler in the proper place	Because it is the weekend, both store orders and takeout orders start to drop, and D's work pace becomes slightly slower than before

(continued)

(continued)

Time	What D and ZL did	Remarks
12:42	D, basically having no work to do, nods to the observer from the kitchen window	
12:47	ZL comes back to the restaurant from deliveries	
13:00	Both stand by at their working stations	
13:15	Start to clean the lid of each ingredient box at their working stations and put the lids back onto boxes after washing	At this point, the morning's work is basically over
14:00	One-hour lunch break starts; they have lunch, eat fruit, have a rest and check their mobile phones	
15:00	Lunch break ends and they are interviewed by us respectively	During the interview, D is eager to invite the observer to lunch and asks if the observer wants to drink something; ZL smokes a cigarette while waiting for his turn
16:00	End of interview	There are not many store orders and takeout orders that day, so the workload of the two is not heavy

Translated by Si Zheng

Edited by Andy Boreham and Zijian Che

Open Access This chapter is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits any noncommercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if you modified the licensed material. You do not have permission under this license to share adapted material derived from this chapter or parts of it.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.



I Will Raise Him Up



Zhuojun Zhang

Interview with Mr. WY's Mother

WY, male, born in 1991. The only child in the family. Grade IV intellectual disability. Graduated from a special education school—Shanghai Primary Vocational and Technical School of Changning District. Started working at Shanghai Papa John's in 2009.

Interviewee: WY's mother

Interviewer and writer: Zhuojun Zhang

Interview dates: August 12 and November 12, 2016

Interview place: WY's home.

“The Big Head Baby” Has Strong Vitality

Q: May I ask how you and your husband got to know each other and got married?

WY's mother: We were working in the same factory. After having known each other for some time, we started a relationship (laughing).

Q: What kind of work did you do?

WY's mother: Do you know fishing cord? Our job was to make that kind of cord. The cord we made was also used for national defense purposes. My husband's task was to weave the cord, and mine was to distribute it onto machines to roll it up and tie it. Our factory was called XX Polyester Factory.

Z. Zhang (✉)

Fudan University, 220 Handan Ro., Shanghai 200433, China

© The Author(s) 2020

W. P. Alford et al. (eds.), *An Oral History of the Special Olympics in China Volume 1*, Economy and Social Inclusion,
https://doi.org/10.1007/978-981-15-5132-1_2

Q: XX Polyester Factory. Was that considered a secure, state-owned “iron rice bowl”¹ enterprise job?

WY’s mother: Yes, it was a so-called iron rice bowl job.

Q: Are you still working there now?

WY’s mother: No, I’m retired and our factory has been sold. Later I worked as a cashier at the Entry and Exit Bureau for several years. My husband has bought a car, and has become a driver at a company. Whenever needed, he’ll drive and bring people to places.

Q: Are you both from Shanghai? Do you have any siblings?

WY’s mother: Yes, we are both from Shanghai. My husband has two elder sisters, one is in the US and the other one lives close by, while I have two elder sisters and one younger brother.

Q: When did you get married?

WY’s mother: We got married in 1986, after having a relationship for 2 or 3 years. I was pretty young when we married, only 24. He is more than 2 years older than me. Our son was born in 1991.

We lived here right after getting married. Later the old house was pulled down to make space for new buildings. We lived in a rented place for 6 years and moved back here when the new buildings were completed. At that time there was this “Moving Back Policy”.² Currently we live together with my parents-in-law.

Q: WY has a good name. Does it have any special meaning?

WY’s mother: Originally, he was named “Ren Yi”³ by my father-in-law. Grandpa didn’t have a very good relationship with his own siblings. He always felt that his family lacked kindness and integrity. Therefore, his grandson must have these two virtues. He still has very traditional ideas. We were fine with any name chosen by the grandparent. Unexpectedly, during registration, the nurse mistook the two characters as one, which is “Yi”. I thought that it was actually a pretty good name, so I just kept it that way.

¹In 1978, educated urban youth started moving back to the cities. To create employment opportunities, the government encouraged factories, schools, and communities to establish affiliated enterprises. State-run factories were owned by the whole people, whereas enterprises affiliated with factories or schools fell under collective ownership, which was further divided into large collective ownership (for local enterprises) and small collective ownership (for enterprises in cities and towns such as factories run by towns and neighborhood communities in Shanghai). Workers were categorized into those working for factories owned by the whole people and those working for enterprises with collective ownership, and the former enjoyed higher salaries and better benefits than the latter. At that time, factories owned by the whole people, enterprises with large collective ownership, and enterprises with small collective ownership were referred to as iron rice bowls, porcelain rice bowls, and clay rice bowls, respectively.

²“Moving Back Policy”: When an old building is pulled down and a new building is constructed on the same site, the original residents have the right to purchase the new houses at a favorable price, to compensate for their old residence. During the construction, the residents are expected to rent a temporary place to live in, either with a subsidy from the developer or other units, or at their own cost.

³Phonetically equals the phrase “kindness and integrity”.

Let me tell you the details. He was born early morning, but the labor pains started the night before, so I went to the hospital. But from the moment I arrived at the hospital until midnight, I didn't feel the pain anymore. The doctor said it was fine since the cervical dilatation hadn't started yet. So I told my husband, "Go home, it's not clear when the delivery will take place. The doctor said that possibly I won't deliver tonight at all." Then he agreed to go home.

Immediately after he left, I began to feel the labor pains. I called the nurse. She checked me from time to time, but kept on saying that the cervical dilatation hadn't started, and didn't take it seriously. I didn't know why, but I was just very drowsy. When it was 5 or 6 am, I had such serious pain that I called the nurse. But she said that it was fine and that the cervix was still not open. Then at around 6:00 am I felt that something was wrong, since it felt as if my belly was dropping down. When I called the nurse again, she said, "Wait a moment, we're changing shifts soon."

I was young and didn't know much at the time, so I thought I should just hold on for a while. When the nurse of the next shift came, I asked her to check on me again, because I suffered so much from the pain. She had a look and was startled because I was about to deliver. She said that she could already see the head of the baby. I was transferred to the delivery room immediately. The baby was born before the sterilization could be done.

Probably because I'd been holding for too long during the labor, there was a mark on his head when they showed him to me. I didn't know much about it and his Apgar score was high, so I thought that he was just fine. Five days after the delivery, I was back home.

When we got back, he seemed to be a crybaby, but we didn't know why. All the time we thought that it might be because of hunger, since I hadn't got enough milk. So I just kept on breastfeeding him but still wondered.

Probably on the thirteenth day, the problem started. It was in June. I was still weak from the delivery and couldn't hold him in my arms. Instead I put him on my lap and was gently rocking. Out of nowhere, he made an "ah ah" noise, like the meowing of cats at night, which was very unpleasant. I was scared and checked on him. I couldn't find anything wrong but still found it very strange. When WY's dad came back in the evening, I told him about the noise, which was so unpleasant and harsh. He said, "Sounds impossible! Maybe he got hurt somewhere." But we couldn't see anything abnormal.

I was worrying a lot and suspected that there was something wrong with my baby. The grandparents came to visit and they thought he was fine. So they said to me, "Don't take him to the doctor's, he's doing fine." But I still had my doubts. It is said that there is a close affinity between mother and child. I think that I really sensed it and that was why I insisted on having him checked. My parents-in-law said, "If that's what you want, go to the doctor then." But actually they were not happy about my decision. It seemed to them that there was nothing wrong with the baby and that I was being fussy.

So I took him to the hospital, but the doctor also couldn't notice anything wrong. I told him that my baby had made some noise twice. Then the doctor said, "Okay, let me feel him." So he started to feel his body little by little. When the doctor

touched the back of his neck, my baby made that noise again. The doctor became alert and believed what I described. He said, “It’s already evening, we can’t give him a check-up with advanced equipment—he should be hospitalized.” Just 1 h after the hospitalization was settled, the doctor came out with the news that they would issue a “Critical Condition Notice”. That was scary! Why was my baby suddenly in critical condition?! The doctor said, “There’s something wrong with your baby, he has to stay here. You two can go home now.”

Q: Which department did you take him to? Pediatrics?

WY’s mother: We went to the hospital at night, so it was the Emergency Room. It was at the Children’s Hospital, close to Jing’ an Temple. I said, “Oh, what can we do now?” I was extremely worried and refused to go home. At that time, there were just wooden benches in the hospital. I was just sitting there. Still weak from the delivery, I barely could sit by myself. So my husband sat there, and I was lying on his lap.

It was already 1 am in the morning, and I was lying there but couldn’t fall asleep. Who could we possibly turn to for help? My mind was wandering. I kept on thinking and remembered that the girlfriend of my neighbor was working at a Children’s Hospital. I wasn’t sure at which Children’s Hospital she worked, but I just didn’t want to miss any opportunity. As soon as it was 8 am, I called that neighbor’s home. I said, “My son is now in this hospital—does your girlfriend work here?” He said, “Yes, she is the Head Nurse of the In-patient Department. Don’t worry. I can come immediately, or I can ask my girlfriend to come to you.” Later the girlfriend came to tell us, “Yes, your baby is now in critical condition, but we don’t know the reason. Today we will check him thoroughly with all available equipment. Just don’t worry and go home—it won’t help if you stay here. I’m here and I will keep an eye on him.” From then he was at the hospital for about 3 months. About 2 weeks after he was hospitalized, my husband began to disclose the truth to me. Before that he was still keeping the truth from me by telling me that my baby couldn’t come home because of fever.

Q: Was your husband going to the hospital all the time?

WY’s mother: Yes, my husband visited him every day. I was still taking the post-natal confinement after childbirth and couldn’t go.⁴ My husband wanted to make sure that I took a good rest during that first month, so he kept on lying to me. When the first month was almost over, he thought it was impossible to keep the truth from me anymore, so he started to release the situation to me gradually. He first said that the baby had a fever and that the reason was unknown. But actually he already knew the reason, because the doctor had found the problem. And the baby also began to change a bit. His tiny head suddenly grew much bigger due to hydrocephalus. He became a so-called Big Head Baby. And that looked horrible when he was little. I was kept away from those facts, but actually I was mentally prepared. I was almost sure that my son had a problem, otherwise he wouldn’t have been hospitalized for that long. And they told me that the problem was in his brain. Anyone who’s told that would be mentally prepared. In a way I could guess the situation.

⁴Traditionally, Chinese mothers are expected to rest indoors for one full month after giving birth.

The day after my post-natal confinement, I went to visit him in the hospital. I could hardly recognize him since he had totally changed in appearance. His body was so tiny, but his head was huge. Even now you can see that his head is a bit bigger, right? You might feel it's a bit weird or abnormal. But actually his brain is now kind of fine. At that time, I was worried to death. What could we do? I had no solutions so I could only go home. Then the grandparents were talking about abandoning him.

Q: Who said that, your parents or your parents-in-law?

WY's mother: Not my parents. When I saw my son, I didn't have other thoughts. My son was ill, so we had to have him treated. But others were thinking about what options we had. What could we do? So I asked my husband about his opinion. My husband said to me, "Let's first have him treated." But my father-in-law had different ideas.

Actually, my father-in-law and uncle-in-law had already been to my parents' place. They said, "According to the doctor the kid is hopeless and incurable, therefore it's better not to keep him." They didn't want to face me directly, so they tried to make my parents persuade me. My mom refused on the spot. She said, "No, I couldn't say that to my daughter. She loves kids." When my elder sister had her kid, my mom was taking care of him. We used to live in an old-style two-story building. One day the kid somehow slipped over on the wooden staircase, got a big cut on his chin and was bleeding quite seriously. I was so worried that I took him in my arms and rushed directly to the hospital. The doctor gave him three stitches. I blamed my mom as soon as we were back, "Mom, this poor little thing! How could you let this happen?" My mom then realized how much I love kids and remembered ever since. "She felt so sorry for a wounded kid who's not even her own kid. How could she abandon her own kid!" So my mom directly refused and said, "We can't tell her to abandon the kid. He is the grandson of Family W, isn't he? You do whatever you think is appropriate." My father-in-law and uncle-in-law were both very angry after that visit. Since my parents didn't want to persuade me, they also kept silent.

Three months passed. The hospital had also communicated with us that they'd tried to feed him only a little food, but he had strong vitality and survived. You couldn't just make him die, could you? Several doctors in the hospital were acquaintances of our family. They implied that my parents-in-law might take the child back from hospital and then could let some accident happen. You see, we are parents so how could we possibly agree? I gave birth to him. How could I possibly take away his life? Absolutely not! My parents-in-law also talked to their son, but my husband also wouldn't agree. Therefore, we took him home.

When my son was still in the hospital, my husband had told the doctor that even if there was 1% hope, please rescue him for us. The doctor said, "We've done our utmost, but it still seems hopeless. So you'd better take him back and search for other solutions. It would be the best if he could survive. If not, we've also tried our best." Later the doctor explained to us, "His brain is blank. Normally kids like this won't reach eight. They commonly suffer from sequelae. Because the head is huge, the body can't take the burden, so they can hardly even develop the ability to walk. Possibly they would be paralyzed in bed, so you have to be prepared."

Seeking Help from Doctors or Buddha Without Giving Up

WY's mother: After we took him home, we fed him and did all the other necessary things. After taking care of him for more than 1 month, I felt like he could understand quite a lot. For example, when he peed, I would just treat him as a normal kid and explained to him, "Isn't it uncomfortable if you pee in your pants? Next time you should signal me. If you want to pee, you just move your feet a bit, then Mommy will know. So I just raised him the same way you raise a normal kid. He seemed to understand what I meant. When he peed, he would kick his feet. I told my mom about this, and my mom said that we should get him good treatment.

But how to have him treated? I had to think hard. Several rows in front of my parents' house, there was a neighbor's kid who was born with cerebral palsy. He was 2 or 3 years old but still couldn't walk. They had him treated with acupuncture, on his head. It seemed to have some positive effect. I thought my son also suffered from brain problems, so maybe we could give it a shot as well. So I asked the neighbor for the address of this female doctor, Dr. Wang, who lived around Zhu Yuan Community in Pudong. She specialized in that kind of treatment. Some kids who couldn't walk started to walk a bit, after her treatment. So I took my son to her. At that time our old house was torn down and we stayed in the rented place around Yang Jia Bridge in Putuo District, which was very far from the doctor's. I had to transit twice by bus. Three times per week, I got up about 5 or 6 o'clock in the morning, got food and everything ready, packed a bag with water and many other things, and set out to see the doctor. My mother-in-law also accompanied me several times.

Q: So you, your husband, and your mother-in-law went together?

WY's mother: No, my husband didn't go. He had to work at that time, so my mother-in-law was with me. She didn't want to go anymore after several times. Then I asked my dad for help. He just went there once and got so scared that he refused to go anymore. You know, my son looked so miserable during the treatment that your heart would break. He began to cry as soon as the first needle went into his head. In total he would get 35 needles on his head, which would stay in for half an hour. And then he would get the needles on his body. My son would keep on crying, and so would I, seeing him crying. But there was no other solution. If we didn't have him treated, it was desperate. So I had to be tough and went on. At first his head kept on growing, 49, 50 cm. Every time you measured it, it was bigger. I was really worried sick. After we started the acupuncture his head stopped growing, gradually. It didn't shrink though. That was impossible. But it didn't get bigger anymore. That seemed to me a positive effect, so I continued with the acupuncture. Three times per week, sometimes on Monday, Wednesday, and Friday, and sometimes on Tuesday, Thursday, and Saturday. We had low salaries at that time, because I stayed home from the beginning of my pregnancy. Then my son was sick so I also didn't go back to work. It was like that for about 6 or 7 years. Only when he was in grade two of elementary school did I resume working. In 1991, the acupuncture cost 20 yuan per treatment, which was pretty expensive. I only received a bit over 100 yuan per month, which was all spent on his treatment. After just several treatments, he could

understand, even though he was barely 1 year old. In the neighborhood of the doctor's place, there were many bamboo plants. I had him in my arms. As soon as he saw the bamboo, he would cry, because he realized that he would get the needles again.

I kept on taking the same route by bus, back and forth. The bus staff began to know me. There was a seat behind the bus driver. The bus driver and the conductor would help keep others from sitting on that seat. They would tell others that later a woman holding a baby would get on and sit there. I basically kept the same schedule. I set out at about 6 or 7 o'clock in the morning, had the treatment and then came home at around 1 or 2 pm. You see, that was tough, wasn't it?

Q: Really tough!

WY's mother: It was really tough! But I had no choice. At that time, my mother-in-law also gave up on my son. Her daughter was in the US, so she applied for immigration to the US. One day at the dinner table, my father-in-law said, "We'll just give it a shot. If we are granted, we'll go. If we get rejected, we'll stay. It wasn't that easy to apply for the visa." Then it was approved because she was aged. So she got the visa and left for the US.

I have been to every single hospital. There was a Professor Wang in Xin Hua Hospital, who specialized in brain problems. After checking my son, he told me, "My suggestion is that he'd better not have surgery. During surgery, the skull will be opened and a tube will be inserted, all the way to the chest. The liquid of hydrocephalus is not so easy to be absorbed because it's viscous. It's hard to guarantee that the tube won't be clogged one day. If that happens, another surgery is needed. The surgery won't help at all. He might suffer a lot of times, and there are numerous nerves in the brain. Maybe the current problem is cured, but then he might suffer from another problem." He didn't put it in a direct way, but I could sense his subtext—it would be useless to have my son treated further, so I'd better stop.

Q: The doctors think that this kid won't live very long?

WY's mother: Yes, according to the doctors, he wouldn't survive beyond 7 or 8 years old and that it was most likely that he would be paralyzed in bed. So they regarded my efforts as futile. But I just couldn't believe it. I had to get him treated.

I'd been discussing with my husband whether we should have one more child, because the country's policy allowed parents in our situation to have a second child once the first one reached 4 years of age. "Your parents wouldn't want to help, then we would be exhausted taking care of two kids. Just imagine. Then what's the point in having a second child? If you want a second kid, I support you. If you don't, then you must think it through. You shouldn't regret later and say that we should have done it." I said, "Human beings are strange (paused and held back tears). We all prefer good things. If you have a second kid, no matter if it's a boy or a girl, even if he or she is not as good as other kids, he or she might be better than the elder brother. Then you certainly wouldn't have energy left over to take care of our oldest son anymore." My husband gave it a thought and said, "No more kids" (wiping tears). My parents also wouldn't help us take care of the kid. If my mother-in-law had helped us out, I might want a second child. You see, how could we have managed it, if they didn't help us?

Now that we decided not to have a second child, we just focused on having him treated. If he gets cured, that's the best. But if he couldn't, at least we tried. When he was little, he had to skip many vaccinations. A doctor once said that the kid had extra liquid in his brain, so he shouldn't get the vaccinations that might cause fever. Therefore, every time I would check with the doctor, and if the vaccination might cause fever, I wouldn't let him have it.

I've taken him to all the hospitals in Shanghai, as well as hospitals in other cities. Later I became superstitious. I went to temples to plea and to have ceremonies organized. Whenever somebody said that something might help, I would try it out (held back tears). We didn't have enough money then. Dad had no choice but to take unpaid leave and to work as a taxi-driver. What a hard job it was! But anyway he could earn some more money, which was used for our son's treatment. Medical costs were high, but fortunately our employers let us claim it partially and provided us with some subsidy. At that time, I kept a detailed record of all the expenses. More than one hundred thousand *yuan* was spent on his treatment. That was a huge amount in the 90s. We could hardly make ends meet, so we borrowed money from others. We had a lot of debts. We had no choice. You want to have the kid cured, so all you think about is how to get treatments for him. But his situation doesn't get better. Fortunately, he was responding. I always treated him with ideas and principles for normal kids. Gradually he became more capable.

My son is not like others. Due to his brain problems, his brain is very vulnerable. One time he got the mumps. That wouldn't be serious for other kids. When we were little, we just spread some mud from a well onto the face and it would be fine. But now that there's no wells, we couldn't use a natural therapy like that. One day we were sleeping, but he was crawling back and forth in bed and said, "Mom, it hurts. Mom, it hurts." I was worried so I took him to the doctor immediately. I insisted on going to the doctor. After having him checked at the hospital, the doctor said that he needed to have a bone marrow aspiration. The results showed that he had meningitis. How serious was that? This was purulent meningitis. My doctor neighbor told me that if a normal kid gets meningitis, his intelligence would drop a bit and that purulent meningitis is especially harmful to the brain. So my son had to be hospitalized, even though he didn't like it. He was jumping in bed and repeated, "I don't want to stay! I don't want to stay!" He understood it. But we had to force him to stay. No choice.

One thing was quite interesting during his stay in the hospital. He used to like eating mini dumplings a lot. I was afraid that the home-made dumplings wouldn't be fresh. So every day I would take him to a restaurant to eat the dumplings. He got used to it and began to remember the way. Then I gave him cash and let him do it by himself. He was still very little, probably about 4 or 5 years old. At first I was worried, so I would follow him. But I still insisted that he did it all by himself, so that he could practice. Several times later, he got it. In the morning, he would have mini dumplings and milk. He didn't accept plain milk, but drank chocolate milk. I gave him 3.50 *yuan* and he would buy his breakfast by himself. Now that he was hospitalized, what to do? The breakfast in the hospital was congee, but he didn't want it, absolutely not. Because it was the same hospital as his previous stays, some staff knew him. The nurses would say, "Look, No. 217 is back again." He was frequently

ill and got hospitalized, so the staff knew him well. The nurses would ask him, “Why don’t you eat your breakfast?” He would answer, “I don’t want to eat this. I want milk and dumplings.” At that time I was only allowed to visit him twice a week. I had no choice but to give a nursing worker 50 yuan per month so that she would take mini dumplings in the morning for my son. The head nurse also knew my son, so she would spare some milk for him when she prepared milk for other kids.

Later there was a doctor from another city. He noticed that my son was doing pretty well and could manage communication and other things. So he asked me one day, “Could you let me have your child as an experiment patient? If you agree, your medical expenses could be waived.” Each hospital stay would normally cost two to three thousand, which was a lot of money. I discussed with Dad when I was home. He disagreed, “How could we do this? Our son shouldn’t be an experiment.” The next day, he asked the hospital to discharge our son. The doctor said that he was not fully recovered from meningitis and that we had to sign to take the responsibility if we wanted to take him home. We did it accordingly and took him back. Then we just made him take the medicine, and brought him to the nearby hospital for IV therapy.

Great Achievements from Hard Exercise

Q: How old was your son when your mother-in-law left for the US?

WY’s mother: He had just turned one. That was a tough period. My elder sister is 5 or 6 years older than I am, and my brother 5 or 6 years younger than me. So when I was young, my two elder sisters were competing to take over more housework. When I was old enough for housework, my mom was retired. So you could guess whether I was capable of doing housework. Not at all! When I just got married, we ate together with my parents-in-law. They hardly let me do any housework, because I had a full-time job.

You see, it was such a hard time, and she just left. I didn’t know how to handle housework at all, and there were three men to be fed—my father-in-law, my husband, and my son. Both my father-in-law and my husband had full-time jobs, so they were not home in the daytime. And my son is disabled like that. What do you think I could do? I didn’t know how to cook. So I would just call my dad and ask how to cook a certain dish. My dad would then teach me over the phone. By then we’d moved back to the original address. Our next-door neighbor of Room 05 was a very kind retired lady. When I was cooking, I would ask her how to cook this or that. She would put down her work and teach me. She stayed aside to watch me cooking. Every morning I put my son in a stroller and went grocery shopping. I came home with the groceries tied onto the pram. When we were back, I would spend some time with my son. When he slept, I would hurry to rinse the vegetables and prepare for the cooking. I didn’t even have time to prepare a warm lunch for myself, nor did I have time to pause. And there was so much laundry to do. Though it could be done in the washing machine, I would still have to hang it out.

I had to keep an eye on my son. His head was big, so he was top-heavy. He fell out of the pram easily when he sat in it, if I didn't pay attention. I had to cook, so what could I do? I found a solution. We had a double-tub washing machine in our bathroom. When it was time for me to cook, I would drag out the washing machine, put a round cushion in it and let my son stay in it with his toys. This way I could keep an eye on him while cooking. The neighbors all knew about this, so if they came in and saw this scene, they would say, "Ah, you are cooking now with your son in the washing machine." I didn't dare leave him alone. Once he was playing with a toy, and there was a plastic inserting piece, round but very hard. He rushed forward, then the toy poked on his forehead and made a big hole. I was scared to death. Ever since then, I wouldn't let him out of my sight.

He started walking much later than his peers. Other kids could walk when they were 10-plus months old. He couldn't walk until he was 25 months old. In order to train him to walk, I came up with several ideas. We used to have detachable furniture. I would take out a drawer, put up the bed, spread a cotton quilt or summer sleeping mat on it, and let him exercise walking. Whenever I had time and he was awake, I would let him exercise like that. It wouldn't be enough just to exercise at home. So I took him outdoors to exercise as well. I cut a piece of cotton, wrapped it around his waist and tied a rope on it. That way he wouldn't get hurt. I just let him dash forward, gave him a pull by the rope if I noticed that he was losing balance, and let him go forward again. But he still didn't quite master the walking skill. He couldn't walk on his own.

Then one day, we were about to visit my parents. We had to change clothes, so we let him stay in the room of Grandpa. We were still halfway changing, while he toddled into the room. I asked, "Did Grandpa hold you and bring you back?" "No," he said. I asked again, "Then how did you come over?" He could talk but not so fluently, so he just giggled. I said to my husband, "Our son can walk! Let's send him back in the next room and try again." Then we saw him walking, holding a small blanket in his hands as if it was a supporting point. I remember the timing—25 months old. Look, 2 years old! Have you seen another kid who couldn't walk at that age!

Q: So you really have put in a lot of effort!

WY's mother: Yes, I kept on training him. When he learned to walk, I relaxed a lot. I would ask him to sit close to me. But if he wanted to walk away, I would still follow him, wherever he went.

His eating was also troublesome. He didn't eat well, so I had to entertain him and sing to him. You'd sing a line of a song, then he would take a bite. Besides he had to have something in his hand to play with while eating. For example, when you were singing, he would knock the table with a spoon. At that time, a porcelain spoon cost 10 cents. He liked no other spoons but the porcelain ones, so I bought 100 of them. If he broke a spoon by knocking, he would be happy. What else can you do? In this way, he gradually grew up.

Then it was time for him to go to nursery school. It was too lonely for him to stay at home on his own. He had to mix with other kids. When I took him to the nursery school, the teacher looked at him and said, "We can't accept him." I said, "Please give it a try. I won't force you to accept him, but please let him try it out for 1 week."

Then the teacher asked, "Can he indicate when he wants to go to the toilet?" "Yes, he can. He understands," I said, "but maybe he can't say it clearly." "Then we just give it a try," the teacher said. So he tried there and it turned out to be acceptable. He could signal, but he just wouldn't call the teacher. He didn't understand that. He would just say, "Mom, I need to pee." He was admitted anyway.

At that time, I always pushed him to go out. In the neighborhood, there were also kids who would bully him. I would then talk to the parents or the kids, "Please don't bully my son. He can't help it. He is just sick." These kids were adorable. After some time, they became very kind to my son. Besides, when my sister-in-law came back from the US, she would bring fancy toys like balls and so on. Every day I would take him to play outside, no matter what. I told him, "You should play with older boys. Don't play with the younger ones, but with the older boys and girls. If they want to play with balls, we have different ones. Whichever ball they want to play with, we have it at home." The kids in our neighborhood were all very kind to him, and the old people in the neighborhood would also protect him. They would interfere if they noticed any kid bullying my son. It's not like we made him put on clothes of famous brands, but we kept him neat and tidy. He had bright skin color, and he was in tidy outfits. Kids were willing to play with him, though his head was very big.

There is something unusual about my son. He appeared to be quite popular. His classmates of elementary school often came to play at our place. When a group of seven or eight kids play together, they sometimes would make a mess at home. Some parents don't like it and might scold them. But I liked to have them playing at our place. So they always came to our place after school. Handheld electronic games were a hit at that time, so everyone would then sit around with a device in hand to play the games.

Q: Why did you ask him to play with older boys rather than younger ones?

WY's mother: My idea was that if he played with younger ones, he wouldn't have a chance to develop his abilities. The older kids are more developed in language skills and motor skills and so on. When he was in elementary school, several neighbor kids of middle school would also accept him to play together, when they were back home for vacation. It was summer vacation. Other kids didn't have balls, but we did. Then they would play with balls together. Some people would comment that the weather was too hot for our son to play outside. But I thought it was fine. I just let him exercise. As long as there were playing companions, I would let him out. Some kids couldn't take the heat and came inside. Then I would let them play at our place with the air-con on and would prepare fruit for them. Being with these older kids, his intelligence developed. Later he became very lively.

Q: What would be the concrete forms of his "liveliness"? Could you please give some examples?

WY's mother: For example, when he was in elementary school, his classmates were all riding bicycles, but he couldn't. Others were riding all over the place, while he just ran after them. I said, "You can also learn it. Just learn from them." He said that he didn't dare and didn't want to learn. Then his classmates said to him, "You have to learn, then we can go out by bike and play together. We can't take you on

the bike.” I asked him, “Do you want to learn then? If yes, I will buy a bicycle for you.” He still said no.

Grandpa had a bicycle at home. My husband and I both went to work. He asked, “Grandpa, may I use your bike to learn riding?” Grandpa agreed. He held him from behind and told him how to ride. Soon he learned it. Then I told him, “You can only ride the bicycle in our neighborhood. Don’t go out and ride on the streets.” I was afraid because he didn’t know about traffic rules. If he got into a car accident, that would be horrible. When my husband was home in the evening, he taught my son the traffic rules, such as what he should do when the traffic light was red. He explained twice to him.

One week later, I found the bike missing when I was home. I couldn’t find it anywhere. Grandpa said, “Take it easy—he went to school by bike.” I said, “How can that be? I’ll be worried to death if he rides in traffic.” “Don’t worry! Just let him give it a try,” Grandpa said. When my son was back, he began to smile as soon as he entered and asked, “Have you been looking for the bike?” I said, “Did you ride it to school?” “I do know how to ride a bike,” he replied. So he just mastered it like that.

So he wouldn’t necessarily accept the advice of his family members. But if he gets in touch with people out there, he can see what others are up to. He would think that he should also learn it, then he will do it. That’s why I insisted that he should go out and get in contact with others.

Sunshine After the Rain—He Became the Monitor

WY’s mother: I was still a stay-at-home mom during his first year in elementary school, so I was monitoring his study. I was very strict with him. At that time, he had grasped *pinyin* and other subjects well. He also got good scores for exams.

During his second year in elementary school, I thought I would be disconnected from the society if I kept on staying at home. I had to have a job. My husband had no other solutions, so he said, “Go out and find a job then—in any event it’s good to have more income.” Then I started to work again. Dad would pick him up after school and help him with his homework. My son knew that dad couldn’t be hard on him, so he complained that his hand hurt from writing homework. Dad asked, “How much homework do you have? So much! Then let’s just stop doing it.” My son said, “The teacher will criticize me if I don’t finish my homework.” Dad said, “Don’t worry about it. I will talk to the teacher tomorrow.” In this way his grades gradually dropped. Also because his intelligence is not as good as others, it was very hard for him in elementary school. First and second grades were still fine, but starting from third grade, he was behind.

Q: Which subjects were difficult for him from third grade onwards?

WY’s mother: Math and English. He couldn’t keep up anymore. Actually he didn’t work hard enough. If he worked a bit harder, it might still be okay. On the other hand, his dad also spoiled him.

Q: Did he go to ordinary school or special school?

WY's mother: Ordinary school. I didn't send him to a special school, because I figured that his intelligence should be good enough for an ordinary school. Besides I was tutoring him strictly.

Q: How did you tutor him?

WY's mother: I used flashcards for *pinyin*. I taught him every day even before his schooling started. Whenever I had time at home, I would make him practice that. I even painted the cards with a different color for every day. I also taught him how to read the time. Soon he mastered all these skills. It wasn't that he was totally incapable. He got a new teacher when he was in third grade. The teacher for first and second grades was pretty good and strict with him. I prefer it if the teacher is a bit strict. The third-grade teacher was not so patient, and didn't like him because of his poor intelligence. And he was also afraid of the teacher. We kept on getting phone calls from the teacher, complaining about this or that. The teacher also said that his poor scores had a negative influence on the performance of the whole class. What can we do about that? That is how he is.

Q: From third grade onwards, did you or his dad still check on his study in the evening?

WY's mother: Yes, we did. At that time, the teacher would list down item by item the homework of the day on the blackboard. The students should then write it down. That way parents could supervise the kids in finishing their homework. But every time he would miss something when copying down the homework list. What was on his list, he would finish. But some items he just didn't write down. The teacher frequently complained that he didn't finish his homework and blamed us for not checking. But we said that we did check his homework. Later I became more cautious. Several kids in our neighborhood were his classmates, so I would call them every evening, checking item by item the homework list. But he was also not concentrating. The teacher said that he seemed to be serious, but actually he was not listening. He was roaming around in his own world, playing.

Q: So he didn't listen attentively during lessons. Did he work hard to finish his homework when he was home?

WY's mother: Nope. He would just do it for a little while, then would want to stop and play. He did finish his homework, but very slowly. He just wanted to play.

Q: What level could he get for the exams?

WY's mother: It was already satisfactory if he could pass. Math was a bit better, but his Chinese was poor. Before the graduation of elementary school, the teacher gave us her advice, "In my opinion, it might not be very useful to let him continue in middle school. Why don't you check out the special schools? If you think that is fine, he could go there." At first, I was against it. I still held the idea of providing him with a normal environment. If he is sent to a special school, everyone there has an intellectual disability, then how can he still develop and improve? But on the other hand, it was so hard for him to make academic progress. In the middle school, it would be even harder and he might fail. What if he abandoned himself to despair?

It took me a long time to think about it. Then I eventually decided to check out the special school. The environment of the school was pretty good, and it was middle school plus vocational school. After 5 years you could graduate. We took him to visit

the school, and asked him afterwards, “Do you want to go to middle school?” We made it clear to him that he might encounter a lot of difficulties, if he went to a normal school. For example, you might have a lot of pressure, and others might look down upon you because of your poor scores. But at the Sunshine School, it would still be pretty good if you work hard and learn things that you are interested in. He didn’t give us an immediate answer. Several days later when I asked him about his decision, he said that he chose the Sunshine School. He studied cooking and gardening there.

Q: So he could pick two majors?

WY’s mother: Yes, he could.

Q: What exactly did he learn during gardening lessons?

WY’s mother: For example, how to arrange fresh-cut flowers, how to nourish the soil, and so on. It seems that gardening is not so practical. But if I take care of plants at home now, he will give me advice. For example, I kept the water when I rinsed the rice and used it for plants. He would say, “That is not correct. You should leave the rice-rinsing water for several days before watering the plants with it.” He wouldn’t really help me with the plants. But it seems that he still remembers some of the things he has learned.

Q: Did he choose these majors by himself?

WY’s mother: Yes, he did. He was very delighted after he began to learn these. On one hand, he didn’t have much pressure. And on the other hand, he performed better than others. He was the top student there, and therefore had more self-confidence. At that time, he was the monitor of the class. And he was handier than others. For example, the teacher planned to teach the next day how to make steamed buns, he was asked to make a sample at home and bring it to school. I bought flour and tools for him. He was very attentive. He was extremely strict about the weight of the dough. If the teacher has said 100 g, then it has to be exactly 100 g.

Q: Did he have other school activities besides study? For example, school trips in spring or fall?

WY’s mother: When he had school trips, we packed some food for him to take. But when he was back, he told us that the teacher said they didn’t need to take any food. Because the school has sponsors, food would be given to them each time they went out for activities. When he was studying at that school, we hardly paid any tuition.

Q: Was he looking forward to these activities? Or did he prefer the lessons?

WY’s mother: It seems that he didn’t really care. It seems that he has never shown great interest in anything in particular.

Q: Has he received any rewards during school activities?

WY’s mother: Yes, he has. Once he took part in a dance competition organized by the Chinese Disabled Person’s Federation, and he got a reward certificate. The school taught them tap dancing and they went to a competition. They could all dance pretty well. More than ten kids in his class did it together and won third place. And also running... So he had quite a few medals, all bronze ones.

Q: As this is a vocational school, did the school arrange an internship for him?

WY’s mother: Internships started from fifth grade at this school. He was sent to a restaurant kitchen. When he was back from his first day of internship, his clothes

were all messed up. I asked him why. He said that he fell because of the slippery floor. The second day, his pants were again very dirty. I was curious and asked, “How was your work?” He said that it was fine. I asked him if he was tired. He also said no. Everything was good if I asked.

The third day, I asked my husband to check on him, and to see what on earth was happening. So Dad ordered something to eat and sat there to see how he worked. All the waiters were just chatting and they made only my son and several of his school-mates serve the customers. They allocated the heavy work to these kids, and only came out to help during peak hours. My husband was very angry and immediately told the kitchen supervisor that we would quit. When he was back at school, the teacher was also not happy with us and said, “That’s how society is—you will have to go through hardship.” My husband said, “Working hard is fine, but if others want to take advantage of the kids, we as parents won’t accept it.”

But he still needed to have an internship. Later he was sent to a supermarket—it was all physical work there. Merchandising is to arrange products on the shelves. That was not bad, but his wage was just several *yuan* per day, and five to six hundred *yuan* per month, while others would earn two to three thousand. Anyway, at that time we also didn’t really expect him to earn money. Being included into society was more important. After a half-year internship, he graduated and got the job at Papa John’s.

Q: When did he get his disability certificate?

WY’s mother: He got it when he turned 16. According to the state policy, he could be assessed by a certain evaluation institute. He was classified as Grade IV, which is quite good, close to normal. He could complete all assignments during the assessment. But due to the fact that his head is big, he got Grade IV.

Big Progress After Getting in Touch with Society

WY’s mother: After graduation, we were asked by CDPF (China Disabled Persons’ Federation) if he’d like to work in the kitchen of Papa John’s. We said that we would like to try it out. But the recruitment included exams; that is, to make a pancake, and so on. He got first place in the exam. Two days later he received the notice to start the job. Up to now we are all satisfied with this job. Sometimes I will pay a visit to the restaurant after my work and check on him. The managers are kind to him, and we didn’t get the feeling that anyone wants to take advantage of him.

I told my son, “It’s okay if one suffers a bit. Your brain is not as good as others, but you could be more diligent and more observant than others. If others are busy, you should help whenever possible. Don’t pretend that you don’t see it. You shouldn’t do that. And you have to do your work attentively. If you’re in a good mood today, you should do your work well, but even if you’re in a bad mood today, you should also do your work well.” He listens to me. And because of his good performance, the restaurant managers are all kind to him.

Sometimes I was a bit worried, and would check with the manager to see how my son was doing. The manager said, “He’s a very good boy—it’s also the result of the good education he got from his parents.” I said, “We don’t have great expectations for him. We just want him to take the job seriously. How much he earns is not such a big issue, but we hope that nobody would take advantage of him.” The manager said, “Here nobody will do that. He also makes jokes with his colleagues.” Therefore, we are pretty satisfied with Papa John’s. Some parents think that the salary at Papa John’s is too low. Not necessarily. You earn less if you have less working hours. My son has recently got 3,400 or 3,500 yuan per month. He earned more when he worked more hours. And there are different types of jobs there. Some parents complained that people took advantage of their kids. I think it could also be related to your own behavior. My son has made some comments. One colleague also had disabilities, just like my son. But he didn’t do anything in the restaurant and only played with his mobile. You see, even my son could see the difference. So the current job is pretty good.

I hope that he can get some kind of security from society. If he is no longer needed at Papa John’s, he could get other jobs. As long as he has a job, we as parents won’t worry about him. The salary doesn’t need to be very high. It will be good if he could be self-supporting. We also won’t ask that the country provides him with certain special treatment, but we hope that their basic living conditions could be guaranteed. We are old. What to do with him when we pass away? We don’t worry about our life when we get older, but we do worry about him. Sometimes we think that in our generation families normally have one child. We couldn’t really rely on the kid if we are old or ill. But even if the kid is without any problem, he could still neglect his filial duties. In that sense there’s no difference.

Q: Do you get any help from the community?

WY’s mother: Hardly. Once or twice a year, for example, they bring something to us in the hot weather.

Q: There is no monthly subsidy?

WY’s mother: No.

Q: During an interview with another family, they said that if your only kid has an intellectual disability, and if you choose not to have a second one, you would receive several hundred yuan per month.

WY’s mother: Oh, that’s the subsidy for the parents. For couples older than 49, it used to be 120 yuan per month. Now it’s increased to 400 yuan.⁵ The intention is for the parents to save money for their retirement, since it’s obvious that you wouldn’t be able to depend on your kids when you get old. This is not for the kids. If a kid has Grade II or Grade I disability, he doesn’t need to work at all. The government will provide him with minimum living expenses.

Q: How much is the minimum living expenses?

WY’s mother: More than 1,000 yuan per month.

⁵ According to the “Implementation of Special Assistance System to One-Child Families of Shanghai City,” the Shanghai Government will provide a monthly subsidy to each parent of 49+, whose only child is disabled or is diseased, effective from 2007.

Q: If your family is very rich and the life is guaranteed, would you still let him go out to work?

WY's mother: Yes, for sure he should work. He shouldn't be without a job. It won't be good if he doesn't have contact with society. Though he is disabled, he should also have friends. What can you do if you don't have a friend? Whenever there's a charity campaign in our neighborhood, I will ask him to participate. For example, they were collecting donations, and I asked him to donate. I told him, "You should give back to society." In the restaurant they were also collecting donations, and he said, "Nobody donates." I said, "You should do it. It doesn't matter how much you give, even 10 yuan is good. If you donate money, you can tell me and I will give you the money." Nowadays he doesn't carry a lot of money with him, maximum one or two hundred. Why is that? Once he got the salary and I let him carry 500 yuan so that he could invite friends to eat or to hang out. He brought the money with him to the restaurant and put 300 yuan in his uniform and forgot to bring it back. The next day, he found the wallet there but the money had disappeared. He told me and I said, "This is not such a big deal. Don't worry, just tell the manager about it. Tell him you don't care who took the money, but it's not good that things like this happened." He didn't want to tell the manager and I agreed after re-consideration. From that day onwards, he wouldn't carry too much in his wallet. He would just buy his breakfast every day. When the money is spent, he will ask me for more. He spends of maximum 500 yuan per month. I prepare a packed lunch for him, and he has dinner at home.

Q: Does he have many friends?

WY's mother: Too few. I think that he has too few friends. After work he usually just stays at home and doesn't want to go out. I wish that society could provide them with a community and organize more activities for them. He normally doesn't even want to make phone calls. Sometimes he would chat a bit on We Chat.

I think that he's rather introverted and doesn't want to have much contact with others. Two close ex-classmates were about to join the army. I asked him to see them off, but he only called them. When they were back from the army, I asked him to invite them for a meal. But he said that others wouldn't let him do it. Actually, his ex-classmates from elementary school are quite close to him. But the classmates from the special school don't have further contact anymore. They didn't exchange telephone numbers. His classmates from elementary school all live in the neighborhood so they see each other frequently. They all have decent jobs, for example, at the airport or automobile factory, and some are in the universities. He feels that he is inferior to others, and is therefore ashamed to contact them. Others would greet him whenever they meet him on the streets. He would answer if others called him, but otherwise he wouldn't take the initiative to greet others. He has a degree of self-contempt.

Sometimes the son and daughter of my elder sisters would like to ask him out. But he sometimes doesn't want to. I think that he should just go out with them. We don't care about money that much. We wouldn't mind if he goes out and spends several thousand, but he just doesn't want to. He sometimes worries too much. For example, others might arrange something with him on his workdays, and then he has to exchange his work shift. But he's not willing to do it. I told him just to try exchanging it. It doesn't matter if you just ask about the possibility. If your manager

doesn't agree, we could look for other solutions. But what if your manager agrees? And then it will be all solved. We have taken him travelling several times, and each time the manager agreed. Once we even asked for 2 weeks leave for him, and it was also granted. But he was just too afraid to ask. He is too timid, and that's his only shortcoming. He's too nervous and can't take responsibility. This is not so much like a boy.

Q: So he gets nervous when he has to arrange things. Will he get nervous when he meets strangers?

WY's mother: No, he won't. He can start a conversation with a stranger in no time. I just feel that he doesn't take responsibility. Unlike other daring boys in their twenties, he's still too dependent. I'm pretty easygoing, and allow him to make mistakes. Previously he damaged things when playing in other people's place, and ran back home. I told him, "It's okay, Mom will compensate the damage." So I wouldn't give him any pressure. But somehow he is just timid. He is not willing to have contact with society and prefers to stay at home all the time. Alas...

Q: When I came in just now, I saw him using the computer. Is that his hobby?

WY's mother: Yes, he knows everything about it.

Q: Does he have other hobbies?

WY's mother: Computer, that's the only one.

Q: Does he play online games or does he surf the Internet?

WY's mother: He mainly plays games. He also watches movies, but he hardly browses the Internet. He really has a lot of games. Besides, he takes care of the photos we took during our trips. He would download all photos to the computer, save the good ones, and delete the unwanted ones. He also likes taking photos. So he takes photos with his own camera, and afterwards saves them on the computer.

Q: When did he start using the computer? Did he learn it by himself?

WY's mother: We bought a computer when they had just come out. Probably around the 90s or just after the year 2000. Of course, we wish that he could learn more things by himself at home. At first, he was just playing games. Later, when he studied at the school of CDPF, the school offered computer lessons. They were taught how to type and edit, and that kind of thing. He has learned all these skills. My current job requires invoicing and typing, and he taught me how.

Q: Is he willing to do housework?

WY's mother: Yes, he is. Like his father, he's not so talkative, but he's very capable, and can do everything. When I'm cooking, he would say, "Let me help you." When it's time to change his uniform, he would soak it and wash it by himself. He's good at working and is quite handy. But his brain is not so good, and he doesn't like using it. That's the main deficiency. You see, now he's pretty tall. The doctor once said that he wouldn't live to 7 years of age, but look, now he's 26. It was predicted that he couldn't grow tall, but look, now he's 1.8 m tall. So fortunately we didn't listen to all that advice and abandon this child. We shouldn't do that, should we?

Q: How do the grandparents treat him now?

WY's mother: We are not so close, not at all. Grandpa still treats him as his grandchild. And Grandma... She couldn't get along with her daughter in the US, so she came back. Now she still lives with us.

He's now in his twenties. I asked if he'd like to have a relationship and he said no. Nowadays many young men are over 30 but still want to be single. I asked him if there are girls in the restaurant. I told him I wouldn't mind if the girl is not from Shanghai, as long as they can get along with each other. When the time comes, you could have this house together and your father and I could buy another smaller place to stay, I said. He replied, "No, no. I will just stay with you two." It's also fine if he wants to stay with us. After the grandparents pass away, we could re-decorate this house. Now we live with the grandparents, there's actually no place if he brings back a girlfriend. But we could rent a place for him if he did have one now—the problem is that he's not interested. Some people want to have girlfriends. There's one boy with an intellectual disability in our neighborhood. He kept asking his parents to find a girlfriend for him so he could get married.

Q: Do you still hope that he can get married?

WY's mother: Yes, we do. We don't mind if the girl is from another city. We just hope that she will be diligent. They wouldn't have a good financial basis, but we would do our best to help with our pension. It would be better if there was some kind of matchmaking service, but preferably not with somebody with an intellectual disability. The best would be with someone who's rather normal, otherwise we don't have high requirements. But he still seems to be immature. We can wait for several more years, until he gets older and more mature. If he prefers to live with us, the bigger room can be used as the living room, while the smaller one can be their bedroom. We could build an extra room in the courtyard for us. Well, we just have our minds totally set on him. Fortunately, his current job is pretty stable.

Q: What does he usually do when he's free?

WY's mother: He normally goes cycling in the morning, and plays some games when he's back. Around lunch time, he goes cycling again. That's it. He's reluctant to go out. Sometimes his cousins ask him to hang out with them. If it happens to be his dayoff, he will join. Otherwise he will refuse to change his shift, no matter how hard we try to persuade him.

Q: Then how about during his annual leave?

WY's mother: We will take him out travelling during his annual leave. Now that we have a car, it's flexible whether we go to a nearby or farther away place. Last year we went to Anji⁶ in July or August. This year we didn't travel because he didn't want to. His cousin has asked him if he's willing to go with her to the US next year, when he can have over 10 days of annual leave, but he said no.

Q: Did he say why he didn't want to go?

WY's mother: He didn't say. I suspect that he's afraid of getting lost and not being able to find the way back home, in case something unexpected was to happen. If we go too, he'll go. But if we won't go, he won't either. I told him there's nothing to be afraid of. When he was little we also let him go out alone. "If you get lost, just take a taxi home. When you arrive, we can come out and pay for the taxi. Go on, don't worry about not finding your way home." But he still doesn't want to do it... Hey,

⁶In neighboring Zhejiang Province, China.

are you married? When you are about to have a baby, you must be cautious with everything. Bear and rear a good child.

Q: So he was just squeezed during the delivery?

WY's mother: The hospital didn't admit it. We wanted to sue, but we were told that it might have been easier if the problem started when the kid was staying in the hospital. But we only found the problem after he had been home for more than 10 days... We have had him checked but now his hydrocephalus hasn't got better. Now that he has grown up, it's getting less obvious that his head is big. His dad has small bone structure, so I hope that he could be more like me, to have bigger bone structure. I also made him buy dumbbells and that sort of thing, to exercise. As a result, he now has a pretty strong build, and his head seems not as big.

I have a colleague, whose child also had hydrocephalus. But now the kid has become a lawyer! She also suffered from hydrocephalus when she was little. The treatments didn't deliver obvious results so they just let it be. Later it was gradually cured by itself. Afterwards her study was still not so good, but she started to teach herself law. She became more and more interested, so she went for the lawyer test and even passed it. Now she has her own law firm. You see, this is really hard to predict. I asked my colleague if her daughter's head is also big. She said that it is also pretty big. So I always concluded that my son didn't study hard enough in elementary school. If he had studied hard, maybe he could catch up. He didn't work hard at the time, and we felt sorry for him for having gone through such a big illness and having poor health. This way his performance just got worse and worse. Actually, if we were a bit stricter with him, he would be better. To some extent, his big head ruined his appearance. When we go out, there are always people who will stare at him. When he was little, if people stared at him, I would have scolded them. Now he has grown up, I just let it go. Once in the metro people were staring at him, then I asked them, "Do you stare at him because he looks weird?" They became embarrassed. Look, what is worth staring at? If you stare at him, the kid might feel sad and so would we as parents. But others just keep on staring. Not just that, they would even whisper with each other. Don't you think that is annoying? It really makes us sad.

Q: Yes, for sure. As a conclusion, please tell me your expectations of society.

WY's mother: We just hope that society can provide them with some kind of security. But probably we shouldn't ask too much. Nowadays a lot of normal kids are also jobless. So we only hope that he can always have a job, which allows him to be independent and self-supporting. It's impossible to expect him to get rich, you know. When we get older, we can stay at an old people's home. Look, if my son gets married, I could set my mind at ease. But if he doesn't, how can I stop worrying and stay at the old people's home? So the country should have a system to guarantee their lives. They must have a job. Staying at home is not a solution. That way they would only get sillier.

Interview with WY's Co-worker (I)

Interviewee: Restaurant Manager

Interviewer and writer: Zhuojun Zhang

Interview date: October 28, 2016

Interview place: Restaurant where WY works.

WY Is Self-motivated

Q: How long have you known WY?

Manager: Three or 4 years now.

Q: Could you please describe what kind of employee he is?

Manager: He is quite self-motivated. He will remember very well the things you teach him. I must say that he is a pretty good one among all the employees being cared for.⁷

Q: Is he a quick learner?

Manager: For completely new things, it will take some effort. But he accepts things pretty well. And he can accomplish tasks according to our standards.

Q: Could you please describe the procedure for them to learn a new product?

Manager: First of all either the Training Manager or I will demonstrate it, while he observes. Then he will get materials in written form to memorize at home. The next time he will try it by himself. If there's any problem, we will point it out on the spot. Normally this won't be too difficult for WY. He can usually do it well during the first trial.

Q: I observed today and noticed that, as a leader, you could sometimes criticize an employee seriously, but you didn't really criticize WY. Is it because you have different requirements on him or is it because he performed well?

Manager: Our employees are divided into different levels. Due to the current promotion, we all wear the same uniform. That's why you couldn't distinguish who is in the management team, who is superior and who is at a lower level. What you saw today was that I criticized our employees in the management team. But it was not just for what happened today, but for a lot of things that have built up lately. As for the employees being cared for like WY, we need to be flexible. They have their ability limitations. They are our employees being cared for. Therefore, we shouldn't treat them in the exact same strict way as we treat our employees without disabilities. We would apply moderated requirements on them. And we guide them gently and skillfully.

Q: According to my observation today, though WY is an employee being cared for, he responds quite quickly in all aspects.

Manager: Yes, he does.

⁷In Shanghai Papa John's, the employees with disabilities are referred to as "employees being cared for." (爱心员工) Words such as "handicapped" are not used.

Q: He hardly makes mistakes. His EQ is pretty high. He takes initiative to help others. I don't feel that he's very different from normal people. Do you see the difference?

Manager: If you just meet him for the first time, you can hardly tell the difference between WY and employees without disability. He responds quickly. And because he's been here for 5 or 6 years, he is very familiar with others. He will voluntarily help others, and he gets along with them pretty well. But sometimes it can be hard for him to look at things from a different perspective. But anyway, this happens very rarely. If it does happen, we will give him rules and regulations to follow or we will guide him. Normally there won't be any serious issues.

Q: Do you know much about how the colleagues get along with each other?

Manager: Actually, the relationship among colleagues is pretty much like it is among classmates. Small conflicts are certainly unavoidable. But WY has a pleasant personality. The key point is: they've been colleagues for years, not just 1 or 2 months. Other employees all know that they are employees being cared for, so they won't haggle over the conflicts too much. Therefore, they all get along pleasantly.

Interview with WY's Co-worker (II)

Interviewee: Team Leader

Interviewer and writer: Zhuojun Zhang

Interview date: October 28, 2016

Interview place: Restaurant where WY works.

He's Like a Gentleman

Q: WY is one of the employees being cared for. How many of them are there in this restaurant?

Team Leader: There are four.

Q: Could you please evaluate WY's performance among the four?

Team Leader: They are all good. Actually, they are all pretty good.

Q: What are the good things about WY?

Team Leader: He is already an old employee, so he takes initiative. Besides, he sets pretty high standards for himself at work.

Q: How would you describe WY's personality?

Team Leader: WY is... I wouldn't say reserved. He's rather like a "gentleman", with a cautious personality. He has high requirements of himself, and he's quite open and sanguine. If you know him long enough, you will see this side of his personality.

Q: I noticed that he works fast and understands well. There is hardly any difference between him and persons without disabilities.

Team Leader: True, no difference.

Q: Is there no difference at all or just a little difference?

Team Leader: Just a little difference.

Q: Where do you see the little difference?

Team Leader: Actually, the difference is so little that you can hardly tell. I've been working with him for more than 2 years. I can say that he could be quite stubborn. But even normal people can be stubborn. That's why I feel like he's not really different from persons without disabilities.

Q: So you are the leader of WY's team. What exactly does he do in the kitchen?

Team Leader: His task is to prepare the dough.

Q: Is this his only task?

Team Leader: He is also capable of doing other tasks, but mainly he prepares the dough. This includes two steps—to knead the dough and to prepare the pizza crust.

Q: Why does WY get this task?

Team Leader: When WY started working here, he was trained to work on this position. Everybody has a fixed position, so we put him on this one.

Q: How long has he been working here?

Team Leader: Probably more than 8 years.

Q: That's pretty long. When did you start guiding him?

Team Leader: I came here 2 years ago. I don't know who my predecessor was.

Q: What do you usually do when guiding him?

Team Leader: My task is to keep on reminding him about some of the company rules, for example standards for the dough and requirements for the pizza, so that he can do it better.

Q: How is he doing?

Team Leader: Very well.

Q: Do you apply the same standards to him as you do to others?

Team Leader: We actually treat every employee equally. We won't give them extra favor because they are employees being cared for. I have had contact with more than ten employees being cared for. I feel that they are not so different from persons without disabilities. They might learn things a bit slowly, but some persons without disabilities can also be like that, if they are not so smart or if they are lazy. Therefore, I have the same requirements for all employees, and I treat them the same way.

Q: If an employee being cared for does the same thing as others, would he get more compliments?

Team Leader: We don't treat them as kids, but as adults. It's like that.

Q: Is it better for their self-esteem if they are treated equally?

Team Leader: Sometimes we make jokes with WY about being "special", such as "Ah, you have a Special Card!"⁸ After some time, they become less sensitive about this subject and they will also make jokes with us about being "special".

Q: How do the employees get along with each other? Do the employees being cared for and others spend time together?

⁸This refers to the Disability Certificate of the People's Republic of China, a document issued by the government to people with disabilities.

Team Leader: All employees get along with each other naturally. We are not separated into groups. We all spend time together.

Q: Do the employees have some activities together after work?

Team Leader: Honestly speaking, our job is rather heavy. We are all pretty tired after work. So usually we take a rest at home when we have a dayoff. But we do have activities like having dinner together. But the parents of the employees being cared for might worry about them, so usually they will go home early if it's an evening program. It's not that we don't want to include them, but they normally won't stay later than 9 o'clock. If it's too late, they might get lost or they might be afraid.

Q: Has WY ever had any conflicts with his colleagues or leaders?

Team Leader: No, he hasn't. As far as I can remember, I've never had any conflict with him. As for other colleagues, they have never argued, because the workload is quite heavy, so nobody would even have the energy to quarrel.

Interview with Mr. WY

Interviewee: WY

Interviewer and writer: Zhuojun Zhang

Interview date: October 28, 2016

Interview place: Restaurant where WY works.

Q: Let's start with things that happened in your childhood. Do you still remember anything when you were little?

(WY shook his head and didn't answer).

Q: You don't remember much, do you? I just want to know if there's anything that is especially delightful, something that you can remember.

WY: No, I can't think of anything. Nothing at all.

Q: Maybe hanging out with friends or classmates?

WY: I've forgotten almost everything about that.

Q: Then is there anything unhappy?

WY: That would be when I got criticized by my parents.

Q: What for?

WY: For talking back, or not listening to them.

Q: I have just interviewed one of your ex-schoolmates. She told me quite a lot about you from when you were at school. Could you tell me about anything that happened at school?

WY: I don't really remember.

Q: Your mom told me that you were the monitor of your class. Do you remember anything from when you were monitor?

WY: I don't remember much about that, either.

Q: Okay, then we just move on. Did you go somewhere for the October 1st holiday?

WY: We visited some relatives.

Q: Your mom told me that your cousins really want to travel with you. Where do they want to go with you?

WY: Water parks like Maya or Bi Hai Jin Sha.

Q: Did you go?

WY: I don't really want to go, because I prefer to stay at home.

Q: Why?

WY: I can't explain. I just feel that staying at home is better than anything else.

Q: Do you know what we call that? "Home body".

WY: (Smile) Yes, I prefer to stay at home and don't want to go out.

Q: No matter who asks, you just don't want to go out?

WY: Exactly.

Q: You don't like travelling much?

WY: No, I don't like it.

Q: Then how about visiting relatives?

WY: If my parents ask me to go together, I will first check if it's with my parents' friends or with relatives of my mom's sisters.

Q: In which case are you more willing to go?

WY: I prefer to visit my parents' brothers or sisters.

Q: Do you like spending time with your elders?

WY: Not really. I seldom spend time with my elders. Chatting with my cousins is more relaxing.

Q: What would you normally chat about?

WY: Nothing in particular. Just talk about whatever comes to my mind.

Q: Besides your relatives, who are now your good friends?

WY: My colleagues at the restaurant, and the Duty Manager.

Q: Do you still keep in contact with your friends from earlier times?

WY: No, not anymore.

Q: Do you hang out with your good friends? Oh, you said you prefer to stay at home.

WY: Yes (laughing).

Q: Do you contact friends when you are home?

WY: No, I don't. We just chat when we see each other.

Q: Are your parents different in the way they treat you? For example, is Dad stricter and Mom more amiable?

WY: Well... they are more or less the same, no difference.

Q: Are they liberal with you or are they quite strict? Do they have very high requirements of you?

WY: They are quite liberal. I don't feel that they set very high requirements for me.

Q: What do you talk about with your parents when you are home?

WY: It seems that we don't talk much. We just mind our own business.

Q: By the way, your mom is looking forward to seeing you getting married. Do you want to have a girlfriend?

WY: Not now... and I haven't wanted to in the past either.

Q: Hasn't everyone thought about that at some point? For example, what type of girl you like?

WY: I really have never thought about it.

Q: Just now I interviewed one of your colleagues. She has married and has recently given birth to her child. Have you ever thought about having your own family?

WY: If I want to get married, my parents will be very strict. Even when I just have a relationship, they will be very much involved. They would request to see the girl, or others might want to check how the boyfriend looks. The parents will give a lot of opinions. I just think that it would be quite troublesome.

Q: Yes. Many of my friends and I all think that it would be quite troublesome. But in China, parents' opinions are essential for marriage. That's the case for everyone.

WY: Yes. You will have to get the permission of your parents.

Q: So, have you never thought about marriage? Or, do you think it would be so troublesome that you don't even want to consider it?

WY: It's too troublesome to get a girlfriend.

Q: In case you get married, would you want to stay together with your parents or would you move out?

WY: Uh... I'd move out.

Q: Why?

WY: I will have to be independent after all. I should also take the responsibility for my own kid.

Q: That's true. Just now your superiors were all giving compliments about you. They said that you set high requirements of yourself. I heard that you call the Restaurant Manager "Boss". It sounds very close. Have you known him for a long time?

WY: He used to be the Restaurant Manager of Da'an Branch, where I worked before. When that branch was closed, we both came here.

Q: Now that we are talking about your work, can you describe your daily schedule? For example, when do you get up and when do you arrive at work?

WY: I get up between 6 and 6:30 am and leave home around 7:45. I can arrive here by 8:05. My work starts at 8:30 am and finishes at 7 pm.

Q: What does your workday normally consist of?

WY: Preparing the pizza crust, and sometimes I substitute if any post doesn't have enough people.

Q: How long have you been working here?

WY: I started on July 16, 2009.

Q: You remembered well! Some other things you might not remember precisely, but this date you did remember clearly. So, you've been working here for more than 7 years. Have you always been preparing the crust?

WY: Yes, that is my task.

Q: So you must be very skillful at doing that. Would you have the opportunity to act as a trainer, now that you've done this for such a long time?

WY: I was indeed offered a promotion to become a trainer. But I think that I haven't mastered the theory well enough and therefore might not score well when

taking the written test. So I refused it. If you can't pass, you won't get the promotion anyway.

Q: So you think that you wouldn't pass the written test and therefore don't want to get the promotion?

WY: Yeah.

Q: Why don't you give it a try? Sure, if you can't pass the test you won't be promoted, but if you don't try, you'll never know.

WY: (With a bit of a spoiled tone) I just don't want to do it.

Q: But if you try you can become a trainer. Right?

WY: As a trainer you need to supervise others. I always feel that I can't even manage myself well enough. Besides, I also don't want to be a trainer. All I want is to fulfill my current tasks.

Q: Okay, I understand you. What do you usually do during your lunch break?

WY: Just eat and play with my mobile.

Q: What do you normally do with your mobile? Internet surfing? Playing games or watching video clips?

WY: Playing games.

Q: Which game are you playing currently?

WY: Snake Off.⁹

Q: So when you get home after seven in the evening, you will have dinner. Does your mom cook or do you cook?

WY: I live with my parents, so they cook.

Q: Have you ever cooked for your parents when you are at home?

WY: No, I haven't.

Q: Oh! Didn't you major in cooking?

WY: I majored in noodles and pastries.

Q: Oh, but then you could also make some noodles or pastries at home, right?

WY: I don't have so much time at home. Besides, after a whole day busy at work, I will also need some rest when I'm at home.

Q: Who will keep your salary, your parents or yourself?

WY: I gave my bank card with my salary to my parents. They give me 100 yuan every week as an allowance.

Q: How would you spend your allowance then?

WY: Buy some snacks, like cola and chocolate, that kind of thing.

Q: Would you top up money for your games?

WY: I don't like to play games that require topping up. I don't want to be a cash player. I just try my best.

Q: Do you watch TV?

WY: Yes, I do.

Q: What are you watching these days?

WY: Pleasant Goat and Big Big Wolf.¹⁰

⁹The Chinese version of a fun casual game that requires speed and strategy.

¹⁰A Chinese cartoon series especially popular with school children.

Q: I also like it a lot... To finish up our interview, could you please talk about yourself? According to yourself, what kind of person are you?

WY: I... I like to be quiet. I don't like to be too active. In terms of friends I like the same—I prefer to be friends with relatively quiet people.

Observation of WY at Work

Observation date: 10:00–19:00, October 28, 2016

Observation place: Restaurant where WY works

Observer and writer: Zhuojun Zhang.

Time	What WY did	Remarks
10:00		There are only two people in the restaurant, WY and the Restaurant Manager
10:04	WY walks around, prepares ingredients, and switches on the exhaust system, etc.	WY is familiar with his tasks and acts very quickly
10:14	WY examines if there's any expired ingredients, with instructions from the Manager	The Manager discovers one expired ingredient, and scolds WY slightly
10:16	When the courier from the Baidu Takeaway Service comes, WY hands over two packed pizzas to him	The Manager works now at the cashier counter in the dining area
10:18	Another staff member shows up and discusses various issues with the Manager and WY	
10:20	WY prepares ingredients at the preparation table	
10:23	WY kneads the dough, prepares the crust, spreads the sauce, adds ingredients and puts it into the oven	
10:28	WY discusses with a colleague about how to make a new product	
10:31	WY makes a pizza and puts it into the oven	
10:32	WY checks the status of the two pizzas in the oven, together with a colleague	
10:33	WY receives an order request for two portions of chicken wings A colleague asks, "Are the onion rings ready? We need seven more portions of them"	This "colleague" is in fact the delivery person of the restaurant. He doesn't participate in the food preparation. Now WY is the only person in the restaurant preparing food

(continued)

(continued)

Time	What WY did	Remarks
10:34	WY discusses with a colleague at which temperature he should set the oven and waits for the pizzas to be ready	
10:38	WY goes to the dining area and asks the Manager how he should handle one particular order	The Manager comes into the kitchen and explains the handling procedure of a “Reserved Order”. He says, “Remember it—this is the second time I’ve told you the difference between a reserved order and a postponed order”
10:44	The Manager calls WY to help clean the hand-washing table and the hand soap dispenser in the external site. He then refills the dispenser	
10:50	WY brings out the hand soap and puts it in place	Now other staff gradually arrive in the restaurant, preparing to start their work
10:55	WY kneads the dough and makes pizzas	
10:58	WY adds more ingredients onto the preparation table	
11:06	WY kneads the dough, makes pizzas and puts them into the oven	WY makes eight pizzas in a row. He works very fast
11:22	WY waits for instructions at his post.	Up to now there’s not a single dine-in guest. All orders are for takeaway
11:32	Two dine-in customers come in. WY begins to make pizzas. He makes three or four more pizzas	
11:47	WY cleans up the preparation table and waits for orders	
11:53		WY goes behind the kitchen and is out of sight
12:15	WY comes back to his preparation table and makes a pizza	
12:20	WY makes two more pizzas and goes inside again and is out of sight	He probably goes to help colleagues make snacks
12:24	WY kneads the dough and prepares the crust	
12:30	WY fetches something from the freezer and puts them down	WY goes out of sight regularly
12:37	WY makes one crust and gives it to a colleague, who spreads the sauce and arranges ingredients on it	
12:38	WY goes to check at the ordering desk, and voluntarily answers colleague’s question about “which order is for which table”	

(continued)

(continued)

Time	What WY did	Remarks
12:42	WY makes a pizza	
12:49	WY sees a colleague carrying a heavy box with used tableware, who wants to get into the internal site. He voluntarily opens the door for him, and puts out a new empty box	
12:53	WY kneads the dough and makes pizzas	
12:55	WY noticed that the water kettle in the external site is empty. He voluntarily refills the water. And he refills the ketchup bottles there	
12:59	WY waits for further instructions	
13:05	WY is constantly out of sight, probably helping with cleaning in the back of the kitchen	Now the dine-in guests for lunch are almost all gone, and the waiters start to send tableware to the back of the kitchen
13:17	WY sorts out the cooking tools and takes them back to the kitchen	
13:22	Following the lead of the Manager, WY looks around to see if there's still anything to be done	WY chats and discusses work matters with the Manager and colleagues
13:30	All employees are cleaning up, wiping devices and tables	There are no dine-in guests
13:51	Suddenly two more orders pop in for WY. WY says he needs to have lunch. A colleague says that he will take over the orders	
14:00	The lunch break begins	WY eats his lunch, plays with his mobile, and chats
15:00	The lunch break ends	WY is back at his post 10 min early
15:33	More customers come in. WY takes out five balls of dough and starts to prepare pizza crusts	
15:46	WY clicks on the screen to check the order. He cleans up the preparation table	
15:51	The waiter is absent. WY helps serve	
The observer interviews the colleagues in the restaurant. The observation is interrupted		
17:20	WY prepares crust to make pizza	
17:26	WY cleans up, washes, and wipes	
17:32	WY asks the Manager about his task	

(continued)

(continued)

Time	What WY did	Remarks
17:38	A big takeaway order comes in. WY is busy making pizzas. Once he finishes, he helps colleagues prepare other unfinished items such as rice, noodles, and snacks, etc.	
18:05	WY adds and sorts out ingredients and tools	
18:14	WY kneads the dough and makes pizzas	
18:20	WY helps serve	
18:23	WY kneads the dough and makes pizzas	
18:26	WY refills water into glasses	
18:29	WY keeps on making pizzas	WY makes more than ten pizzas
18:45	WY adds sauce packets	
18:46	WY kneads the dough and makes pizzas	
18:53	WY cleans the preparation table and gets ready to finish	
19:00	WY is off work	

Translated by Ying Ding

Edited by Andy Boreham and Zijian Chen

Open Access This chapter is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits any noncommercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if you modified the licensed material. You do not have permission under this license to share adapted material derived from this chapter or parts of it.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.



Once a Supermarket Cashier



Yi Zhang

Interview with Miss S's Mother

Miss S. Female, born in 1983, only child, has moderate intellectual disability. She graduated from a regular technical secondary school in Shanghai and once worked at a supermarket. From 2008, she joined a Sunshine Home of a subdistrict in Shanghai.

Interviewee: Miss S's mother.

Interviewer and writer: Yi Zhang.

Interview dates: October 21, 2016 and January 1, 2017.

Interview place: Sunshine Home of a subdistrict in Shanghai; Tian Jiabing Building, Eastern China Normal University.

Dangerous Childbirth

Q: How did you meet your husband?

S's mother: My husband and I both studied at a vocational school in two different classes.

Q: What did you learn?

S's mother: You know, there is a factory in Shanghai making towels and sheets. My husband learned pattern design of towels, while I learned cotton textile. After graduation, he was assigned to the suburban area. Some of his classmates were assigned to Chuansha and Jiading, and later came back to Shanghai.

Q: When did you get married?

Y. Zhang (✉)

East China Normal University, 3663 Zhongshan Bei Ro., Shanghai 200062, China

© The Author(s) 2020

W. P. Alford et al. (eds.), *An Oral History of the Special Olympics in China Volume 1*, Economy and Social Inclusion,
https://doi.org/10.1007/978-981-15-5132-1_3

S's mother: In January 1983, about 6 years after our graduation. Both of us have several siblings. At that time, there was a shortage of apartments in Shanghai. So, we were mainly waiting for an apartment before we got married.

Q: Did you get pregnant immediately after getting married?

S's mother: About 2 months later. Everything was normal. The expected due date was November 15, but she didn't come out until November 20, 1983.

Q: Did you have any expectations before the delivery?

S's mother: I didn't expect anything like this. None of my colleagues, friends, and sisters encountered such a situation. My sisters gave birth to big babies. My eldest sister's baby was more than 4.5 kg; my other sister's baby was over 4 kg. Both babies were healthy. My baby was 3.9 kg at birth. Everything was normal during my pregnancy.

At that time, every family had many children, so the doctors and nurses were not as responsible and careful as they are now. It seemed that they didn't take it seriously. During my hospitalization, I shared a bed with another woman before delivery; I was sent to the delivery room when I was going into labor, and I had a whole bed to myself after delivery. There weren't enough beds.

I gave birth at the Second Textile Hospital, the designated hospital for employees in our factory.

I went to the hospital with obvious signs of labor, but my cervix remained closed during my first days there. Though both of my sisters gave birth by C-section, my mother warned me against it, as she thought a C-section could do harm to my health according to her old and conservative opinions.

I had no experience at all. I just thought that my mom must know something, since she had given birth to six children. After entering the delivery room, it actually hurt so badly, but I was too embarrassed to cry out loud. I just endured silently. Because of this, I received basically no attention from the doctors and nurses. I entered the delivery room in the evening, but I was still showing no sign of the delivery starting until the next morning. The doctors said that my cervix was not open. I really didn't understand anything back then.

The pain became unbearable the next evening. After disinfecting my skin, the nurse in the delivery room told me to lie on the delivery bed and simply said, "Go ahead." Then everyone left. This was strange. I had thought that there would be someone to help me during labor. How could they just leave me alone? It was a little past 5 pm, when they needed to hand over to the next shift. All of them went to the dressing room, thinking that I was giving no sign of going into labor, so it was okay that they took this time to get changed. My daughter was later delivered at 6:30. Before that, I felt a severe pain in my belly. That was a contraction, and the abdomen should be bloated according to the doctors. They would also ask me, "Does your belly feel bloated?" But it didn't. I couldn't understand what that should feel like. Though I had learned something about labor, I never discussed it with others. I knew little about it. The pain was not continuous, not that acute, just labor pains. I thought, "Maybe every mother feels like this." So, I just endured. I could hear them talking in the delivery room, feeling that something was pushing its way out of my belly, like

going to the bathroom. In fact, the baby had come out. But nobody was there to hold her, so, she went back in.

I guessed the doctor who sent me to the delivery room had got off work, as I heard a cry from the doctors on duty, "Oh my gosh! What happened? How come there is no fetal heartbeat? Hurry!!" The two doctors were nervous. One of them pressed my body from the chest to the belly. Then, they seemed to put on rubber gloves, reached into my belly for her and tried to pull her out, but they failed. Ultimately, they used forceps to get her out.

When she was out, I thought everything was fine, as I had no previous experience. I only knew that newborn babies should cry, but I didn't hear it. I raised my head (turning the head slightly), trying to have a look, but the doctor said, "Don't move. Lie down." To make my baby cry, they lifted her by her feet and patted her on the bottom for quite some time before she gave a feeble cry. After that, the doctor told me immediately, "A girl," and also weighed her on a scale before telling me her weight. I raised my head and finally saw my daughter; her face being partially covered with blood. I saw this for the first time. Seeing that I couldn't see her clearly, the doctor said, "She has newborn jaundice. Her condition isn't that good." As no doctors in the delivery room could treat my daughter, she was wrapped by a doctor and taken to the pediatrics department right away for emergency treatment.

I was left alone and unattended in the delivery room. I heard something dripping down into the bucket below the bed, but I didn't know it was actually blood from my belly. It was November 20, already very cold in Shanghai, but there were no air conditioners, only heating pipes on the wall. I simply wore a thin top, no pants, with a diaper on my belly, waiting for the doctors to come back and stitch my incision into the perineum. They had cut it to make my delivery easier... Unfortunately, that was painful. After the wound was stitched, I stayed in the cold delivery room for two more hours for observation before I was finally transferred to a ward. My feet were almost completely covered in blood when I got out of the delivery room. Back then, no one helped you get changed.

At that time, there was no bathroom in the ward. The next day, the catheter came out when I turned over and I had to use the public restroom in the corridor. It took a lot of effort to get to my feet and I had a difficult time trying to stand, because I was bleeding heavily. Then I just fainted in the restroom. I didn't care, though. All I cared about was my daughter.

After emergency treatment at the pediatrics department, my daughter was sent to a nursery opposite the ward. Due to inadequate conditions, all the babies slept together in a big bed the size of a big table. Perhaps to facilitate emergency treatment, my daughter was put on one end of the bed, closest to the door. I often went to check her through a small window on the door whenever I had the chance. Normally, newborn babies were swaddled, while my daughter was not, because she needed frequent medical check-ups. As she stayed in the nursery, I couldn't breastfeed her. She was fed with a bottle with a rather big nipple, which was actually easier for babies to suck. But my girl was too little. She couldn't swallow the milk, but stored it in the esophagus. Since her cardia wasn't well developed, the milk was often spat up. Therefore, the doctors didn't allow her to lie flat. She was tilted about 20 degrees

head-up like this. I often went there to check on her. All the other babies could be taken out for breastfeeding, so I asked the doctors why my daughter was kept inside. They only told me that she had jaundice, mentioning nothing else. I knew nothing, either. I just thought she would get well anyway. I only needed to wait for a few days.

In the end, she couldn't come out even after I was discharged. The doctors hid the truth from me, but told my husband that my daughter might not live for long. Back then, newborn babies were usually scored from 0 to 10 by the hospital. My daughter was 0. She had no heartbeat, and simply gave a cry even after an injection of cardiotoxic. By current practice, hospitals won't try to rescue her at all. But as the designated hospital for the large number of female employees in our factory, this hospital had quotas for C-section delivery, birth rates, and death rates. By November 20, namely the end of the year, the hospital already had no death quota, and as such they tried their best to save my child to meet the required birth rate. The doctors told my husband that due to her precarious health, she needed to stay at the hospital for observation, which lasted for about 1 month.

Q: So, your daughter wasn't with you in the month following her birth?

S's mother: While I was in postpartum confinement, my husband checked on her every day after work, telling me she was good today, and became worse another day. If I had known better, I would have forfeited her treatment. My husband told me, "The doctors said that she was recovering." I said, "As long as she recovers and she's alive, take her home." I didn't expect the following bitter experiences. I just thought I should take her home if she was healthy. After all, she came out of my womb after the long months of pregnancy. I even prepared some clothes for her, in case she didn't survive—she came into this world naked, but I wanted her to be dressed when leaving. Now that she was rescued, I took her home. At that time, she was less than 28 days old.

Fragile and Listless Due to Illness

S's mother: She was hospitalized again when she was 28 days old.

Q: Why was that?

S's mother: This is her medical record back then (showing the brochure). She suffered from neonatal pneumonia more than five times. Then she had severe asthma and was treated with a new medicine called cefradine. After that, she had stomach bleeding and was admitted to the hospital again, where we received a notice of critical condition. We were issued such notices eight or nine, if not ten times. In those days, my husband always worked overtime on weekends so that he could take her to the hospital on weekdays. He never rested on weekends after my daughter was born.

The household registration of my daughter and I were both recorded in the same register as my mother in Yangpu District, while we lived several districts away in Luwan District. At that time, one could only go to the hospitals in the same district as the household registration. So, what could we do if my daughter had a fever seizure at midnight? With barely no taxis, we had to take the night bus, which came once

an hour. We frequented the hospital at midnight. When she had to be hospitalized, she was also admitted to a hospital near our registered residence. But again, the milk I ordered was delivered to Luwan District, so I had to get the milk early in the morning, take it to the hospital, and leave the hospital after she finished. Parents weren't allowed to stay with kids. It was tough for us.

Q: Why were parents not allowed to stay at the hospital?

S's mother: When she was little, the IV was placed in her scalp. She didn't even have any hair when she was 100 days old (showing the photo). She always needed IV therapy. On these occasions, she was taken to another room where parents were not allowed, as the steps were difficult and the sights could be horrible. Anyway, my daughter spent her childhood going in and out of the hospital and taking medicine. She was hospitalized many times. Each time she was discharged, the doctor would write in her record that "this kid is intellectually disabled". I was always so mad to see the words "intellectually disabled" that I would cross them out. I felt reluctant to accept the fact, thinking about why they had to draw this conclusion when my daughter didn't come to the hospital for this. I was sad to see the note at that time. This one is from 1992. You see (flipping through a medical record), every medical record contains a similar statement. Whatever. I just hid the record at home and I wouldn't show it to other people.

Q: Did the doctors conduct any tests before coming to such a conclusion?

S's mother: No. They simply concluded based on what they saw. At that time, my daughter's eyes looked...

Q: They only judged by appearance?

S's mother: Right. But I didn't consider her as intellectually disabled.

Q: What was she like after she was discharged from the hospital?

S's mother: Her health had been poor ever since. Her cardia became normal only when she was much older. As my husband had to work, I needed to take care of her by myself. After each feeding, I had to pat her for half an hour before I could lie her down into the bed. But soon after I left for other chores, she would spit up, with vomit in her eyes, ears, and around her neck. In those cases, she needed a hot bath even in the cold winter days, when there was no proper device except for a plastic cover. No one could help me. I had to light the coal stove and get her changed on my own, leaving no time for me to eat. I just had to constantly keep an eye on her. When I wanted to start cooking as the stove was hot enough, she would vomit again. After I cleaned her for the second time, the stove had already gone out. Thus, I didn't have any time to cook at all. I didn't have much entertainment, either. I never watched TV. We couldn't afford our own TV until my daughter was 3 years old.

Always ill and listless, she didn't have enthusiasm for anything. For example, when she woke up and I took her downstairs, my neighbor would say, "Ah, Mrs. Zhou, why is your daughter sleeping?" It seemed that her eyes were always narrowed, but the truth was that she didn't have enough strength to open up her eyes. She always looked ill. I could only joke that, "My daughter has small eyes."

She was late in talking and toddling. Due to illness, she remained weak. She often tripped over and fell while walking. In the past, old houses in Shanghai had garrets, the door of which led to the staircase. I installed a small door in addition to the main

entrance, so that she could see me from the garret through the closed small door while I was working downstairs. But she wanted to go downstairs when she grew older. I told her, “Come down here, but be careful, hold the stairs.” Then she would come down, with her feet followed by her bottom.

The coal stoves heated up quite slowly. To make it faster, my neighbor made something like a chimney with iron sheets and put it in above the stove to attract the wind. After the fire was made, this object was placed next to our staircase. My daughter fell down the stairs while she was trying to come down, and her forehead was scratched on the iron sheet (pointing at the forehead). She started bleeding and I could even see her flesh. In those days, we had good neighborhood relationships. I yelled “uncle”, then my neighbor immediately carried my daughter to the hospital. I followed as well. It was late. There was no emergency treatment at the ophthalmological department. So, we went to the surgical department, where a doctor asked me and my neighbor to fix her head and feet respectively, cleaned the wound roughly and stitched her wound without any anesthetics. The stitches were very long. The ash was even left inside. Until now, this tiny scar still remains above one of her eyebrows with the dust inside.

Considering her situation, I proposed to change to another job in Luwan District as no one could help me. At my home, though I got married, I had five other siblings, so my mother still shouldered a heavy burden. She had to work and take care of my younger sisters and brothers. As for my mother-in-law, she had three other sons to take care of. In terms of commute, I needed to set out every day from my home in Luwan District, took the bus, transferred the routes twice, and took at least 2 h before I arrived at the office on the Jungong Road in Yangpu District. I also needed to work early shift, noon shift, and night shift. I was allowed to take 1 year off to take care of my daughter after she was born, but I had to go back to work when my leave ended. How could I do that with my daughter ill at home? So, I changed to a different job in Luwan District, which was near my home.

Hard Days in the Kindergarten

Q: Did she go to kindergarten?

S’s mother: Our factory has its own nursery and kindergarten. I took her to the kindergarten when she was the right age. There were two aunts taking care of many kids there. They either put my daughter in a chair designed to prevent falls by making her sit down before she might fall, or tied her to a small chair with a spittoon under it to prevent her from falling off. My heart hurt at the sight, but I had no choice. If I complained, the aunts would say, “How about taking her home and looking after her yourself?” So, I could only bear with it, leaving her in the kindergarten.

Over time, when people in the kindergarten realized that there seemed to be something wrong with my daughter, they kept asking me to take her to do an IQ test. The head of the clinic of our factory told me, “Take your daughter to test her IQ and see how it is going.”

I was disgusted and couldn't understand why they treated her like this. I thought maybe they wanted to drive my daughter out of the kindergarten. But I really had no other choice. The current arrangement was the most convenient option for me, because I could take her there on my way to work and pick her up when I got off. If I had to send her to a kindergarten for kids with ID, she would have been worse off. So, I just procrastinated.

I was aware that she had some shortcomings, but I just couldn't face it. I never considered her as an intellectually disabled kid. I am a person of strong character. In my opinion, she was just dim-witted, since kids may vary in their intellectual level. I believed that slow birds should fly ahead. Actually, it was painful to have a kid like this. I knew the kindergarten intended to drive my daughter to a special kindergarten with the excuse of the IQ test, but I decided to not let them succeed. I just kept on refusing their demand.

The kindergarten was not well equipped. Outside the classrooms, there was a long corridor. Next to the corridor was a balcony with square columns. Once, her teacher was sitting there, legs crossed, and chatting with others. My daughter tripped and bumped against the edge of a column. A new vertical scar was thus added to her original horizontal one. The clinic of our factory used a new medical glue to treat it. Though no stitches were needed, the wound would open when my daughter cried. I said, "This is not working at all. You must take her to the hospital!" Again, she got more than ten stitches. You can still see the scar now. "I was really sad," no parent could bear to see their kids injured like that.

After she was discharged from hospital, the factory granted me a leave of several days to take care of her. At this moment, the leaders of the kindergarten visited us, trying to convince us not to take my daughter back to their kindergarten, because they "couldn't shoulder the responsibility". This was ridiculous. I didn't even have the chance to complain about it. So, I firmly refused their requirement to send my daughter to a special kindergarten. At last, we negotiated an agreement with this affiliated kindergarten through my supervisor, saying that we would be responsible in case my daughter had any further problems.

During that period, my daughter was ill and hospitalized; my husband still worked overtime so as to be able to accompany her on weekdays, while I brought dinner to the hospital after getting off work. This was because my meagre salary would be deducted if I took leave. During 8 weeks of hospitalization, I visited my daughter every day. It was lucky that my factory understood my difficulties, granting me leave if we weren't that busy.

I knew that kids would start to learn to read and acquire new knowledge in kindergarten, but as a slow learner, my daughter wouldn't be able to keep up. The first day she was admitted to the kindergarten, I enrolled her in an afterschool *pinyin* class at my own expense, because I believed that this was very important. At that time, kids didn't learn *pinyin* before primary school. I wanted my daughter to learn earlier. It turned out to be helpful.

In the meanwhile, we kept taking my daughter to Ruijin Hospital at our own expense. The doctor kept a record of my daughter from her birth to 3 years of age, according to which he found that my daughter had been improving. The doctor always

encouraged us, “Other kids may learn quickly after being taught once or twice, but she can also learn if you teach her 10 times, or even 30 times. It will work.” Thanks to this, we always had hopes of my daughter getting better. With her dad and me taking care of her, she wouldn’t encounter difficulties at school. Otherwise, we would have given up over time.

Q: Did she like the kindergarten?

S’s mother: No, but she had no choice. There was nobody at home to take care of her. Simple-minded and timid, she didn’t talk much about things in the kindergarten. Once, we met her aunt. She worked in a hair salon in Hong Kong and braided my daughter’s hair. It was beautiful, no one had ever seen it before. But when my daughter returned from kindergarten, she told me that people gossiped about her looks. She couldn’t understand why her teacher criticized her hairstyle and asked other kids not to play with her, while other people said it was pretty. Her dad was furious. He questioned the teacher the next day when he took her to the kindergarten, “How could you treat her like that?” Of course, the teacher denied it. My husband failed to control his temper and they had a quarrel. Later, I tried to mitigate the conflict and explained, “My husband is ill-tempered. There must be some misunderstanding because my daughter didn’t communicate clearly enough...” There was no use. The teacher continued to ignore my daughter and asked other kids not to play with her. My daughter was left alone in a corner whenever they were having some activities.

Once, all the other kids in her class went to a supermarket to learn about vegetables, but my daughter was sent to the junior class. During the break, the kindergarten required everyone to pee together. My daughter didn’t want to pee at that time, but she wanted to defecate during the class, which wasn’t approved by the teacher. Eventually, she pooped her pants. It was a cold winter day. When I got off work and saw her pooped pants, I had to borrow a pair of padded pants from my colleague who lived nearby and take my daughter to have a shower in the bathhouse of the factory. I had no choice but to put up with it.

In another case, my daughter was left alone again in the junior class. The teacher of that class also felt upset, just asking her to sit alone in the yard, where the teacher could see her through the door of the classroom. I happened to check on her during spare time, as I didn’t feel reassured. “This is strange, where’s my daughter?” “In the junior class.” “But she wasn’t there, either!” Then suddenly, I saw her... I couldn’t complain to anyone, because she had to stay there. Anyway, I felt depressed at that time. Few people seemed to have any sympathy for us.

Due to illness, she was weak and had a poor appetite. She didn’t like the food and would always cry at lunch. I saw it many times that my daughter didn’t want to have dinner. So, I told her teacher, “Please don’t give her so much food. Just take it away if she doesn’t eat. Don’t force her.” Every time when I went to the kindergarten to check on my daughter after lunch as my work at the canteen was done, I saw my daughter standing and eating next to the trashcan containing leftover food, with a bowl of cold rice in her hand. It was already 1 pm. Who could bear to see this? I was really angry, but still, I couldn’t complain. It wouldn’t work. I just emptied the bowl and told my daughter to give the bowl to her teacher, but she didn’t dare to. Then I took the bowl and tossed it on the desk without a word. What could I say?

Q: Did her teacher punish her because she didn't finish her meal?

S's mother: They always forced her like this. I had told them to give her less or take her meal away if she was full. I wouldn't blame them for it. I could still feed her after school if she was really hungry. But they wouldn't listen. I already treated them well enough. When they came to the canteen during lunchtime, I gave them more food in larger bowls. We seemingly got along well, but they despised my daughter. The nutritionist of the kindergarten's separate canteen always looked at my daughter like this (showing an expression of disgust), so did her teacher in charge. I felt upset, but I couldn't say anything, or my daughter would suffer more.

Q: Did this situation continue throughout her days at the kindergarten?

S's mother: Yes, but she also met some good teachers. Teachers would change from junior class to the senior one. When she was in the senior class, a teacher surnamed Xu and an old aunt were very kind to her. In the music class, my daughter could hum the prelude after the teacher just taught them a song for several times. This attracted the teacher's attention, who pulled my daughter closer to observe her carefully. Though my daughter was simple-minded, she could understand it. She would take her stool and sit really close to this teacher when everyone was sitting on the small playground, for example, because she knew the teacher was kind to her. The teacher found her adorable despite the intelligence level, so the teacher encouraged her and told her, "My dear, you can do it." Because of this, she enjoyed her days in the senior class.

Q: Did she like singing?

S's mother: Her teacher found that she could hum the prelude, I discovered her interest in singing, too. As we didn't have a karaoke machine at home, she liked to sing on her bed like this (gesture with hands), pretending to hold a microphone in her hands. Later, I managed to buy a stereo so that she could sing to music. She learned to talk much later than other kids. I still encouraged her to sing even though she wasn't good at it and couldn't sing clearly. People often said, "Oh, she doesn't sing well. I can't even understand the words." I replied nothing. I was used to that kind of comment. I didn't take them seriously. I just told her to sing whenever she liked. She can sing pretty well now.

Study Late into the Night

S's mother: As she grew older, she needed to attend primary school in Yangpu District. She had just recovered from stomach bleeding by then. How could I take care of her while having to go to work in another district? So, I asked my mother-in-law, "Would it be possible to transfer my daughter's household registration to your residence? I promise I'm not after your house. I know it's for my brother-in-law. I only want my daughter to go to school here." She agreed.

This way, my daughter was admitted to a school affiliated to the railway system not far from my mother-in-law's home. The teachers there were relatives of the railway staff. They were really nice. As they only knew that my daughter was weak, but

nothing about her previous story, they took good care of her, and often praised her even for minor progress. She was good at *pinyin*. This was the only exam that she got 100. In the first semester of her first grade, she got 80-plus for Chinese and 70-plus for math in the final exam.

When we went to the Ruijin Hospital again, the doctor was satisfied with my daughter's performance in the exams, saying, "Wow. That's not bad. Not bad!" That was based on my daughter's real situation. Since the doctor said her performance was "not bad", we thought she was not bad as a beginner, and that she would be better when she grew older.

Each piece of my daughter's bones was X-rayed and subject to X-chromosomal analysis, but we still didn't know the cause of her problem. My husband and I are just common people, while her problem resulted from the incident at her birth. The doctor kept encouraging us, "She will be fine. Her problem is not caused by congenital or genetic diseases." It's all because of his encouragement that we didn't give up.

Though I went far for work, I still needed to go back to my mother-in-law's after getting off. There were five people in the family, including my brother-in-law. Only receiving a little allowance from my mother-in-law, I was the one who covered basically all the daily expenses and kept paying for everything. When my daughter was in the third grade, about 7 or 8 years old, my mother-in-law said, "Your brother-law will soon get married. Are you considering moving back to your own apartment?" Her words made sense, so, my daughter was transferred to another school in our district.

My mother-in-law lived in Yangpu District, but we had moved from Luwan to Hongkou District. The new school never considered student's previous performance, but required all transferred students to take an exam to see whether they could go up to the next grade or stay down. Shanghai schools used two kinds of textbooks, one was the S version and the other, H version.¹ The former was simpler. My daughter used S at the previous school, but changed to H in the new school. After the test, she needed to repeat the third grade again. I couldn't tell the differences between the two versions of textbooks, but I thought it would do no harm to repeat a grade and lay a solid foundation. However, as the two versions of textbooks varied in difficulty, my daughter's academic performance became poor. The teachers weren't so nice, either. They didn't like slow kids. She struggled all the way up to the sixth grade. Every time when the school bell signaled end of class, my daughter would rush to the bathroom to avoid being bullied by her classmates.

Q: Didn't her teachers stop the bullies?

S's mother: The teachers didn't know, and she didn't dare to report. Once, she came home with swollen lips, telling us that a boy pushed her to the floor and kicked her. Her dad was mad at this. But he didn't handle it properly. He took my daughter

¹In the mid-1980s, the state government allowed the adoption of one or several syllabuses, and several versions of textbooks in some disciplines in some regions. Shanghai published two versions of Chinese textbooks under the curriculum reform. One of them was the H version edited by the East China Normal University and the Education Bureau of Xuhui District, the other one was the S version edited by the Shanghai Petrochemical Complex and the Education Bureau of Zhabei District.

to the class the next day, didn't contact the teacher in charge first, but directly went to the classroom and asked her to identify the boy who had kicked her. Soon as my daughter pointed at a boy, he kicked the boy hard at his bottom. Later, the teacher said to me, "Your husband shouldn't have kicked the boy. It'll be trouble with the kid's parents." I said, "Come on. My daughter has always been bullied. We cannot take more of it. But you are right, my husband shouldn't have kicked the boy. He should have contacted you to get in touch with the boy's parents to talk about this matter." Finally, the teacher called the boy to his office and told him, "Her parents were angry when they found out that you have been a bully and hurt her. Don't tell your parents about this, you know? Otherwise, when both parents start to fight, you won't be able to handle the consequences." The boy was frightened and we were not pestered anymore.

She struggled to graduate from primary school. Generally, these schools didn't issue graduation certificates. However, I went back to the school after some time, explaining my daughter's story. Others might not care about this certificate, but it meant a lot to us. Finally, the school issued a graduation certificate specially for her, with a seal on it. I was extremely happy about her graduation. The doctor at Ruijin Hospital was also glad to know this.

Q: Did she like any of her teachers in primary school?

S's mother: Her teachers were nice to her when she studied at the school affiliated to the railway system in the first, second, and third grade. When she transferred to the new school and repeated the third grade, due to her poor performance in exams and (odd) appearance, the teacher there didn't like her. The teacher told my daughter to her face, "You look so ugly. How come you don't look like your father and mother?" My daughter had grown up a bit. These words always made her feel inferior to others.

Her eyes also suffered from serious problems. She started wearing glasses even before going to school. Actually, the size of her both eyes were the same; the pupils and eye white were also of normal size, but they were not in the right position because of contamination by the amniotic fluid at birth. Her eyes had more white and her pupils were smaller. She also suffered from anorthopia and amblyopia. As I enjoyed 50% reimbursement of the medical expenses through the factory's insurance until she was 16, we had been trying to cure her eyes during those years. Before reaching 16, the doctor said that she was able to accept the operation. So I took her to the Tongji Hospital for the surgery. It was painful. The doctor was actually quite considerate, since the operation wouldn't be possible nowadays due to its danger. He also advised, "We should try to avoid general anesthesia for kids like her", as he could tell that she was intellectually disabled and general anesthesia might harm her brain. But unfortunately, considering the optic nerve of kids could be very sensitive, we had to carry out general anesthesia eventually, and pulled the nerve to a specific position with a certain distance to the center, but not the exact center. This was because when my daughter grew up, the nerve would gradually come to the center, just like now. You can still tell a slight difference if you look carefully.

After that, I accidentally got pregnant again. My husband and I were determined that we didn't want another child. Our house was small, and we barely had any savings. My daughter also attended expensive afterschool classes.

Q: Did she need extra classes?

S's mother: Of course! She had extra classes for math, Chinese and English.

Q: Did it work well to have extra classes?

S's mother: Just so-so. The teachers only wanted to make money, asking students to do exercises. Every day, my daughter couldn't finish her homework before midnight; we also tried to help her with the exercises. Though I still worked three shifts, I didn't even have any time to take a nap between the shifts, as I kept trying to figure out the answers to her exercises. From the first to the third grade, I could be of help. But after she went to middle school, it was indeed beyond our capability. Studying up to midnight, she tended to fall asleep, but we had to wake her up, urging her to finish the homework. Due to her precarious health, she couldn't afford to stay up like that. It was a vicious circle. She would faint when we took her outside on a hot day.

At night, I had to hold her in my arms when she slept, otherwise she would have had difficulty breathing. I stayed up late and went to work early in the morning. That explains my poor health now. Her teachers didn't know about her condition. They couldn't understand it, either.

Q: You mentioned that she couldn't finish her homework before midnight. What grade was she in?

S's mother: Since the third grade, when she was transferred to the new school. The new H version textbooks were harder for her. From the third grade to specialized secondary school, she always went to bed around midnight. Her dad stayed up with her.

Q: What about summer and winter vacation?

S's mother: She stayed at home alone. Her dad and I needed to work, and my office was far away. I asked her to do a certain amount of homework every day, but she always procrastinated. Sometimes, she encountered difficulties. She would just wait for us to do the homework with her after we were back and finished the housework. As her homework during summer and winter vacation was relatively easier, she didn't need to stay up late.

A Kind Teacher in Middle School

Q: Did she go to middle school in the district of her household registration?

S's mother: Yes. Her teachers in the middle school didn't like us. At that time, I didn't want to communicate with others, either. My daughter sat at the front of the classroom because of her poor eyesight. At a parent-teacher meeting, her teacher singled my daughter out, saying that she lagged far behind. I couldn't explain to the teacher, so I tried to flatter him. What else could I do? He couldn't understand it until one day he experienced it himself.

In the second year, there seemed to be quotas for students going up to the third grade, but the teacher wanted my daughter to stay down. I tried to persuade the teacher, "My daughter did lag behind, but we had tried our best, so did she. She studied until midnight every day and finished all the homework. There might be

mistakes, but she really worked hard.” The teacher didn’t change his mind. Then I continued to beg him, “If possible, please just allow my daughter to go up. I don’t think she will make much progress by repeating the second grade. I don’t want much. Simply graduation will do.” My words still didn’t work. So, I stopped trying.

After that, it was decided that my daughter should repeat the second grade. Receiving the notice from the teacher who came to my home, I was really upset. I just blurted out, “We had no choice. You should be happy that it goes the way you wanted.” I exactly said so. I didn’t care about his feelings at all. He was the one who insisted on the grade retention and even brought the matter to the headmaster. The headmaster had sympathy for us, but he had to side with the teacher, who was the only teacher available for that class at the time.

So, we repeated the second grade. I was frustrated, but what could I do? Being afraid that she would be further despised in the new class, I told my husband on the first day of the new term, “Let’s accompany her to the classroom. We can’t leave her alone in the new class.” We knocked on the door of the classroom, walked her in and told the teacher, “She has difficulties in learning. We don’t expect the teachers to be strict with her, but we hope you won’t despise her.” The teacher assured us that she would be kind to my daughter, “Don’t worry. I won’t do that to anyone. They are like my own kids.” We thought it was just an offhand remark, but anyway, that was all we could do for her.

When we needed to pay her tuition, I put the money in a bag for her. Being poor, we were careful with the money. But that was possibly not the case with other students. My daughter found a 100-yuan note and handed it over to her teacher, but the teacher failed to find the owner. In another case, students made the classroom messy at lunch. My daughter found a broom and cleaned the mess away. The teacher saw it. But she didn’t tell us about the two stories.

Once, the teacher asked parents to go to school to collect a transcript, but my daughter didn’t tell us. At that time, I was on leave at home after surgery for a hysteromyoma excision, and her dad had to go to work (sobbing for 1 min). When I was in the hospital, she asked my elder sister to take me a note written by her, which read, “Don’t worry, Mom. You’ll be fine. I have prayed for you. You will come home safe and sound.”

Then the teacher called while I rested at home. I told the teacher, “I didn’t know. I will go to school right away.” I went there with my hands holding my belly. The teacher used to blame us whenever we went to her office, but this time, as soon as I arrived there, I said, “I was on leave, but my daughter didn’t tell me about this notice. I didn’t know.” Seeing my hands over my belly, the teacher asked, “Are you OK?” I answered, “I was recently discharged from the hospital after surgery. I’m having a rest at home.” She gave me a seat and told me, “Don’t blame your daughter. She has been good. I asked you to come to let you know that she has made great progress.” The teacher who insisted on grade repetition was also in the same office. All the other teachers disapproved of what he had done to my daughter. Then the current teacher told me how my daughter handed over the money she found to the teacher, and how she cleaned the classroom and praised her. The teacher in charge taught Chinese and my daughter was good at Chinese. The teacher said, “Now your

daughter often comes to talk to me. She also goes to read in the library. After the students were divided into groups for English class, her English improved a lot.” I wondered how all these things happened, but I said, “I am glad to learn that she has made progress.”

Thanks to the new teacher, my daughter became livelier and continued to make progress in her studies. This teacher came to Shanghai from northeast China. Later, she underwent the same surgery that I had, and stayed in the hospital just across the street. Learning that her classmates were going to visit the teacher, my daughter wanted to join them, but was refused. So she followed them secretly to the hospital and found out the teacher’s ward. Knowing that I had the same surgery, she told me, “Mom, my teacher is in the hospital. The same surgery as yours.” She asked me to visit the teacher with her. I agreed and prepared a dove soup. I explained the process to the teacher, who was moved to tears. The teacher said, “I know she works hard, though she doesn’t make much progress. But I never expected that she would come to visit me.” The teacher probably criticized her classmates and praised her as caring and considerate. After that, her classmates began to play with her.

After she graduated from middle school, considering that she had difficulty in learning but worked hard, her teacher suggested that she didn’t need to take the college entrance exam. The teacher was kind to advise us, “You may consider specialized secondary schools. They are more suitable and affordable. She can study e-commerce and become a cashier after graduation. This kind of job is needed everywhere without fierce competition. Also, there’s no limit on age. She can do it for a long time.” Following this advice, we mainly considered such schools and my daughter was later admitted to one.

Her middle school was not famous. As my daughter was considered a poor student, the headmaster thought her admission to a specialized secondary school was worth publicity. He asked us to share our experience of education, based on which a blackboard bulletin would be prepared. As my neighbors’ kids went to the same middle school, I didn’t want them to know about my daughter’s real situation. So, I declined the request, “I don’t want to discuss it in public. No matter whether her study performance is good or bad, it’s our own business.” Then the headmaster didn’t insist. Anyway, she had graduated. We should be optimistic.

Q: How did you help her when she prepared for the entrance exam of the specialized secondary school?

S’s mother: We learned the same books with her. If she had any problems, we would check the books to work it out and then teach her, or consult others, like the senior students or her classmates living nearby. After we understood the answer, we would teach her again and again. She worked hard. We also did a good job cooperating with her teacher. We all made a lot of effort. The teacher said, “You’ve done a nice job.” I told her, “Yeah, we never watch TV at home. We are afraid that it may distract her. Let’s work together to improve her performance.”

Q: Did she take any IQ tests during the period from elementary school to middle school?

S’s mother: I took her for this test secretly when she was in middle school. The scores were graded as low, medium, and high. Her score was between 60 and 70,

“high” among kids with intellectual disability, but “low” among kids without disability. If the score was really poor, I probably would have bowed to the inevitable. But it was just because her score still showed a glimmer of hope that I didn’t give up on her. However, we didn’t want others to know the test result.

Q: Do you accept the result?

S’s mother: Basically yes. The test was very strict.

Admitted to the CYL at a Specialized Secondary School

S’s mother: Her teachers at the specialized secondary school were kind to her, too. Though all the other classmates weren’t slow, they just didn’t devote themselves to studying. Under such circumstances, my daughter still worked hard. The teachers thought highly of her. She handed in homework every day, despite possible mistakes. I thought her performance was gradually improving.

She was admitted to the Communist Youth League (CYL) at that time. It was not easy, but she finally made it. We had this tradition in my home. Apart from my mother, a CPC member, there are still many CPC members in my extended family. I didn’t get the chance to apply for membership since I often asked for leave to take care of my daughter, but I believed that she should try everything that normal kids did. We were admitted to the CYL when we were students, so I thought it would be nice if she could join the CYL at the same stage. Whatever the result, I would accept it. I asked her, “Did you apply for admission to the CYL? I think you can make it. Anyway, you should give it a try.” Later, the teacher noticed that she worked hard and took her task of cleaning the classroom seriously, so, they made an exception and admitted her to the CYL. She was glad.

An incident happened concerning this admission. There was a review meeting before she was admitted to the CYL, where others would comment on whether she could be admitted. It was normal that people would have different opinions and unfavorable remarks. But my daughter couldn’t stand it. I could have prepared her, but I didn’t know the review meeting for her would be held on that day.

My daughter is ill-tempered. After the review meeting, she held her anger in for a long time, until she cut her wrist after returning to the classroom. You can still see the scar now. She could have killed herself. But luckily, the wound was not deep. Her teacher noticed the wound and sent her home after treatment at the clinic.

After I went home from work, she cried as soon as she saw me. I was also sad, but I didn’t stop her. When she stopped crying, I asked her to explain and I analyzed the situation for her, “You are simply too vulnerable. Today’s meeting is completely normal and inevitable. You are admitted to the CYL, but you haven’t met the requirements. More effort is still needed. You may encounter much trouble in your future. So, you must have a strong mind. You’ve gone through a lot since childhood. Sometimes, we just can’t control everything. You should be prepared. How could you hurt yourself? Now, you feel pain and you think it’s ugly.” Whenever my daughter had difficulties, I had to spend a lot of time and effort to talk with her till

she could understand it. Regarding the review meeting, ultimately, she could make sense of it.

This school was actually good. When she was admitted, the teachers wouldn't think of the accident at her birth. Maybe the teacher was doubtful, but we told the teacher she was just in poor health. People of poor constitution are generally not so energetic. So, her teacher only knew she was weak.

At that time, I was quite strict with my daughter. If she didn't finish the homework that I assigned her, I would spank her when I got home. Looking back, I think I shouldn't have done that to her. Such pressure would only affect her health, but I wasn't aware of this back then. Being young and inexperienced, I just felt upset to see my child like this, when others have normal kids. I was just too reckless.

Working Diligently at the Supermarket

S's mother: After 2 years of study at the specialized secondary school, all the students started their internship at a supermarket in Pudong. It was far from our home and she needed to take two bus routes. Back then, there was no bus going from Pudong to the downtown area of Shanghai after 10 pm. There was no bus to take her back if she worked the day shift and no bus to take her there if she worked an early shift.

So, she took an internship at a nearby supermarket, upon the recommendation of a friend. It was hard work. My daughter didn't know how to get along with her colleagues, most of whom were of my age. She also tended not to talk about her experience at work. The supermarket didn't let her go after the end of her internship, nor did they sign a contract with her. She kept working there without any pension, housing fund, or medical insurance, until she was formally employed after an examination by the authorities.

She was still willing to learn more back then. She didn't go to high school, but she still wanted to learn after graduation. She said, "Even though I won't sit in the college entrance exam, I want to learn something." She wanted to keep studying while working. In the supermarket, foreign customers came often, but they seemed to have difficulties in communicating in Chinese. Seeing this, she thought English was a necessary skill. She decided to learn this at the foreign language school near her workplace. She passed by it every day on the bus. She said, "I'll learn some basic English."

I supported her totally. Young people should learn as much as possible. So I enrolled her in a basic English class at the nearby foreign language school. My salary then was about 800 or 900 yuan a month; the tuition fee would cost more than 800 yuan. She went to the school twice each week, once on Saturday and once on a weekday. At that time, she could take a day off on weekends. But the manager probably didn't like her. My daughter had only had a few lessons when the manager came to tell her, "Why not ask for leave on a weekday and leave the weekend session to people with kids? They need to take care of their children." I replied, "My daughter has just signed up for this and paid over 800 yuan. We wouldn't have done so if you

had raised such a requirement earlier.” The manager said, “We had no choice. Other people have to take care of their children.” Later, my daughter said, “Never mind. I’ll quit.”

My daughter’s job was tiring. When she worked the day shift, she needed to move the shelves around. If she worked the day shift, she would not be able to come home before midnight. If she had to tidy up the workplace after the customers left, she could not get off until early morning, like 3 or 4 am. In the beginning, she could still take some rest and even lie down for a while and come home the next morning by bus. Later, their shifts became a mess. People working the noon shift were required to take stock after getting off and continue to work the next day. On those occasions, she had to start working again at 9 or 10 am.

Q: So, she didn’t have time to sleep, right?

S’s mother: I told her to take a taxi to return home and sleep for a while after getting off at 3 or 4 am. Due to her poor constitution, she often had a fever. Once, she didn’t feel well at midnight, so I took her to a hospital for an IV infusion. Her body temperature was over 39 °C, which required 3 days of leave, but the supermarket allowed only 1 day off. At that time, few young people would work in a supermarket.

She started in the supermarket as a cashier, handling over 10,000 yuan every day. Once, a middle-aged woman paid for part of the things, and went back to weigh one item that wasn’t weighed. She told my daughter the paid items were left at the cashier, but they were nowhere to be found when she came back. She asked my daughter, “Where are my things?” My daughter said, “I have no idea. Maybe somebody took them away.” There was no video surveillance at that time. The woman asked my daughter for compensation. Facing this, my daughter reported to her supervisor and checked the receipt at the cashier register. The things were indeed paid, but disappeared. I don’t know how they dealt with the situation ultimately.

Afterwards, my daughter was transferred to another job in the underwear department as a tally clerk. When customers asked for a return, her colleagues of my age would tell her to deal with it. But how was my daughter able to handle this? She wasn’t good at communication at all. She was cursed by customers, but she didn’t tell me until later.

Q: Did she make friends with any of her colleagues at the supermarket?

S’s mother: She was close to some of her colleagues. But they didn’t work in the same department.

Q: Were there any good friends among colleagues in the same department?

S’s mother: When her supervisor got married, I told her to give her 500 yuan as gift money, even though her salary was merely 800 yuan. The effort was in vain. Ever since she was little, we kept giving gifts to her teachers and other people. Even a new cotton sweater that we treasured a lot was given to others as a gift.

Q: Were her teachers kind to her after receiving your gifts?

S’s mother: Unfortunately...Perhaps it could have been worse if we hadn’t done so. I’d rather suffer myself than see her suffer. We didn’t have much savings as well. Our life was indeed hard.

By 2007 or 2008, due to the financial crisis, the supermarket sent her home before the expiration of the contract and asked her to submit a resignation letter. My simple daughter just did what they said, totally unaware of their trick. If the supermarket would have given my daughter the worker's record immediately, she could still have explored other job opportunities. But it didn't. The staff couldn't even state clearly where the documents were kept, either in the head office or in the supermarket itself. My daughter made many trips in vain.

I was angry when my daughter told me about this. She could have worked there till the end of the year. How could they ask her to leave suddenly? Not knowing about the resignation letter, I went to the supermarket to seek explanation. They told me, "Your daughter wrote the resignation letter herself." I was astonished, "She wrote it under what circumstances?" They started to make excuses. Then I blurted out, "Do you know my daughter's condition? Do you know what happened at her birth? We didn't tell you about her story, simply because we don't want you to despise her! We are all parents. We all have children to care about. Would you allow such things to happen to your child?"

Then I read the articles of the Labor Law. According to its rules, if my daughter was unqualified, she should be entitled to the training provided by the supermarket and shall be only fired when she reaches the requirement of a new job after the training. So, I asked the supermarket, "Did you train her? How can you fire her like that without any proper measures?" What's more, she only received her salary of that month. I complained, "You can't do this to her. My daughter is a special kid. Your decision is completely unfair. Why would you fire my hard-working daughter but keep the careless ones? What's wrong with your policies?" The manager said, "All the formalities have been completed. What can I do?" I told him, "It's your business. Now you know about my daughter's situation, just do as you think fit. She did a nice job here. She liked her job." The manager continued to make excuses. I got mad, "Anyway, you shouldn't have kicked her out all of a sudden and asked her to submit a resignation letter. My daughter needs a custodian to make decisions for her. Did you contact us? What's worse, simply because you didn't give her a worker's record in time, she can't be hired in other supermarkets. She lost her source of income since the day you fired her. She has made many trips in vain to obtain her record. Will you cover her travel expenses?" I asked for 3 months of salary as compensation, but the manager required that we pay the tax. This was totally insane. I yelled, "Oh my god, it doesn't make sense at all. You force us to take the lump-sum payment. How dare you deduct the tax!" Finally, we didn't pay tax for the money we received.

Q: Can you remember when she received her first salary?

S's mother: She received several hundred yuan during her internship. I have always considered my daughter as a normal kid. Though my colleagues advised that I should tell her to hand in the money and teach her to save it and spend it wisely, I didn't follow it exactly. I just told my daughter, "Now you have your own salary. I don't want any of it, but you should save 100 yuan for your dad and buy some gifts. He has done so much for you. When you were in the hospital, he stayed there to keep you company day and night." At that time, there was a downturn in the textile factory, so

I found a new job at the Oriental Pearl Tower and her dad became a taxi driver. Our life was hard.

She received 300 yuan for her internship. I remembered she probably spent 50 yuan and bought a box of cigarettes for her dad. Later, she started working and received her first salary of around 900 yuan. Considering that her dad was taking supplements of Only, I told her, “How about buying Only supplements for your dad every month? It costs more than 100 yuan.” She agreed. She’s really grateful. I told her that I didn’t need her money. “You can keep it to cover your daily expenses and save the rest of it.”

I told her to open a deposit account when she still earned 300 yuan a month, but she didn’t agree. She asked, “Why? All the students have money in their wallets, except me. I envy them a lot every time I saw them shopping, but I didn’t have any money with me. Our family is poor as well.” I told her, “You can save as much as you like. If you can save 50 yuan this month, I will give you another 50 yuan. That way, you will save 100 yuan.” She couldn’t come around, but told me she would save 20 yuan, so I said you could get 20 from me as well. Later in the first month, she probably saved 50 yuan, so, I gave her another 50 and we put the 100 yuan in her account. Gradually, she understood the mechanism. She would tell me, “Mom, I have enough pocket money this month, I’ll save all the rest in my account.” I said, “Fine. You have saved 300 yuan, then I’ll give you 300 yuan. You can put it all in your account.” That’s how I encouraged her to save money. When she was at school, I gave her 1 yuan every day as her allowance and some more to buy bus tickets. As she grew older, she was in charge of her allowance.

Now, she receives a monthly salary from the factory. I put the money in a term deposit account for her. She already sets her own savings goals. This makes her confident and happy.

She understands that my husband and I are working to support her. Actually, we are not that poor, but I want to make her aware of large expenses in the family so that she can also contribute. I would tell her, “We are a bit stretched this month. I spent a lot buying gifts. Can you help us?” She would offer to give me some money, and said, “No problem, Mom. Here is 100 yuan for you.” That’s already a lot for her. I don’t need it actually, it’s just that she should be aware of the responsibility.

Q: Is she willing to give you money?

S’s mother: Yes. She also bought food as gifts for me. On my birthday, she bought me a small birthday cake. In fact, she herself wanted to eat the cakes (laughing). It’s fine. Some kids do not know how to manage their money.

Q: Does she buy you gifts on holidays like Mother’s Day?

S’s mother: Yes. She is grateful. When she was at the specialized secondary school, I gave her 1 yuan per day as pocket money, but she would save it and buy me gifts on Women’s Day.

Q: What did she buy?

S’s mother: Like a small cake, maybe several yuan, or a card holder. Different small objects.

Q: Do you like them?

S's mother: I do, even if they don't appeal to me. I don't care about the price, but her affection and gratefulness. I need to prepare her for many things. For example, she should get prepared if we pass away some day. I often ask her, "How are you going to live on your own?" When she answers, I give her some advice. "Who can you ask for help if you have difficulties?" "The neighborhood committee and similar organizations." She knows a lot.

Applying for the Disability Certificate in Desperation

Q: Why did she stop working later?

S's mother: Previously, as my daughter still wanted to work, we went to the employment agency of the neighborhood committee for help. The staff there were very nice. There are eight major supermarkets in Shanghai, but young people here don't like tiring or poorly paid jobs, including in the supermarket. My daughter, however, was willing to work hard in these places.

A staff member in the agency offered to help us, but he was confused after my daughter failed all the interviews with supermarkets. He said, "How could this be? Her major fits the job perfectly." Then he recommended another supermarket. "The person in charge of the interview is my friend. You can have a try. I'll see where the problem lies." She failed again.

You can't even imagine what the interviewer said. He told us, "This girl is odd-looking. She can't work here." At that time, my daughter still suffered from a slight squint. With a strong sense of inferiority, she never looked at people directly in the eye, but like this (lowering her head while raising her eyes). Before she had the eye surgery, others often said that she was rolling her eyes. She couldn't control it, nor could she explain it to anyone. The interviewer was just blunt to say so. It was mean. You're hiring staff, but not supermodels, after all.

Before that, I never thought about applying for the disability certificate. At the neighborhood committee, the director asked my husband, "Why would your daughter stick to this struggle among ordinary people? Do you feel hopeless?" My husband and I didn't want to acknowledge that my daughter had an intellectual disability, but the people there could tell. They were deeply moved, "You can't solve the issue of your daughter alone, but you still try your best to find a job for her. We think you should turn to the government for help."

It was a hot day. The temperature was about 37 or 38°. My surgery wound was itchy after accompanying her to so many interviews. My job wasn't that tiring, allowing me to spare some effort on her. Now that the neighborhood committee advised us to apply for a disability certificate, we thought it might work, but we were not sure.

Q: How did she obtain the disability certificate?

S's mother: If she hadn't lost her job at the supermarket, we wouldn't have applied for it. This was our last resort. The formalities were complicated. First, we had to submit applications and other required documents to the subdistrict. They had an

office dedicated to services for the disabled. We applied in 2009. It was already very strict at that time, because people with disability certificates can receive an allowance.

At birth, my daughter was discharged from the hospital a month later than me. I kept all her medical records and her photos we took since her childhood. A lot of documents were handed in. Everyone said it was difficult to obtain the certificate. I said, "I have no other way out. In addition, as she grows older, so do we. We won't have enough energy." Later, the clerk said they would submit the documents to the relevant administration. We lived in the Hongkou District. Perhaps there was a fixed day for subdistricts to submit documents.

After a long period, we received a notice for a physical examination and went to the mental health center of Hongkou District for a test. The doctor read the medical record and asked us some questions. Then, my daughter was taken to a room next door for an IQ test. It was very rigorous. My daughter was required to build an item with blocks within several minutes or solve a problem. She thought it was too difficult to solve, while the doctor was patient and explained the question to my daughter in great detail. Anyway, the doctor tried to help her with the problems, so that she could proceed with the test. However, sometimes, my daughter was still unable to work out the answer. She was probably nervous and scared because of the doctor's attitude or language. When she saw me after finishing the test, she burst into tears. I asked what was wrong, and she said, "I couldn't work out the answer. The doctor forced me and scared me." She was perhaps too nervous to answer the questions. The doctor had a procedure. After the IQ test, she had an EEG scan, the results of which were not good. The doctors then spent some time in discussion after the IQ test and EEG scan before they spoke to us. According to the results, my daughter had moderate intellectual disability.

I was simply confused. I didn't think her intellectual problem was so serious. Anyway, we had to face the fact. What could we do? If the disability certificate was issued, it would be even harder for us to find her a job. Considering her poor health and that she was often bullied in her workplace, I asked others about information in this regard. I learned that persons with moderate intellectual disability could apply for an allowance for the severely disabled and unemployed. I thought that was the only choice. Initially, her monthly allowance was only a bit more than 400 yuan, but it gradually increased every year thanks to the efforts of the government.

Q: How did she obtain the allowance for the severely disabled and unemployed?

S's mother: The application was made through the subdistrict. I have forgotten the specific formalities, but I remember that we submitted the application after receiving the report of moderate intellectual disability. With the allowance, she didn't work any longer. On one hand, I was concerned with her health. On the other hand, she had suffered from her tiring job in the previous 3 or 4 years. People of the subdistrict said I had been too harsh, "How could you allow your daughter to compete with kids without disabilities? Have you ever considered that it may have had a negative effect on her personality and mentality?" It still scares me. At that time, she could have received an allowance as severely disabled and unemployed, but persons with mild disability could not. Now, all persons with disabilities have an allowance.

Being A Monitor at the Sunshine Home

Q: How did she come to the Sunshine Home later?

S's mother: After the disability certificate was issued, she stayed at home all the time. Once, I went to the subdistrict office. A woman there was very nice. She was concerned with my daughter, and asked, "How's your daughter now?" "She stays at home every day." "What a pity! We have a Sunshine Home here. It is very good."

I knew about the organization. However, just as I didn't want to enroll her in a special kindergarten when she was little, I didn't want her to go to the Sunshine Home. People say that one can be improved by spending time together with smart people. What would become of her if she went there? But... anyway, I couldn't make up my mind.

While I hesitated, the woman said, "How about I show you around?" I thought it was a good idea. So, she took me to visit the Sunshine Home. The teachers in the office showed me many videos on their computers, which showed that the students here made great progress in a year. I was deeply impressed. How could the teachers transform the students in the classroom to the kids shown in the video? I couldn't believe my eyes. I told them immediately, "I'll discuss it with my daughter. If she wants to come, I won't object. If not, there's nothing I can do."

My daughter resisted it. "I won't go there," she said. But I was worried about her future if she stayed at home all the time. So, I tried to persuade her, "Just go and have a look. You don't have to stay. Think of it as an interview."

The next day, I took her to the Sunshine Home. We visited the classrooms and teacher's office. The teachers showed us some documents on their computers. When she walked out of the office, she was surrounded by many students, who were friendly to her. They were all simple-minded. She seemed to be included into the group of kids very quickly, which was beyond my expectations. She was happy to be there. The Sunshine Home wasn't open to every kid with ID in the subdistrict.

Q: Does she need to satisfy some requirements to be admitted to the Sunshine Home?

S's mother: Some people may not want their kids to come here, especially kids with problems. The parents are afraid that the kids won't be able to have access to motivated people, and gradually become worse. But if they knew about classes here, they would change their minds. At the Sunshine Home, students go on outings in spring and fall. They have summer camps as well. An annual physical examination is provided by the government. Now they have full schedules. They have art lessons lectured by a retired teacher free of charge. Watercolor tools are offered as well. The dancing teacher is also a volunteer. I think the Sunshine Home is well organized.

Let me show you some photos (showing photos of her daughter as a small child). The teachers didn't believe this was my daughter. These are taken recently (showing photos of her daughter now). First, she is smiling in every photo. In the past, she was shy. If we came across somebody in the street, she would immediately hide behind me. After coming to the Sunshine Home, she became much more confident. Second, her health is improving. These are photos I took when we went swimming

and traveling (showing photos on her mobile phone). I want to take my daughter to travel as long as I am capable. She doesn't have any friends. My relatives are not reliable. So, I can only count on myself. I have decided that I will give my poor daughter whatever she wants as long as I can afford it. This is a photo of them in a dancing competition. My daughter is a monitor at the Sunshine Home.

Q: What does she do?

S's mother: Nothing special, except for announcing the beginning of class and reporting to teachers in case of any problems.

Q: What lessons do they have at the Sunshine Home?

S's mother: Painting, music, and dancing. Also, as half of the students here have mental problems, a doctor here lectures on medicine and mental health. These kids know about a healthy diet and how to take care of themselves now.

The Sunshine Home is really good. Without it, these kids would have no place to go. They are pure and simple. Compared to them, my daughter knows how to use money wisely. That's the benefit of going to school. My daughter is weak in health, but she is better in other aspects. The other kids here didn't go to school, but they have stronger bodies. Every coin has two sides. Sometimes, I feel regretful that my daughter didn't receive further education, but on a second thought, health was more important. For kids who know nothing about money, their parents are worried. They don't make efforts to push their kids into the society like we do.

Q: What makes you think your daughter is more confident and optimistic?

S's mother: She was always on tenterhooks when she worked at the supermarket, because others bullied her. At the Sunshine Home, she seems very relaxed. In the beginning, they didn't have many activities. They did radio gymnastics exercises in the morning, then the teachers would talk about the news of the day, just everything they deemed fit. There were no fixed lessons. The classroom is also very good with inspiring banners, "If you can do it, then I can do it." The teachers here are very patient. Over time, she adapted to this place.

They have a summer camp every year. My daughter not only drafted the opening and closing remarks, but also acted as the hostess. When her teachers told me about this, I couldn't believe my ears. Afterwards, they had a Spring Festival get-together, at which my daughter and another girl were hostesses. Their performance was excellent. I was amazed! The Sunshine Home considers the characteristics of every student and allows them to give full play to their strengths.

Q: Develop the strength based on their characteristics?

S's mother: Yes. They can do what they are skillful at. My daughter is not very handy and doesn't know how to string beads. This actually requires certain skills, right? Another girl close to her is just very good at it. Not long ago, their teacher bought some knitting wool from an online store. There were knots in the wool. She has finished two pieces and is now working on the third piece. I am impressed with her teacher's skills. It seems easy for the teacher to teach them knitting.

Q: Does she take her work home?

S's mother: Recently, she brought home a papercutting. It was the Chinese character "Fu" (meaning happiness). She is not the best among her classmates, but I'm happy that she can make these things. Anyway, I don't know how to cut the paper

(laughing). The Sunshine Home organized various activities. Once, she brought home a picture frame with a photo inside. I can't figure out how it was made. Sometimes, she has brought home a potted plant. Anyway, she often brings her new works home.

Q: What do they do in the art and music classes at the Sunshine Home?

S's mother: I can't remember what she painted recently. Anyway, she has been painting. Portrait, still life, animals. They have different subjects.

Q: Does she use *gouache* or watercolors?

S's mother: I think it's the latter. I once went to buy the material with her. Initially, she messed with the watercolors and used them up very quickly, so, I had to buy her a new set. Then, she gradually mastered the techniques. Her paintings now are not bad. I am amazed that she could make such great progress with the guidance of her teacher.

One of her classmates, the son of their dancing teacher, is illiterate, because he didn't go to school. Once, at a get-together, maybe the Spring Festival party, he was asked to write "I love my mom" (in Chinese) on the blackboard. He did a nice job. At the sight, his mother burst into tears as the boy had never written a single character. We were deeply touched by his writing on the blackboard. These kids must have made great efforts to achieve such progress.

Q: Do they have other activities at the Sunshine Home?

S's mother: They learn dancing. It takes a long period for them to learn a dance, because they have to learn over and over again. You saw it when you came here last time. The teacher soon gets tired. Each student does the move differently, and they have to be corrected one by one. It's really hard for them. When they command one dance, they will proceed to the next. If they are going to the nursing homes or other places to participate in charity performances, they'll practice the old dance again. Previously, she couldn't dance at all, because her limb movements were uncoordinated. The teachers must have made a tremendous effort to teach the students. It's amazing.

Q: After she was enrolled in the Sunshine Home, did she go to work?

S's mother: Due to her registered status as seriously disabled and unemployed, the Sunshine Home could not recommend any job. Otherwise, she could seek employment after receiving training here.

Q: Can you still remember her participation in the Talent Show for Sunshine Homes?

S's mother: After learning about the talent show, the teachers of the Sunshine Home chose several students, including my daughter, to practice dancing every day. Later, they went to the talent show several times. There were at least two costumes. In the first round, she wore a pink, shiny long-sleeve top, a skirt like yours, and white sneakers. She looked pretty. They competed over and over again, and it got increasingly hot. So, when the competition was approaching the final round, she had a new costume: a blue and red striped short-sleeve T-shirt, white sports pants, and white sneakers. They really wanted to make it to the final round, but they were eliminated in the second-last round. Seeing the depressed students, the teachers and parents comforted them, "You have done a good job. It's not easy." Contestants from other subdistricts were also great.

Q: Was the competition fierce?

S's mother: Very fierce. The contestants were all excellent. A little boy played the saxophone very well. It was quite impressive.

Improved Health Thanks to Special Olympics

Q: Did your daughter participate in Special Olympics?

S's mother: Yes. She competed in Special Olympics twice after she was enrolled at the Sunshine Home. Special Olympics is not held annually. It is held after the Olympic Games.

Q: Did she compete in events of different levels, like in the subdistrict, municipal, and international ones?

S's mother: No international ones. I'm not sure about municipal level, either. But I know that she participated in Special Olympics for the subdistrict. She also participated in a Special Olympics competition held by the Disabled Persons' Federation of our district.

Q: Can you remember the details?

S's mother: She was involved in a variety of activities. She was a member of the waist drum team of the District Disabled Person's Federation. She could play the waist drum and flat drum. She also participated in performances, in addition to training in her spare time. They have a lot of activities relating to Special Olympics, like table tennis, dancing, and singing.

Q: Did she win any medals?

S's mother: She won several award certificates, but maybe no medals. She was once the third in a competition and was granted a little award certificate.

Q: What's her specialty among the Special Olympics activities?

S's mother: She always had a passion for singing, but the other skills are newly acquired.

Q: What about table tennis and other sports events in Special Olympics?

S's mother: She likes calligraphy, but there is no calligraphy competition in Special Olympics. There are only sports. She competed in many sports games, like table tennis, jumping rope, carrying a basket and throwing balls, things like that. Her health was not bad in those days, so she could go to the District Disabled Persons' Federation every Saturday and Sunday for half a day each time and participate in such sports activities. But later, as her health became poor, she didn't go there very often.

However, my daughter and her classmates all participated in the Special Olympics activities. A major benefit is that their health is much better. Their physical coordination and hands-on abilities have also improved. They can compete in simple sports activities like table tennis. The government is kind to them and offers each participant some awards. This makes them very happy. Some of the participants are strong competitors. A girl from the Sunshine Home is one of the Special Olympics youth leaders.

Relatives Unable to Accept the Situation

Q: Did you conceal her intellectual disability from your relatives and friends?

S's mother: Not from my siblings, because I couldn't have. It reminds me of a story. Once, my mother-in-law had a fever and didn't feel well. She stayed in bed and told my daughter, "Sweetie, can you play by yourself? I need to rest." My daughter was playing with toy blocks. She looked at her grandma, and perhaps she thought she should take care of her grandma. So, she dipped a towel in cold water, and asked her grandma to put it on her forehead. Her grandma likes her, so do our other relatives. My mother-in-law told me about this after I got home from work. She was moved to tears, saying that my daughter was a good girl and that we should be nice to her. As for my colleagues and friends.... I didn't talk much with others at that time.

Q: Is that because of your daughter?

S's mother: (Nodding). We got together with our friends on holidays. They often asked, "How did your daughter go in her exam?" My daughter would immediately hide in the bathroom, to avoid being asked. I understood her. So, I would say, "Don't mention it. My daughter is hiding away again." Then, they would drop the topic.

I don't like it when people talk about their children dating or getting married. But there's nothing I can do. My daughter suffers, because we tend to be mad at her when we are upset. When she was little, we spanked her and sometimes scolded her, "Why are you such a dumb head? Why couldn't you be smart like other kids?" Now, I also tell my daughter, "You have to grow up. I am getting old, and someday, I won't be able to help you. How are you going to take care of yourself?" I worry about her future so much.

Q: How do your friends and colleagues view her?

S's mother: People gossiped. When she was little, people would point at her and show a weird look when I took her from the kindergarten to take a shower in the bathhouse of the factory. What could I say?

Q: Do your friends also gossip about her?

S's mother: They don't. You know my daughter's situation now. They also know her situation, so, they don't gossip about her. But we can't afford to tell everyone about her disability.

Q: Do you speak your mind to your friends? Do they encourage you or try to comfort you?

S's mother: Well...Suppose you are my friend. You know my daughter has an intellectual disability, but have no idea of my life with my daughter. Therefore, you won't focus on my daughter. In most cases, I just listen to them talking about their kids. When you don't have a child who has been ill since birth, you can't understand my hardship. I have a very good friend living across from my house before we were married. We were really close back then, but we rarely met each other after we both started a family, even when I went back to my mother's home. Decades later, we suddenly encountered each other in the street and have got in contact. She knew my daughter was intellectually disabled, but she didn't know the details. She said that my personality has changed a lot. According to her, I never acknowledged

defeat, but now I am mentally strong, and talk less. She said I was like a different person. I wasn't afraid to try things before I got married, because I would bear the consequences alone. Now I need to think about things more. I have learned to take things easy.

Q: Has your daughter brought about a lot of changes in you?

S's mother: Too many changes. To be frank, my husband and I had been classmates for 6 years before we got married, we once had deep affection for each other. But we often quarreled. I can tell that he has grievances. Now, he is a chauffeur at a company. It's natural that he feels upset to think of his daughter, while the other young girls at the company are clever. We both have grievances. Who is to blame? I told my husband, "There is nobody to blame. You can't blame me, because I didn't understand the situation when she was born. You can't blame our daughter, or she'll be sad. I want to blame you, because you could have refused the emergency treatment. But you didn't understand the situation, either." My mother was also at the hospital when my daughter was born, but she didn't say anything since my husband didn't refuse the emergency treatment. Anyway, everyone is upset. Sometimes, we quarreled over trivial incidents because of different opinions. We are not happy together. Had it not been for my daughter, we probably would have divorced a long time ago.

Sometimes, other kids' mothers talked about our marriage. It is natural that husband and wife may have different opinions. In any case, I had to take good care of my daughter. I had to. Now I am getting old, and my health is not very good. My daughter is gradually better than before. So, for many things, I just don't take them to heart. My husband is ill-tempered. He is a dotard, I mean it.

Parents of kids like my daughter have been suffering. We suffer a lot. We do not have the heart to think about the future. My daughter has a classmate, whose father often came to the Sunshine Home. In the past, it was his mother who often visited here. His mother suffered from heart disease, high blood pressure, and osteonecrosis and had several operations. She's a procurement agent and makes a lot of money from her work. Thus, his dad is responsible for housework. Old people usually have difficulty in sleeping. Once, when the father couldn't sleep at midnight, he cried at the thought of his sick wife and son with ID. Parents of such kids are usually not cheerful. But we must perk up.

Q: You mentioned that your husband accompanied your daughter to the hospital when she was little. Wasn't he nice to your daughter?

S's mother: He is indeed nice to our daughter. At the beginning, we both went to the hospital and spent much time waiting, so we had no time to eat. Over time, we learned from experience and took turns to stay at the hospital and do household chores at home. That way, we could have dinner ready when either one got home. At that time, it was impossible for us to keep dining outside. When I got pregnant again, both of us were determined that we didn't want another child. My husband was considerate. I had an abortion and continued to focus on my daughter. When my mother-in-law learned about this, she said, "Why did you have an abortion? It might have been a boy." I told her, "If we had a second child, what would we do with the elder one? We don't even have enough energy to take care of her." My mother-in-law

said, “She can stay with me. I will treat her like my own daughter and teach her how to live.” I don’t think she could teach my daughter as well as we do.

Q: Do you and your husband fight less now?

S’s mother: Well, as a menopausal woman, I still quarrel with him sometimes. The key factor is that I don’t want to fight with him.

Q: Do you fight less over your daughter?

S’s mother: She’s still the main reason why we quarrel. My husband couldn’t help comparing her to other kids, and I would refute. Once, he told my daughter, “You deprived me of my right to be a grandfather.” Hearing this, my daughter looked at me. I thought his remarks were too much for her, so I argued against him, “How could you say something like that? People may get married, but many couples don’t have kids. How did she deprive you of your right to be a grandfather? If you want a grandchild, go and adopt one from the orphanage and have him or her call you Grandpa!” Now, I just don’t want to quarrel with him. My heart can’t bear it. I don’t mind whatever he is doing, as long as it is not excessively unacceptable, and his money is brought home.

Yearning for a Carefree Future

Q: Does your daughter receive any support from the government?

S’s mother: My daughter receives an allowance from the government every month, which increased from over 400 yuan to 1,150 yuan. She also receives another 480 yuan for monthly nursing fees for the seriously disabled and unemployed. Altogether, she receives about 1,600 yuan per month now. As my husband and I have this only child with ID, we can receive 400 yuan respectively from the government every month, increased from about 80 yuan initially. Then that’s a total of 800 yuan every month. It has not been a long time since we first received the allowances, because my daughter didn’t apply for the certificate until in recent years.

Q: Do you give her any advice when she has difficulties?

S’s mother: My husband was previously a taxi driver and had rich experience dealing with various people. We talked about this over dinner. I also shared my experience in dealing with difficulties with her. So, she made it a habit to talk with me whenever she encountered any difficulties at the Sunshine Home. There was only one time she didn’t tell me. While the students were taking a nap at noon, a girl had a seizure. We usually refer to such a situation as having a fit. My daughter’s classmates cried, “S! S! She has a fit!” Feeling nervous, my daughter ran out of the classroom and cried, “Teacher! She has a fit!”

The girl told her mother about this incident, and she complained to me at a meeting, “It was improper for your daughter to say something like that.” I had no idea what had happened at that time, so I said, “Really? If that is the case, I apologize to you. My daughter shouldn’t say it that way. I had no idea that she might say something

like that. After all, she may suffer from the same situation. I'll tell her to mind her wording."

I don't conceal anything from my daughter. She needs to understand the society. Nowadays, people are not so warm-hearted. There's nothing you can do about it. It is natural that people favor rich people. I told my daughter, "Don't take gifts from others or accept others' help indiscriminately, because you can't repay them. Don't count on others if you can do it by yourself. You don't need to strive for reciprocity like I do."

I have a weak heart now. Once, I asked my daughter, "What would you do if I don't feel well some day?" She said, "Mom, I will call 120 (the emergency number) immediately and feed you pills." I must tell her how to deal with it in advance. Otherwise, she would be perplexed in case of any emergency. If I need emergency treatment, I couldn't afford to waste any time. It will be helpful to both of us. I want to spend more time with her. Currently, my husband and I don't desire much. We only wish to be happy and joyful every day.

Q: Do you have any other hopes for your daughter?

S's mother: At her age, she should start thinking about getting married. We introduced her to many boys. But her disability certificate has both advantages and disadvantages. The advantage is that thanks to the certificate, she has settled down. She's happier, more confident, and healthier. But due to this certificate, others would hesitate to date her as she is jobless. Though some boys with a similar situation have an unsatisfactory job, their parents still look down upon my daughter. While in fact, I believe my daughter outperforms them in capability. She's simply weaker. When dating these people for some time, my daughter would find it difficult to communicate with them since she has her own opinions. So, she rejected them directly. She tends to go to extremes. We also thought of the possibility of finding her a husband who has no disability certificate, or who is slow but doesn't have an intellectual disability. But parents of those boys still worry that my daughter is simple-minded and unemployed.

Q: Do you want her to stay at the Sunshine Home all the time?

S's mother: Yes. Now my only wish is that she can live a happy and carefree life.

Q: Have you considered her future?

S's mother: We don't dare to. I hope the government will take care of her health and housing, etc. when my husband and I pass away.

Q: That concludes our interview. Thank you for your cooperation. I wish you all the best for the future.

S's mother: These kids are lucky (laughing).

Interview with Miss S's Teacher (I)

Interviewee: Teacher A from the Sunshine Home.

Interviewer and writer: Yi Zhang.

Interview date: December 7, 2016.

Interview place: Sunshine Home of a subdistrict in Shanghai.

Q: Do you remember the situation when S arrived at the Sunshine Home for the first time?

Teacher: I don't know. You'd better ask Ms. Li. She joined the Sunshine Home before me. I came here a little over 3 years ago.

Q: Can you remember when you first saw her?

Teacher: She looked very good. I don't know what she was like when she first came here, because I joined later.

Q: How would you describe her personality?

Teacher: She's friendly, outgoing, and talkative (laughing).

Q: Does she have many friends here?

Teacher: Yes. She is the monitor here.

Q: I suppose she gets along well with her classmates. Are you impressed with any incidents?

Teacher: Nothing special. She learns faster than other students. After years of training, she is now good at artistic performances. She is keen to outdo others.

Q: Is she eager to outshine others?

Teacher: Yes. She would be upset if she lost in a competition.

Q: Is that also the case in class?

Teacher: Yes. She tends to strive for perfection. That's also the case when she is painting. So generally, she performs very well.

Q: Do you have any hopes for Miss S?

Teacher: I hope she'll be able to lead an independent life and further improve herself, so that she can find a job. We teachers don't want her or other students to stay here all the time. We hope all of them can be self-reliant someday. That's the best we can expect. If that happens, we won't mind even if the Sunshine Home is closed.

Q: Do you expect her to make progress in class?

Teacher: It is up to them. The most important thing is whether she is eager to learn. I can't do anything to improve her intelligence, but I can try to arouse her interest in learning. For example, she paints very well now. Other students would simply complain to teachers when they ran out of brushes or watercolors, but she will go shopping on her own. She's better than other students.

Q: Is she a good monitor?

Teacher: She is capable in every aspect, including learning and performing her tasks as the monitor.

Q: Thank you.

Interview with Miss S's Teacher (II)

Interviewee: Teacher B from the Sunshine Home.

Interviewer and writer: Yi Zhang.

Interview date: December 7, 2016.

Interview place: Sunshine Home of a subdistrict in Shanghai.

Q: Nice to meet you. Were you here when Miss S first came to the Sunshine Home?

Teacher: Yes.

Q: What was she like?

Teacher: She thought she was here to be a volunteer, because her mother lied to her. She said, "I'm here to be a volunteer." She refused to join us. After all, she graduated from a specialized secondary school. It is natural that she didn't want to stay here. She thought she was different, she would become a volunteer.

Q: After she was enrolled, how was her performance?

Teacher: Not bad. She could express herself.

Q: What about her fine motor skills?

Teacher: Those were poor. She couldn't spread her fingers when we taught her finger gym and sign language. Her body was stiff.

Q: What about singing? Does she like singing?

Teacher: She sings well. She could sing well when she first came here. She can sing several pop songs very well.

Q: How long has she been here?

Teacher: Since 2008.

Q: Has she made any progress?

Teacher: Yes. She is much better now. At the beginning, she had great difficulties in memorizing things.

Q: Her classmates say she is always eager to outdo others.

Teacher: Yes, she always wants to excel.

Q: Can you remember any incidents that left a deep impression?

Teacher: She was ill-tempered. Previously, we had a male teacher. Once, he criticized her for improper remarks. She got mad and ran away to the bathroom, locking herself inside. I was terrified. She was a stubborn girl. If we wanted to criticize her, we needed to mind our wording and avoid other students.

Q: You couldn't criticize her in the presence of her classmates?

Teacher: No (shaking her head). We needed to talk to her in private. We always started with praise, otherwise, she couldn't bear it. Now, she seems much better in this regard. She likes to outperform others, especially in large events.

Q: Since she has been here, has she made significant progress in any specific aspect?

Teacher: She has made great progress in painting and dancing. In the past, when she needed to dance, she always said, "I can't. I'm weak. I can't do that." Now, she can control her temper.

Q: How would she react now, if you criticized her in public?

Teacher: Sometimes she still doesn't like it. In most cases, we just criticized her by name and don't say much. She would get our point right away. She will be fine as soon as she calms down.

Q: Does she lose her temper if she has difficulties while practicing dancing?

Teacher: She tends to lose her temper if she can't learn the dance. She gets angry with herself.

Q: Does she continue practicing when she calms down?

Teacher: Yes. She knows how to calm herself down. She goes to the bathroom.

Q: Do you know how she does it?

Teacher: She washes her face with cold water in the bathroom. Sometimes, I wondered why she spent so much time in the bathroom, and I would go and check secretly. She didn't know. That's how she calms herself down.

Q: I suppose you won't criticize her under such circumstances?

Teacher: No, we won't. It is okay that she can calm down on her own.

Q: Is she the monitor in the class?

Teacher: Yes.

Q: How did she become the monitor?

Teacher: The students elected her.

Q: Is she recognized by all the students?

Teacher: Yes (Nodding).

Q: Does she have any special tasks as the monitor?

Teacher: She needs to write reports and take care of her classmates when they go on an outing.

Q: Do the students follow her instructions?

Teacher: Yes.

Q: Do you feel at ease leaving the students to her when they go on an outing?

Teacher: Yes. She does a good job and takes good care of her classmates, especially those with difficulties in walking and younger students. She helps her teacher a lot. She knows when to stop when they are crossing the road.

Q: Do you have any hopes for her?

Teacher: I hope she can control her temper and find a job. She has been hampered by her moderate intellectual disability.

Q: That concludes our interview. Thank you for your time.

Interview with Miss S's Classmates

Interviewee: Miss S's classmates A, B, and C at the Sunshine Home.

Interviewer and writer: Yi Zhang.

Interview date: December 7, 2016.

Interview place: Sunshine Home of a subdistrict in Shanghai.

Q: Are you familiar with Miss S?

Classmate A: Yes, I am.

Q: You have classes with her every day, right?

Classmate A: Yes.

Q: Is she nice?

Classmate A: Yes, she is.

Q: Does she perform well in class?

Classmate A: Yes, she does.

Q: Is she the best? Do you consult her when you have questions?

Classmate A: (Shaking head).

Classmate B: Who are you talking about? Miss S?

Q: Yes, Miss S.

Classmate B: She is not bad. She always wants to outdo others. Whatever we are learning, she will master it.

Q: She wants to be the best, right?

Classmate A: She has been practicing a dance, because she doesn't want to affect the team due to her poor performance.

Classmate B: We are talking about Miss S. Come on (waving to classmate C).

Q: In your opinion, what are her strong points and weak points?

Classmate C: I shouldn't comment on her.

Q: It doesn't matter. You can say whatever you think.

Classmate C: She paints well and sings well.

Classmate B: She is conceited. If we have any unfavorable remarks about her, she becomes upset.

Q: What about her temper?

Classmate B: Not bad.

Q: Does she ever lose her temper?

Classmate B: Sometimes. She is generally kind to us.

Q: Is she the monitor? Do you think she is a good monitor?

Classmate B: Not bad.

Q: What does she do every day as the monitor?

Classmate B: Sometimes, the English teacher asks Miss S to check our English homework.

Q: Was she careful while checking your homework?

Classmate B: Yes, very careful.

Q: Could she identify your mistakes?

Classmate B: Yes.

Q: What else does she do?

Classmate C: We can ask her if we can't work out any problems.

Q: Does she teach you? Can she express herself clearly?

Classmates B and C: Yes, she can.

Classmate C: When we were painting, I asked her how to make dark green, she told me how to mix the paints.

Q: Does she have other tasks in addition to the one in English class?

Classmate B: She is good at singing.

Q: I mean, what else does she do as your monitor?

Classmate B: Sometimes, she checks our personal hygiene. She checked if we had clipped our nails.

Classmate C: And if we had brought our napkin.

Q: What would she do if you didn't clip your nails?

Classmate B: She would mark "bad" on her form.

Q: And then?

Classmate B: That's all.

Q: What if you didn't have the napkin with you?

Classmate B: The teacher would ask the student to buy it.

Q: So, she tells your teacher that you didn't bring your napkin?

Classmate B: Yes.

Q: Does she have other tasks?

Classmate B: She helps check our homework.

Q: Nothing else?

Classmate B: Nothing.

Interview with Miss S

Interviewee: Miss S.

Interviewer and writer: Yi Zhang.

Interview date: March 7, 2018.

Interview place: Miss S's home.

Q: Do you still remember your experiences in kindergarten?

S: I don't recall much.

Q: It's OK. At primary school, which was your best subject?

S: I was good in Chinese. I got good marks on the Chinese exam.

Q: Did you find any of the subjects difficult?

S: Yes, I thought math and English were difficult.

Q: Did you like any teachers? Did you have any special experiences?

S: Teachers in primary school didn't impress me. But I was deeply impressed with a teacher in middle school.

Q: Can you tell me about the teacher?

S: She was my Chinese teacher, a straightforward woman from northeast China. She was kind to me, cared for me, and often encouraged me.

Q: Why were you impressed with the teacher?

S: Once, my mother was ill and needed to have a surgery at the hospital. But I had to go to school that day. I couldn't accompany my mom. I was absent-minded in class, which was noticed by my Chinese teacher. She asked me to read the article I wrote about my mom. I was so concerned about my mom that I cried. The teacher came to me immediately and asked me why I was crying. I told her about the surgery. She comforted me and said, "You are a good girl. Your mom will be fine." She told me not to worry and keep on studying. I appreciated her kind words.

Q: Are there any other teachers that you like or dislike?

S: Of course, I have teachers that I like. And I don't want to mention those I don't like. Let bygones be bygones.

Q: How did you get along with your classmates at primary school?

S: Generally, just so-so.

Q: Did you have close friends at that time? Someone you often played with or went home together after school.

S: I don't think I did.

Q: Were you close with any of your classmates in middle school?

S: I don't think so.

Q: Your mother mentioned that before the high school entrance exam, your parents worked together with you at night to prepare for the exam. Can you recall any such experiences?

S: Of course. I remember that before examinations at primary school and middle school and the high school entrance exam, they were more nervous than me. They stayed up late and helped me with my homework. They wouldn't sleep unless I went to bed. Since the second grade in middle school, they didn't need to sit by me when I did my homework.

Q: Did your parents scold or encourage you when you got poor marks in exams?

S: They didn't scold me when I got poor marks in exams. Instead, they would encourage me and tell me to work harder to make progress.

Q: I see. Did you still have great academic pressure at the specialized secondary school?

S: I didn't feel as much pressure as before.

Q: Your mom didn't tell me much about your experiences at the specialized secondary school. So, I have an additional question for you. What courses did you take?

S: During that period, in addition to the compulsory courses of Chinese, math, and English, I also had politics, philosophy, history, physics, and chemistry.

Q: That's a lot. The school prepared you for job seeking, right?

S: Yes. I majored in e-commerce, so that I could become a cashier after graduation.

Q: Were your marks comparatively better at this school? Your mom mentioned that you worked hard during that period.

S: She was right. I worked very hard. I got better grades in courses for liberal arts than science.

Q: Did you get along well with your classmates?

S: Not bad. We had been together since the military training outside school. But I wasn't confident in those days and I didn't talk much. I didn't often communicate with most of my classmates, except a few.

Q: Do you remember how your internship was assigned?

S: At the beginning, the school assigned me to work as an intern cashier at a Lotus Market in Sanlin. I didn't go there because of time constraints and long commuting distance. Then, I was assigned to work as a conductor and courier at an office on Tianmu East Road for Shanghai Airlines. My parents were concerned for my safety because I needed to carry a lot of money to work and the place was far away from my home. In addition, I couldn't come home on time. So, my parents asked me to quit. After that, I took internships at KFC and a supermarket, where I was formally employed by the latter for some time, till I lost my job during the financial crisis in 2008.

Q: Compared with your experience at work, did anything change after you came to the Sunshine Home?

S: I think I am happier here. At least, I don't feel any pressure.

Q: I know you are a monitor at the Sunshine Home. Can you share some experiences that give you a sense of achievement?

S: I've been despised by others outside the Sunshine Home, but everyone is equal here. The teachers here care for me and my classmates respect me. It is the feeling of being respected and trusted that gives me the greatest sense of achievement.

Q: Do you have any hopes or dreams for the future?

S: I have three wishes. First, I hope there will be more non-profit organizations to care for us and interact with us. Second, I hope the Sunshine Home will flourish. The last and most important one is that I hope my parents will have a long and healthy life, so that we can be together all the time.

Observation of Miss S at Sunshine Home

Observation date: 9:00–15:00, December 7, 2016.

Observation place: A Sunshine Home of a subdistrict in Shanghai.

Observer and writer: Yi Zhang.

Time	Activity	Remarks
8:55	S came into the classroom and put her bag away	The class begins at 9:00 in the morning at the Sunshine Home
9:05	Radio gymnastics exercises	S stood in the first row with standard and coordinated moves. She didn't need to watch the teacher's demonstration
9:10	After the radio gymnastics exercises, S took off her coat and started joint exercises	The joint exercises were practiced to the rhythm of music. The moves were slow but powerful
9:15	S adjusted the volume of the television in the classroom and selected a song	She was preparing for the dancing class. The classroom was in chaos as students had just finished the joint exercises
9:17	Students danced to the music. S was the leading dancer of the second group	
9:20	S stood in a corner of the classroom and chatted with her classmates. They checked the collars of each other and discussed whether the collars were suitable	When the dancing teacher explained the moves to students of the first group, S listened carefully. S nodded and smiled when her classmates did the right move. She laughed out loud and then thought it over if there were any mistakes
9:25	S went to another classroom to fetch a vest and put it on. She combed her hair	

(continued)

(continued)

Time	Activity	Remarks
9:35	S chatted with her classmates about the potted plants at the window	
9:41	S danced and practiced the moves following the demonstration of the teacher	S's moves were basically correct
9:45	The teacher corrected the details of S's moves over and again	S understood soon after the teacher's explanation, but she made the same mistake when they danced to the music
9:57	S took off her vest after the teacher asked if she felt hot	Rehearsal of the first dance was over
10:00	S adjusted the volume of the television in the classroom and selected a song. Instructed by the teacher, she went back to her position	She was preparing for the second dance
10:07	S looked at her reflection on the white board to check if her moves were satisfactory	
10:13	S sat on a chair in front of the classroom, drank some water, and chatted with her classmates	The dancing class was over. Students were taking a break
10:20	Students were called together to set the desks and chairs	
10:26	S watched her classmates playing table tennis	
10:28	S played table tennis	
10:38	S washed her spoon and queued for the meal. She took the meal to her seat and joined the queue for soup	
10:40	S finished her meal. She didn't eat sheet jelly, which she gave to a classmate	S devoured her meal in an intense way
10:55	S put her meal box away and cleaned her seat	
11:00–13:55	Rest	S rested on a sofa
13:58	S went back to the classroom and put her stationery on the desk	The afternoon class begins at 14:00 at the Sunshine Home
14:00	S announced, "Stand up! One, two, three!"	She was performing her tasks as the monitor
14:05	According to the teacher's explanation, S painted a pair of scales. She reminded her desk mate that the circles should be the same size	They were having an art lesson. The first part was about the weight of colors

(continued)

(continued)

Time	Activity	Remarks
14:10	S put a cup on the paper, traced the bottom of the cup and drew two circles	
14:13	S chose the colors. She extruded pea-size white and yellow from the tubes and mixed them	She wanted to make a pale-yellow color
14:15	S asked the teacher whether the color she made was satisfactory and got a positive answer	
14:16	S painted the circles with the color she had made	She traced the circles, then painted them. The color was even
14:18	S extruded pea-size black and yellow from the tubes and mixed them	She wanted to make a dark-yellow color
14:20	S asked the teacher whether the color she made was satisfactory. The teacher suggested that she should add some more black. S thought that there might be too much black	
14:23	S asked the teacher again whether the color she made was light enough. She discussed with her classmate the shade of color and the position of the two circles	
14:28	S drew another two circles, mixed colors and painted them	In her first painting, the two spheres of different shades were on the same level. In the second painting, she considered the relationship between the shades of colors and the position of the two spheres. The bright sphere was above the dark one in the second painting
14:35	S continued to paint. She used the dark green color she had made to show the teacher the color of "bitterness"	The teacher proceeded to the next part of the lesson: taste of colors
14:36	S was still working on the first part of the lesson	The teacher asked her to stop and start the second part
14:39	S used a ruler to draw a table on her picture book, with respective space for colors representing bitterness, sweetness, sourness, spiciness, saltiness, and tastelessness	The table was neat and clean
14:42	S discussed with her classmates about their perception of colors. In their opinion, soy sauce was salty, which can be represented by the color black, and balsam pear was bitter, which can be represented by the color green	

(continued)

(continued)

Time	Activity	Remarks
14:43	S painted the space representing bitterness with dark green and then added some light green according to the teacher's advice	
14:46	S mixed the color for bitterness and sweetness and painted the corresponding spaces in the table	Bitterness: dark green and light green. Sweetness: hot pink and coral
14:49	S mixed the color for spiciness and saltiness and painted the corresponding spaces in the table	Spiciness: red and green. Saltiness: light green and dark green
14:50	S talked to her classmates about light colors	
14:53	S walked out of the classroom to replace the water for washing brushes and washed her brushes	She then painted white
14:54	S's hand was smeared with the paint when she extruded yellow color. She went out to wash her hands and came back	She was running out of yellow paint
14:57	Class was over. S announced, "Stand up!"	She continued to paint as she made the announcement
14:58	S sat down and continued to paint	After the class was over, S continued to paint till she finished the work
15:00	S packed her bag, put on her coat and went home	

Translated by Min Cui

Open Access This chapter is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits any noncommercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if you modified the licensed material. You do not have permission under this license to share adapted material derived from this chapter or parts of it.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.



Find the Courage to Face the World



Mei Liao and Zian Li

Interview with Miss Zengzeng Zhao's Mother

Zengzeng Zhao, female, born in 1988. Has a younger sister. Has Down Syndrome and Grade I intellectual disability. Graduated from a special school—Shanghai Zhabei Intellectual Development School. Image Ambassador for the 2007 Special Olympics World Summer Games held in Shanghai, and Outstanding Special Olympics Athlete in China from 2006 to 2010. Started working at Shanghai Papa John's in 2009.

Interviewee: Ms. Yi Zeng (Zengzeng Zhao's mother)

Interviewers and writers: Mei Liao, Zian Li

Interview date: July 1 and September 23, 2016

Interview place: Zengzeng Zhao's home.

A Child from a Previous Life

Q: Did you have kids as soon as you got married?

Zhao's mother: Yes. I was originally from outside Shanghai and moved to Shanghai in 1987 when I got married. Zengzeng was born in 1988.

Q: We read in the news about how you named your kids. Sounds like you and your husband really loved each other.

Zhao's mother: Yes, we did. When you put together the first names of the two kids, you get my name. My husband was a super nice guy, and we both love the kids very much.

M. Liao (✉)

Shanghai Shida Public Welfare Foundation, 29F, 999 Middle Huaihai Ro, Shanghai 200031, China

Z. Li

Shanghai Foreign Language School, 295 Zhongshan Bei Yi Ro, Shanghai 200083, China

© The Author(s) 2020

W. P. Alford et al. (eds.), *An Oral History of the Special Olympics in China Volume 1*, Economy and Social Inclusion,
https://doi.org/10.1007/978-981-15-5132-1_4

Q: When she was first born, did you realize...

Zhao's mother: She was born healthy. A fair-skinned and chubby baby. There are pictures online of Zengzeng when she was young. She looked like any other kid. You couldn't see anything different about her.

Zengzeng did start walking later than other kids her age. Actually, she still couldn't walk by age two, but we never wondered, "Why can't she walk?" Nowadays a lot of kids can't walk at age two and their parents won't imagine the worst. While she was alive, my mom told me that it's okay if the child starts walking late, because some kids develop early and some develop late.

Her dad had a friend working as a doctor at Shanghai No. 1 People's Hospital. After Zengzeng turned two, we were having dinner at his place during Chinese New Year and he told us, "Your child might have some..." He couldn't go into the details because my husband was almost 40 when we had Zengzeng and she was very precious to him. So this friend said, "When you get a chance, bring your daughter to our hospital. Since we are friends, I will give her the check-up myself."

The check-up was very thorough and painful for Zengzeng. She was crying her lungs out and her dad almost stopped the check-up because he couldn't bear to see her that way. But I insisted on doing it. If there was anything wrong with my child, we had to be mentally prepared to educate and guide her. If it turned out that she was all normal, we'd of course educate and guide her as we would any other kid without disability.

The check-up results came out, which the doctor just told us instead of writing them on the medical record. He said that Zengzeng is slower than smart people but smarter than those who are really slow. I asked whether she could ever be independent, because I wouldn't want anything else from her. As long as she could be independent, I would be patient in teaching and guiding her. The doctor said she could learn to take care of herself. I felt better hearing that. Zengzeng was just delayed developmentally.

Q: Is Zengzeng's condition hereditary?

Zhao's mother: I must have won the lottery. My husband and I have no blood relation. The doctor said that the chance of having a child like Zengzeng was one in ten thousand.¹ There's no family history on either my side or my husband's side, no such genes. So it's like I had hit the jackpot. I just couldn't figure it out. I was in good health. When I was 7 months pregnant with Zengzeng, I fell down the stairs at the old house but she managed to hang on in my tummy. Maybe she is my child from a previous life and has come to meet me in this life.

Q: How did the family feel about the diagnosis?

Zhao's mother: I was so very sad. Zengzeng was the apple of her dad's eye. Her dad's side of the family suggested that we give her away... abandon her. You know, there are definitely kids like her who get abandoned. Her dad said, "There's no way I am abandoning her. You carried her full term, she is our child." If we had really abandoned her, she might have ended up in the wrong hands and come to a worse

¹Medical literature differs on the incidence of Down Syndrome. The rate is around 1/1500–1/3000 for expecting mothers in their 20s, 1/300–1/900 for expecting mothers in their 30s, 1/100–1/130 for expecting mothers around 39, and 1/30–1/40 for expecting mothers around 45.

fate. So it's better to keep her with us. As long as we are alive ourselves, we will guide her. So I decided that I would raise my own child, whatever her condition.

Q: So how did you guide the child?

Zhao's mother: I did research, read books, and consulted other people. Kids like Zengzeng, they have a bad temper when they are young, throw tantrums all the time, and get out of control at home. But I had no choice. Just like her dad said, she is our child, so I needed to be patient educating her. When her dad had time off, every Saturday and Sunday, we would take her to the park. She has been to all the parks across Shanghai where we walked and played with her.

Before Zengzeng started working and before we realized her condition, my younger daughter was born. Having a younger one is a blessing, because she would play with Zengzeng and keep her company. Even now, my younger one is very nice and caring towards Zengzeng. She would come home and joke with Zengzeng and mess around with her. So Zengzeng is lucky to be in our family. She has a younger sister, whereas a lot of kids have no siblings.

Q: When Zengzeng was two or three, she couldn't walk well. Was there anything else that was different about her?

Zhao's mother: No other apparent differences. She just walked slow and threw tantrums sometimes. At first we didn't know she had Down Syndrome because medical science wasn't that advanced yet. Then China succeeded with the research and started naming kids like Zengzeng as Down babies.² When Zengzeng was ten, her dad passed away. I was left alone with the two girls and had to work to support them. I hadn't known about that medical term.

Q: How did you teach her before she started school?

Zhao's mother: I bought a lot of toys and taught her at home, like "1-2-3", "Dad and Mom", reading cards, and poker cards. She still plays poker and board games even now, when she stays home on her days off.

Q: What did you do with the poker cards?

Zhao's mother: Her dad would pick a "2" and ask her to pick a "2" as well, that's how she learned numbers. We also used other cards to teach her reading, like "mom", "dad", "younger sister", "uncle" and "auntie".

Q: So she can read?

Zhao's mother: Yes, she can. She already knew "dad", "mom", "younger sister" and "older sister" by the time she started school. Back then, we taught her daddy's name and mommy's name, and she could recognize them all. But she wasn't good at writing. Kids like her write really slowly. So I had to hold her hand to teach her, the way you teach kids when they first start elementary school.

Q: When did you start teaching her to write?

Zhao's mother: Her dad was already sick at that time, so he stayed home and taught her. She was about eight or nine. Her reactions were slow, so it wasn't easy to teach her. Other kids would have got it faster. It took a couple of weeks just to

²¹Down Syndrome was originally named "mongoloid" or "innate imbecility." In 1965, WHO officially changed the name to "Down Syndrome." In China, in as early as the 1960s, there were geneticists reporting on the trisomy 21 found in children with Down Syndrome.

teach her “1”, because she would forget as soon as we taught her. When she was in a good mood, she would want to learn. When she was in a bad mood, she would tell us “No”. She liked to play and was always holding her toys and playing with them by herself.

Q: What toys did she like to play with?

Zhao’s mother: She liked blocks and really liked building blocks. Her dad bought all her blocks and the blocks had numbers like 1, 2, 3 on them. Back then I wasn’t working, so I took care of her at home and played building blocks with her.

Q: You went to great lengths to educate her.

Zhao’s mother: Yes, we did. Bringing up two kids has not been easy. Looking back now, I still get teary from time to time. If I had to go through it all again, I would probably collapse. I tell my younger one that I don’t even know how I have survived. I moved to Shanghai for marriage, without any relatives here. I am where I am today because I didn’t give up.

Sad Departure of Dad

Q: Was Zengzeng heart-broken when her dad passed away?

Zhao’s mother: She was, because she knew. Her dad had lung cancer and it took him only 6 months to succumb. Our old house had an attic and stairs. I would tell her to go upstairs to sleep and she would do it. I would be with her dad, and as soon as she heard me crying, she would wake up, run downstairs, sit in the recliner, and hold her dad’s hand.

Her dad’s condition kept deteriorating, and the two girls cried and said, “Dad, you can’t die. What are we going to do if you die? Dad, you can’t leave us.”

Her dad was very worried about how I was going to bring up the two girls once he passed away, especially Zengzeng who was like life to him. He didn’t pass away with peace of mind, because he had been the one supporting the family for the 10 years I had been living in Shanghai. He really couldn’t close his eyes.

I said, “Don’t worry—as long as I am alive, I will bring up our two girls. I won’t abandon them. Even if I have to beg for food, I will support them till they can be independent.” That’s when her dad eventually closed his eyes and left. Looking back now, I don’t know how I have managed.

I almost broke down, from the mental and family pressure, in the days following her dad’s death. I had a fever of 41°C and was just lying in bed, unable to even open my eyes. The younger one was at school, and Zengzeng just stayed at my bedside, refusing to leave. She would be touching my head every now and then and asking, “Are you feeling better, Mom?” “Are you okay, Mom?” “Mom, you can’t die. What will I do if you die?” It was so sad. Even now I feel sad about it.

We were living in the old house, so she would run downstairs and bring me a cup of warm water, saying, “Drink the water, Mom, and you will get better.” She wouldn’t leave my side. She just snuggled up to me with her head against my face.

When I reminisce with my younger one now, I will tell her I spoil Zengzeng because she has it in her to be so caring and considerate, and that's the biggest reward for everything I have done for her. Zengzeng might misbehave sometimes, but when some of the kids without disabilities can't even listen well all the time, what more could I have expected of her?

After her dad passed away, I had to work to support the girls. Because of Zengzeng, I had to find a job close to home. There were a lot of people living in the same building and helping each other, unlike today's neighbors who hardly interact. When she was young, Zengzeng didn't understand a lot of things. She was also naughty and couldn't speak clearly. In the old building we lived in, she would be holding a bucket of water and dripping water downstairs, and the downstairs neighbor would yell at her and hit her. The two girls suffered quite a bit when they were young. Zengzeng once picked a flower from a neighbor's pot. The truth is that the social environment is different now. Back then, because of the flower, the neighbor yelled at Zengzeng and used a toothpick to poke her hand till blood showed.

That's why I said at last week's parents' meeting that the Special Olympics movement is good for directing society's attention to kids like Zengzeng to improve the treatment they receive. We have first-hand experience with how difficult it is to have kids like Zengzeng. I am very happy that things are getting done (including writing the oral history).

After my husband passed away, the Community Affairs Committee arranged for me to supervise bicycle parking which was very close to home. Zengzeng would run between home and where I worked. I was devastated seeing the bloody toothpick marks on her hand, so I said to the neighbor once I got home, "We all have kids—Zengzeng has a disability, but your kids are not perfect either. Even though her dad passed away, her mom is still here. You have no right to treat her like that."

Other neighbors showed support for me. Zengzeng was, after all, a child with intellectual disability. Whereas other kids might listen to reason, she wouldn't because she believed what she did was fun.

I said, "How much is that one flower worth? I will pay you. You just can't treat my child like this." That lady then apologized. She was a nice person and felt bad about what she did. So I left it at that instead of making a bigger deal out of it. After all, Zengzeng did something wrong and we all lived under the same roof.

Before I started working, I was watching Zengzeng the whole time and taking her everywhere with me, so people never got a chance to hit her, because I would hold her hand even when we went grocery shopping.

When her dad was still around, the neighbors were nice. Then he passed away and I had to work. Zengzeng was naughty, and kids like her are hyperactive and get into trouble for no reason, but you can't follow them around all the time. So I told the neighbors that whatever Zengzeng broke, I would compensate them for it, but they shouldn't yell at her or hit her, because she is my child and it would hurt me if anyone yelled at her or hit her.

Q: Were there any kids bullying Zengzeng?

Zhao's mother: She didn't play with other kids. It's a habit from when she was young, because her sister would babysit her. Once the younger one got back from

school, she would play with Zengzeng at home or take her out to play. Once the younger one got to a certain age and I had to work, she was the one protecting Zengzeng. She also cooked for Zengzeng. Zengzeng can do things too. She started helping me around the house when she was 17 or 18. By the time I got back from work, she already had the rice cooking. I didn't really want her to cook because of safety issues.

Q: Do you visit her dad's grave every year? To tell Dad Zengzeng's progress?

Zhao's mother: We do. We would tell Dad, "You were so worried about Zengzeng. But she has matured and become part of society, so you can rest easy now." Zengzeng would say, "Dad, I am here to visit you. Do you know, Dad, your daughter has become a celebrity?" She can really tell a story.

It's very far to visit her dad's tomb. We have to take the subway, then switch to a bus. Sometimes we would ask a friend for a ride. Both girls suffer car sickness. Her dad should have peace of mind now, because the one person he had been most worried about was Zengzeng.

Q: How did you meet her dad?

Zhao's mother: If I could start my life afresh, I probably wouldn't have moved to Shanghai for marriage. Her dad's relative was my co-worker at the harvest station in my hometown. He collected the farmers' harvest and I issued receipts, and we worked as a team.

Her dad visited my hometown and came to the harvest station where his relative and I were busy collecting harvest. He asked his relative later whether I was single or had a boyfriend. His relative said, "No, this girl won't just marry anyone." I was pretty when I was young.

So his relative told me that someone was interested in me. I didn't take it seriously and asked him exactly who. He said, "He is my relative. He came to visit me and likes you. He is from Shanghai."

"From Shanghai? I don't know," I said. "I heard that Shanghai is a very nice big city. I have never been there."

Then a matchmaker came to talk to my parents. I was 22 then, and outside Shanghai, that's an age to get married, otherwise you would be labeled an old spinster and no one would marry you. My parents told the matchmaker to find someone for me. I was picky and already rejected a lot of people, so the matchmaker might have better luck with me.

It was my dad who really liked my husband. Since they were happy with him, my parents gave me a lot of pressure and I didn't have a choice. Then he took me to Shanghai to see where he lived. It was a very small room in one of those old-style stone buildings where the shared kitchen was downstairs and coal stoves were used for cooking. I didn't know how to take that.

My husband had a good education and wrote well. He wrote and sent to my house a thick stack of letters (gesturing to show thickness of more than one inch), like a book, telling us all about his birth, experience, and family background. I was at work and my mom received the letters, which my older sister opened and read to my parents. When I got back from work, my parents said to me, "He is such a nice guy. If he is not good enough for you, who is? Look here, he sent a book to you."

My parents really liked him, but I was still resistant. My parents said, "If you reject him, you are no longer our daughter." You know daughters always end up obeying their parents. Once my parents said that, I had to agree. "Okay fine. I will marry him. That's what life is. I don't want to pick anymore, I will make do and have a family." So I married him.

Q: How old was Zengzeng's father at that time?

Zhao's mother: He was more than 10 years older than me.

Q: Not too bad.

Zhao's mother: It was considered a big gap in age back then. My mom said, "You don't have a good personality and are very stubborn, so you should marry someone much older who can put up with you and spoil you." My husband really spoiled me. After I moved to Shanghai, I didn't work for 10 years. My husband supported me. He said that if a man can't afford for his wife to stay home, he should just not marry at all. He was a typical man's man.

Q: What did he do?

Zhao's mother: He had a stable job, which he quit later to start his own business. In the 1980s, it was easy to make money in stocks in Shanghai. He and his friends also contracted for several buildings across from Changhai Hospital, but he got sick before the construction was completed. He had to give up his share of the contractor business and couldn't get any of his own money back. It was a very difficult time. Once a person passes away, however much money people owe him, there's no way to get it back. I did try to get some money back but people treated me to long faces and even threatened me with physical violence. I eventually gave up. I couldn't get any money back, especially as I was not originally from Shanghai. I still have the IOUs. Before my husband passed away, he made calls saying, "Please pay the money back to my wife, she needs it to support herself and the two girls." Once he passed away, no one paid a single penny back.

Q: So you had a happy family and were in a good financial situation, but your husband got lung cancer...

Zhao's mother: Right. My daughter often says that if her dad hadn't passed away, our financial situation wouldn't have been so bad. My husband was super smart. He would at least have guaranteed that the two girls wouldn't suffer. His death was unfair to the two kids, of all people. He totally spoiled them and doted on them...

Grateful to School for Zengzeng's Present

Q: Had you ever thought about sending Zengzeng to preschool or elementary school?

Zhao's mother: I kept her with me and didn't send her to either preschool or elementary school. I did think about that, but decided against it, because she couldn't control herself and threw tantrums all the time. She might hurt other kids at preschool by bumping into them or hitting them, so I figured it was better to keep her with me. Back then, there were no preschools specifically for Down babies.

Our old house was close to Datong Road. I became aware of an intellectual development school there especially for kids like Zengzeng, so I sent her to that school. After 2 years at the school, we were relocated by the government to where we live now. And 2 years after that, the intellectual development school relocated to our neighborhood. So we were really lucky.

I had a hard time with school drop off and pickup. I worked at Wujiaochang. Before going to work, I would carry her on my bike to school. I took my lunch break at 2 pm, which was when I would bike to the school and pick up Zengzeng, then I would go back to work. The truth is that if you have kids like Zengzeng, as long as you can commit on your part, the kids can have a normal life, but you really have to commit. Without that intellectual development school, Zengzeng wouldn't be where she is today. Right now, she can at least understand the news. She really likes watching the news. And she can write her own name as well as simple characters.

Q: When she was new to the school, did she have difficulty fitting in or was she reluctant to go?

Zhao's mother: Not really. Because I had to work and her sister had to go to school, she was lonely at home by herself. There were a lot of kids at school and it was more fun there. Ms. Gong at the school was particularly nice and caring towards her, because she knew our family situation. Sometimes when I was delayed at work and late to pick up Zengzeng, she would keep Zengzeng with her and watch her for me, and always called me whenever there was any issue.

Q: What did she learn at school?

Zhao's mother: The books she used were simpler than those for kids without disabilities. She learned math, Chinese, and drawing. Zengzeng is very good at watercolors, and one of her landscape drawings won an award when the school sent the students' works to a city-level competition. Then a teacher on Linfeng Road told me, "She loves drawing, bring her to my place and I will teach her." I was too busy with work and didn't have time, that's why Zengzeng had to stop going to the teacher's free drawing lessons.

She also learned dancing at school. She danced very well in the number *Grateful Heart* and performed at a show in Zabei District. Now at home, sometimes if you put on some music, she will dance her disco dance. She also likes to watch musicals and to sing along.

There were also craft classes where she learned to make small things like bunnies. On top of that there were PE classes. She ran in the class. The running that took her to Special Olympics World Games got its start at school.

Q: Teachers at that school are all professional special education teachers and very experienced.

Zhao's mother: Just being professional isn't enough. They need to have patience, which some of them don't. Even parents don't have patience, let alone the teachers. So that's understandable and we have to be considerate towards the teachers. Zengzeng was hyperactive at school, and I was worried that she would get into trouble by hitting other students. So whatever happened to her at school, like when she fell, I never really minded. I would just take her to the doctor myself, because I am the parent and I knew that she was a hyperactive child. If I demanded an explanation from the

teacher for every time she fell, that would be extra work for the teacher. Parents should be considerate towards other people and other people will be considerate in return. It's all mutual, being tolerant and considerate. Sometimes the teacher would call and tell me when Zengzeng was injured, and I would say, "No problem, no problem, just a minor one I'm sure. Don't worry about it, I will take her to see a doctor when I have time." When it comes to your own kid, you don't complain. You just take responsibility.

I often tell Zengzeng, "Zengzeng, you are the smartest. Your sister is not as smart as you are and she should learn from you." It makes her very happy and makes her believe that she is smart. She has self-respect, and she understands, not like some other kids who are totally clueless. If you refer to her as slow, it hurts her. Someone joked with her saying that Zengzeng was slow, and she retorted, "You are slow. You are not as smart as I am." She can carry on conversations, so we must encourage kids like her.

The restaurant manager would call me sometimes and I would tell him to sweet talk Zengzeng into doing things he wanted her to do. This trick works as well at home. I would say, "Zengzeng, Mommy doesn't want to move. Can you please pour me a glass of water?" She would say, "You can do it yourself." And I would say, "Zengzeng, you are the sweetest and smartest. You are Mommy's sweetheart, not your sister." That's how I get her to fetch me water. She needs praise and encouragement and is over the moon when you praise and encourage her.

Q: You've got it all figured out. So you said that Zengzeng was pretty happy at school. Did she make friends with any classmates?

Zhao's mother: Making friends! Even now, her old classmates will call her up and ask what she is doing. She'll tell them she is working and they'll visit her at the restaurant.

Q: Did you drop her off and pick her up from school?

Zhao's mother: At first, I dropped her off and picked her up, but then I figured I should let go and have her walk to school and back home, which is how she goes to work now.

One time she was walking home from school and took the wrong turn. I went to school to pick her up and couldn't see her. I felt like I was losing my mind and started sweating all over. She knew which direction we lived and knew that she was lost, so she went to a bus station and just stayed there. A lot of passersby surrounded her and it was clear to them that she had some disability. Someone asked her, "Where do you live? I can take you home and feed you something, then we will send you home." No matter who approached her, her answer was "No".

It got dark and was already seven or eight. I still couldn't see her as I rode around on my electric bike, and I was desperate and ready to call the police. I stopped by the neighborhood police station and no one had seen her.

Several adults sat next to her to keep her company, because she refused to go anywhere or to eat anything offered to her. She didn't cry and wouldn't talk. She just sat there. People asked her where she lived and offered to send her home, and someone asked to see her school bag to look for an address or phone number. She refused to show anyone her schoolbag.

Eventually there was no choice but to call the police and a police car took her to the station. She recognized the place and showed her schoolbag to the officers. They saw the name of the intellectual development school and called the school. The school called me and reached my younger one who had stayed by the phone. So I went to pick up Zengzeng at the police station. I asked how she was feeling, and she said she got to sit in a police car with A/C and felt really comfy. (Laughing).

Q: You did an excellent job teaching her about safety.

Zhao's mother: I had to, I had to. I told her a long time ago, "If you ever get lost, you can never ever go with a stranger. If someone abducts you and sells you, you will never see Mommy again and no one will be able to help you. If you find yourself lost, just stay there and don't wander off. If you see the police, tell them that you are lost." I had been teaching her about this since she was young, because after her dad passed away, I was the only one bringing up the girls and I worried about them getting lost. So I told her and she said she understood.

I taught her to ignore strangers talking to her, to go straight to school without stopping to talk to anyone and to ignore even people from our apartment complex if she didn't know them. People in our apartment complex tell me that I have done a great job educating Zengzeng. Kids depend on education from their parents. Zengzeng knows to give her seat to the elderly on the bus. When I send her to the bus station, people all know me and tell me, "You have such a good kid. She always gives her seat to the elderly. She has such good manners, even better than persons without disabilities."

Special Olympics Star Groomed in Communication

Q: It was reported that in 2004, Zengzeng participated in Special Olympics leadership training. How did she get picked for the training?

Zhao's mother: The truth is that wherever Zengzeng goes, people like her. The teacher at school liked her too and said she was cute. She took Zengzeng to Sichuan for the Special Olympics leadership training and something funny happened on the trip. Ms. Shen rode the train with her. She slept in the lower bunk and Zengzeng took the upper one. I had packed some snacks for her. Ms. Shen said, "It's late, don't eat anymore—you should sleep now." Zengzeng threw a tantrum and just dumped her unfinished food onto the lower bunk. Ms. Shen later said that she couldn't exactly get mad at her. I said, "Yeah, she is too naughty." And Ms. Shen said, "At the parties on some evenings, Zengzeng would sulk. So she just sat down, took off her shoe and threw it onto the stage with a loud 'bang'." Kids like Zengzeng are hyperactive. The teacher said she couldn't exactly get mad at her because when she behaved, she was a model kid.

Q: Was that the first time Zengzeng travelled by train? Did she like it?

Zhao's mother: It wasn't the first time. My hometown is Hefei in Anhui, so I often took them to Hefei by train. But that was the first time Zengzeng was away from me, and she stayed in Sichuan for 3 days if I remember correctly. As long as she goes

with people she knows well, she is okay. Ms. Shen was her PE teacher and taught her to run.

Q: Zengzeng was picked for Special Olympics training not just because she was cute, but because she was good at PE, right?

Zhao's mother: Right. She had been running for a long time. Back then, she was walking to school and back home every day. It took at least 40 min to walk from my house to the school on Baode Road. At first, I would walk with her, then she started walking by herself. She would walk and play on the road, taking in everything on the way, which was fun for her. So it would take her more an hour to get to school.

There's a bus from my house to the school but I made sure she walked instead of taking the bus. Because she got out of school early, she would have nothing to do at home. Walking was good for her and for exercising her legs.

At school, the teacher was always asking her to run. She started by running 100 m and was really good at it. Then she gained weight which slowed her down. By the time she was filmed in the commercial, she had already put on some weight.

Zengzeng started competitive running after she came back from the Special Olympics leadership training. It was back then that various kinds of Special Olympics sports meets started. Zhabei District organized some, so did every other district, and Zengzeng went to them all. The teachers would take them and parents would tag along. I signed on to volunteer and followed her everywhere.

Zengzeng loves sports, so she wanted to compete in all of the events as long as there was no cap. There was a shot put event and she told me it sounded fun, so I encouraged her to participate even though she couldn't even close her hands around the shot. I told her to be careful and not to throw it onto anyone's foot. Since she had to hold the shot with both hands, she couldn't really throw it far and it was hilarious to watch. I asked her if she wanted to compete in this again and she said, "No, Mom, it's too heavy, I won't participate in this again." It was fun taking her to the meets. She even tried competing in badminton and it wasn't really for her, (laughing). There were other events that I can't recall now.

So she tried many events and never went back to them. Running is the only event she trained and competed in consistently. She would train 30–60 min after school sometimes. Then the school found a place in Zhabei Sports Stadium where she would train on Saturdays and Sundays.

Q: In 2006, the TV station went scouting at the school and picked Zengzeng for the Special Olympics promotional film.

Zhao's mother: Right. Zengzeng was still attending that school. It was 2006 and China was going to host the Special Olympics World Games. The director visited the school to scout for a promotional film and picked Zengzeng on the spot. I was at work during the day. As soon as I stepped into the house that night after work, Zengzeng told me, "Mom, Mom, the director is coming to our house to shoot a commercial tomorrow." I said, "What commercial? Are you daydreaming again?" Zengzeng insisted that it was true and she wasn't kidding me, and I was still doubtful until Ms. Shen from the school called me that night to tell me the same thing. Then I believed it.

So the director showed up the next day to film our family and our apartment complex. The TV commercial was to deliver the Special Olympics message of “If you can, I can, too” and to tell the story of “Zengzeng My Child”.

Q: Was that your first time participating in a publicity campaign?

Zhao’s mother: Yes, the first time. We have been doing that a lot ever since. So the promotional commercial had to be shot before the Special Olympics World Games and the filming took place at a sports field in Zhabei. We arrived in the morning and Zengzeng’s shooting started in the afternoon. I was given a lipstick and told to use it before kissing Zengzeng on the face. So I did that and the picture came out really nice.

Q: Pictures of Zengzeng were everywhere back then, and Mom’s love and society’s love were loud and clear in the lipstick marks you had left on her face.

Zhao’s mother: Right, the picture was made into posters on light boxes and public buses. It was such a nice picture.

She had to run many laps during the filming. It was extremely hot, and I found the heat unbearable even though I was just watching her from the sideline. I asked her if it was too much for her and she said she was okay. You know how long it takes to film a commercial? She had to run one lap after another and I joked that she must have lost weight that day. There were two female crew members who took very good care of her, wiping her sweat and keeping her cool. The commercial was filmed at a lot of locations including the ferry boat near the Bund.

Q: Once the promotional film was released and the posters were put up, Zengzeng became a celebrity in Shanghai. How did that impact your lives?

Zhao’s mother: The impact on our lives...A lot of people cared about us, and Zengzeng got really busy. She went to the USA with the Special Olympics committee, TV crew, and special police forces to receive the torch. People from Shanghai TV liked to joke with her, saying that Zengzeng liked good-looking guys and could really talk and was quite somebody. That’s the way she is at the restaurant too. I took her to an activity the other day and she was talking the whole time. So I packed a suitcase for her for the US trip, and she came back and told me, “Mom, the airplane turned round and round and I got so sick that I threw up. And I didn’t like the food there, so I ate instant noodles.” She wasn’t used to the food in the US. Other than that, she had a great time attending the activities there. She was part of the delegation receiving the torch and meeting with the US President.

I was with her for all of the activities held in Shanghai. Mrs. Shriver,³ who has since passed away, came to Shanghai for a ceremony and was opening a bottle of champagne. Zengzeng stood next to her and looked so short. The champagne gushed out with a loud “pop”, and Zengzeng looked at me sitting there in the audience. When she came back, she asked me if I had enjoyed the show. She was so very happy.

³¹Mrs. Shriver (1921–2009): Eunice Kennedy Shriver, founder of the Special Olympics World Games, younger sister of former US President John Kennedy, and recipient of the 1984 Presidential Medal of Freedom for her contribution to the campaign for equal rights for people with intellectual disabilities.

At the Special Olympics World Games, Zengzeng competed in running. It was at a sports field in Pudong and I went with her since I was a volunteer. She came in last, (laughing). It was in the afternoon and so hot. There were six athletes in her heat and she came in last. I asked her if she couldn't keep up with the others. She had a lot of engagements then, almost on a daily basis, which had cut into her training time. The engagements started in a random pattern in 2004 and became much more frequent following the commercial filming in 2006. The commercial was aired for a whole year from June 2006 to June 2007, before she went to the USA for the torch. Zengzeng had such a great time.

You can still find the closing ceremony of the Special Olympics World Games online, where the then-Mayor of Shanghai Han Zheng and Zengzeng handed the flag to the next host city. Sometimes I wonder whether it will be taken offline after a while, but my younger one said it will be on the Internet forever and will never be deleted. Every time I type in the key word, it pops up!

(Showing all kinds of Special Olympics photos and volunteer's certificates).

Q: We will bring a camera next time to take pictures of your pictures.

Zhao's mother: I think you can find all of these pictures online. Just search for them, they should be there permanently. There's also this picture of the Greenberg Outstanding Achievement Award.⁴

After the Special Olympics World Games in 2007, there were the Olympic Games and Paralympic Games in quick succession. Zengzeng was picked as the Olympic torchbearer and took over the torch on the Bund in Shanghai. We still have a replica of the Olympic torch at home.

I can't recall all of the Olympic activities she had participated in, since it has been a while. There were a lot. Sometimes I was exhausted, taking her to one activity right after another.

Q: Did Zengzeng find it exhausting?

Zhao's mother: No. She never complained of anything being too much or too tough. She loved going to the activities. During the Special Olympics World Games, I would take her to four or five activities on one single day, and I worried that she would be tired. But she said she wasn't. I found it hard to keep up myself.

Q: She must be in good physical condition because of the running.

Zhao's mother: I take her to annual physicals and everything is good with her. Because she's overweight, I was worried that she might have a fatty liver. This year's physical showed that she has a slightly fatty liver which is no big deal at all. All of the doctors know her and when they see her, they would tell her that her tummy is getting bigger and she needs to lose weight. And Zengzeng would reply, "What am I going to do when I can't lose the weight?" She knows how to joke around with the doctors.

⁴²Greenberg Outstanding Achievement Award: In 2007, the Special Olympics Families' Forum for the Special Olympics World Summer Games held in Shanghai set up the Greenberg Outstanding Achievement Award to recognize outstanding Special Olympics family representatives, and Ms. Yi Zeng, Zengzeng Zhao's mother, was one of the recipients of the award. The award was named after Mr. Greenberg, Chairman of the Board and CEO of Starr Investment Group in the US who was that year's most generous individual donor to the Special Olympics World Games.

Q: You just mentioned that you saw very apparent changes in Zengzeng after the Special Olympics World Games. What were those changes?

Zhao's mother: She can really communicate with other people now. Before, she would get mad at school from time to time. She has changed a lot and doesn't even throw that many tantrums at home. She feels that since she is the image ambassador, which she is super proud of, she will have to control her temper which is what celebrities do. When she walks on the street, people would know her by name and ask her if she is indeed the celebrity and the image ambassador they think she is. She would say, "Yes, it's me." People often recognize her on the street. When she takes the bus now, several of the drivers are super nice to her and always tell her to watch her step. Kids like Zengzeng have very straightforward thinking. Whenever people ask her, she would proudly tell them who she is.

Q: She has a very open and outgoing personality.

Zhao's mother: Yes, and she has grown even more outgoing because of her participation in those events including the 2007 Special Olympics World Games, and the Olympic Games and Paralympic Games in 2008. Following the Olympic Games, Zengzeng attended activities hosted by the community and the Disabled Persons' Federation, like meet-and-greets, presentations, and Communist Party-building seminars, and we were asked to bring and show her certificates, pictures, and souvenirs.

Then she tried Sunshine Home and didn't fit in because she didn't want to be with those kids. I asked her why and she said it's no fun. Kids like Zengzeng have the same mentality as persons without disabilities, in that they can never forget about their 15 min of glory. I told her to stay put at Sunshine Home while we started job hunting for her. Several weeks later, Papa John's was hiring, so she joined them.

Making Money to Support Mom

Q: According to media interviews, Zengzeng learnt to cook using flour when she was at the school.

Zhao's mother: Right. She stayed at the school for a total of 8 years. Curricula of elementary school and middle school were covered during the first 6 years, and for the last 2 years, she moved on to classes teaching hands-on skills. So she chose for herself a class where she learnt to make steam buns, noodles, and dumplings. When a reporter interviewed her later, she was kneading dough, with hat, apron, and the whole nine yards. The reporter said she looked like a chef, (laughing). I asked her whether the steam buns she made were delicious, so she brought some back for me to taste. At first, the buns were too hard and chewy, but they got better with the teacher's help. I asked her to make steam buns twice at home. She is very good at making noodles and not getting them all stuck together. She is also good at making dumplings. But steam buns are still a challenge.

Q: Does she still make any at home?

Zhao's mother: Not now. Can't rely on her for that. She has to work and is already tired by the time she gets home. People would ask her how she plans to use the money she makes at work, and she would reply, "I am going to use the money to support my mom, because she has had a hard life." She really has changed a lot. When she was interviewed, she kept saying that once she started working, she would use the money to support her mom.

Q: When did she first have this idea of supporting you?

Zhao's mother: After her dad passed away, she saw how hard I had to work, so she started saying, when she was about 15 or 16, "Mom, when I grow up, I will find a job and make money and support you. Then you won't have to work so hard anymore."

Q: How did Zengzeng know that Papa John's was hiring?

Zhao's mother: The hiring information was on the Internet, but it was the Disabled Persons' Federation that told me about it. So I took her to the interview. I didn't really think she would make it, so both of us took it really easy. She later told me that she was asked to carry plates during the interview. Papa John's is a nice company. After several days, they notified Zengzeng to attend training. I took her to training every day. Since she started training late, she had to go to a designated place in Yangpu District, and the training lasted about 2 weeks.

Every day she came home, she would tell me what she had learned at the training, like making pizza, kneading dough, carrying plates, and greeting customers. I asked her to show me, so she opened the door and said, "Welcome. Would you like to take the table over here?" She carried a notebook with her every day and practiced at home.

Then the restaurant notified her to report for work, so I went with her and she signed the contract herself.

She started by greeting customers. A lot of people recognized her and asked, "Aren't you image ambassador Zengzeng Zhao?" She wasn't exactly low-key about it and replied proudly, "That's me." But it got tiring when she had to stand for a long time, so she was moved to the non-dining area to wrap knives and forks in napkins. She didn't really care where she was moved to because she was equally happy at all the workstations.

Q: Does she tell you about what happens at work?

Zhao's mother: She does, every day, like whether business has been good on that day. I would ask her if she has been behaving at work, and she would say, "I was very good at work and the managers all praised me for it." So we talk like that every night.

Q: Does she get to interact with customers?

Zhao's mother: When she first joined Papa John's, her job was to stand at the door to greet customers, so she had been interacting with customers a lot. Then the company moved her to the non-dining area to wrap knives and forks, and she is very happy at that job. A reporter interviewed her last time and asked her if she was happy at work. She replied, "I am happy. My mom works hard, now I want to make money to support my mom." She is such a sweetheart.

If I don't feel well and stay home on a certain day, she would say in the morning, "Mom, Mom, remember to take your medication. I have to go to work now. Wait

for me to come home.” And when she came home again, she would ask, “Mom, are you feeling a little better? Are you feeling a lot better? Are you feeling okay?” She really wants to know how I am feeling.

Q: Has she ever felt work is tiring and thought about quitting?

Zhao’s mother: No, Zengzeng has never had those kinds of negative thoughts about work. My younger one gets tired at work sometimes and wishes for time off, but not Zengzeng. I joked with her, “Why don’t you quit your job and stay home to eat, shop, and play?” She replied, “No, I can’t do that. How can I make money if I don’t work?” (Imitating Zengzeng’s loud voice.) “There are a lot of people at work and no one except for me at home. What’s the fun of eating, shopping, and playing?” Her co-workers are all super nice to her.

The worst Zengzeng ever does is to misbehave. The manager called me last time, “Zengzeng isn’t listening well. She uses two extra napkins for wrapping the knives and forks.” So I called her, “How are you doing at work? Are you behaving? If not, you should just quit and come home.” “Oh no,” she said crying, “I want to work, Mom.” Then I asked her if she knew what she had done wrong and what to do about it. She said she knew and would apologize to the manager. And I said, “Okay, that’s good then.”

I had a talk with her when she came back, “When the manager talks to you, you need to respond, you know? You can’t have any attitude. The manager is supposed to manage you and you need to respect the manager. Do you understand?” She said she understood. Kids like her don’t always get it, after all, so you will have to constantly remind them.

When the manager assigns her work, she gets lazy sometimes and will sit there and play instead. All of the managers at the restaurant are really nice. I am the parent, so I know that kids like Zengzeng are not easy to manage. They have their distinctive personalities and get mad and moody sometimes. As the parent, I am very tolerant. Whatever happens to Zengzeng at work, I blame it on her. I told her to keep the transportation card hanging around her neck so as not to lose it. She had to take it off and of course she lost it. I have had to replace the card quite a few times for her commute. She would cry at the restaurant over the lost card, and the manager would call me about it. I told Zengzeng, “You can’t cry at your workplace—you are already in your twenties.” The manager didn’t know what to do, so he offered to let Zengzeng use his own card. I said, “No, no, I will buy a new one for her. Lost is lost, it’s okay.” The manager knows how to get along with the other co-workers, but it’s not as easy to handle kids like Zengzeng. So parents should be more understanding towards managers and co-workers at the workplace. Parents can be more tolerant because they know their own kids better.

Q: The manager told me that she works hard and takes her job seriously.

Zhao’s mother: Yeah, the manager often praises her. Whenever he does that, Zengzeng will come back and tell me, “The manager said Zengzeng worked very hard today.” She is still a child, isn’t she? One time I went to the restaurant and a co-worker told me, “Zengzeng is being very good. Look at how clean she has wiped this table.” Sometimes I would call the restaurant and ask how she is doing and I would be told that she listens well, really behaves, and does a good job at work.

She works 8 h a day, from 10:30 to 7:30 pm, with 1 h for lunch. She has never complained that work is tiring. Whenever I ask how she feels about her work, she will say that she is happy. She has been working for 7 years now, so she is a senior employee in a way of speaking.

I asked if she wanted me to talk to the restaurant about transferring her to another one closer to where we live, and she said, “No, I want to stay where I am because the managers and co-workers are very nice here.” To go to work by herself, she needs to take bus No. 845 and switch to bus No. 850, which takes less than 1 h. So she leaves the house at 9 am and gets home a little after 8 pm. Most of the time she commutes on her own. If I have free time now and then, I will go and pick her up from work.

When she first started working, she got lost once. I had asked her to wait for me to pick her up, but she left right after work. She missed her stop on bus No. 850 and got to the bus terminal. It was a cold winter in Shanghai and it was snowing. So she stood on the street, knowing that she’d missed her stop, that she lives somewhere in that direction, and that she just couldn’t find her way home. But let me tell you how smart she is. She waved down a motorized cart which was operated by a very nice owner. She said to him, “Uncle, please send me home, and I promise that my mom will pay you.” I didn’t give her pocket money at that time because I didn’t want her to run around wild once she had money.

I went around her restaurant many times looking for her, until past 1 am. Even though it was freezing, I broke out in a sweat. On the way home, I figured if I still couldn’t find her, I would call the TV station to help. As soon as I got home, she came back in the motorized cart, rang the bell and asked me to go downstairs to pay the driver. At that moment I didn’t know whether to be relieved or to be mad. So I went downstairs, and paid and thanked the driver profusely.

I asked Zengzeng, “How did you get lost? You know Mommy almost passed out from panicking.” She said, “Don’t panic, Mom. I got back, didn’t I? Don’t be worried or scared.”

Now she has my cell phone number, which she can recite sometimes. If she gets lost, she will either get a taxi or look for the police since there are many traffic cops around or go to where she sees 110. She reassures me that she knows what to do. She is smarter now and knows directions better. She commutes on her own, although I pick her up if I get worried sometimes.

Q: Does she interact a lot with her co-workers?

Zhao’s mother: I would think so. I don’t go to her workplace often, in fact I don’t go if I don’t have a good reason to go. It’s not good to always check in on her at work, as if I was paranoid. And I should be considerate towards other people at work there. I should also be supportive towards the workplace and not bother anyone there for no reason.

Q: You just mentioned that you saw major progress in her following the Special Olympics World Games, because she feels that she is a celebrity and should be able to control her emotions better. You also saw some major progress in her since she started working. Can you be more specific about this second progress?

Zhao’s mother: Now I can let go. She used to be wrapped in cotton wool by me, like a baby. If I had kept her home, she would have remained the same.

If I go out with her sister and leave her alone at home, I will tell her, “Zengzeng, enjoy your day off. I have cooked something for you. You know how to feed yourself.” And she does know how to feed herself. She will never open the door if a stranger rings the bell. She knows how to protect herself now. For kids like her, you can’t really have too many expectations. I just want her to be able to protect herself.

One time I was going on a trip with her sister and asked her to go with us. She said, “No, Mom, I won’t travel. I’ll stay and watch the house to make sure no burglars come. I saw on TV that there are many burglars around, so I need to watch the house. Have a good time, Mom.” She spoke exactly like someone without disabilities. Another time I asked if she wanted to go to Hainan with me, and she said, “Mom, you can’t go. I watched the news, something happened to the airplane, just like that. So you can’t go now.”

Q: She speaks as if she was the master of the house.

Zhao’s mother: Exactly. Before she goes to work, she will say, “Mom, stay put and watch the house, there are a lot of burglars out there.” She will tell you to watch out for this and that. If she hadn’t stepped outside this house and ventured into society, she would not have made such progress. A lot of kids without disabilities have no common sense nowadays. So the truth is that being out there with persons without disabilities has broadened her horizons. Because she works at a place where the majority of employees are persons without disabilities, it has made a difference to her. She has changed and improved, and has come to understand more about society.

I would leave some money there and ask her to buy food for herself. And she would know how to do it and to wait for change. If I had kept her at home, she probably would have responded by asking where she could buy food.

Now she comes home from work and says, as soon as the door opens, “I am back. Anyone to welcome me back? Anyone at home? Come out and say ‘Hi’.”

Q (pointing at the small dog at her feet): And this is the one to greet her first.

Zhao’s mother (laughing): Right, this is the one that runs up to her first. I will immediately say, “Welcome back, welcome back!” while hugging and kissing her. She is still clingy towards me, since I have brought her up all by myself after her dad passed away prematurely. She has had no one but me. If I don’t respond right away, she will ask, “What’s going on? You are not happy to see me back?”

If I go out while she stays home on her day off, she will hang up the laundry I have done and make all the beds at home. She washes small things like socks. We have always encouraged in her the habit of washing her own clothes. It doesn’t matter if she can’t wash them clean, I will wash everything again for her. But she does need to wash them herself. I had no choice anyway. Since her dad passed away, I have been busy making a living, so I had to teach her to do things for herself.

We are in a good place now. Despite her disability, Zengzeng has come a long way, and being her parent, I am very satisfied. People in our apartment complex always say that Zengzeng may look slow, but she is not. She would greet everyone she knows in the apartment complex and is really smart in other ways. All of the neighbors compliment me on what a great job I have done bringing her up to the way she is today.

Q: When did your financial situation start to improve?

Zhao's mother: When my younger one started working and Zengzeng started receiving a government subsidy for persons with severe disabilities who are unemployed. We used to receive a low-income subsidy which was a little over 100 yuan at the very beginning. It went up to over 200 yuan later which was still next to nothing. But Zengzeng got the Papa John's job soon after she started receiving the government subsidy, so the subsidy stopped. She doesn't make much more than the subsidy. I pack food for her every day she goes to work and have to make it decent. And she brings sodas too. There's also the transportation fee for commuting. She only makes enough to cover her own expenses like clothes and going out on her days off.

But it's okay. I really just wanted to get her out there to help develop her mind. She can't stay home. Now that she is out there, of course it costs money, but it's worth it because she is being gradually included into society. Parents get old and leave, so the least I want for her is to be able to communicate with other people and to make a living.

Contented Life Together

Zhao's mother: My younger one is a sweetheart. Ever since they were young, she had been babysitting her sister, taking her everywhere she went and doing everything with her. They have never had a fight and their emotional bond is very strong.

Q: So your younger one only played with her sister and not with any other kids? Did she ever want to play with other kids instead of her sister?

Zhao's mother: I had to explain everything to her, telling her, "I have no choice. If Daddy were still alive, you would have the freedom to play with whoever you wanted. Now that Daddy is gone, Mommy has to work to support all of us, so you will have to keep your sister company." It might not have been the ideal situation for her, since other kids played with whoever they wanted, right? Sometimes she would bring Zengzeng to play with her classmates. She is 1 year younger than Zengzeng and people used to mistake them for twins.

When I was at work, it was always my younger one babysitting Zengzeng. I would cook two meals in the morning which they would microwave when they got home. I worked at a restaurant and used to get off work at 9 pm. Then I switched to night shift starting at 9 pm in order to take better care of the girls.

Since I would be at work, I always asked my younger one to drop off and pick up Zengzeng. When Zengzeng first started working, my younger one crossed railroad tracks on her electric bike and fell off the bike when she made a turn. She was bleeding all over the place. I cleaned and disinfected the wound and gave her antibiotics, but she has a scar on her tummy now. Zengzeng didn't know how to take the bus at the beginning, so we dropped her off and picked her up on our electric bikes. Then I took her with me to ride the bus, that's how she learned to do it herself.

Sometimes my younger one would joke with Zengzeng, "Zengzeng, you got paid. When are you going to take me out to eat? It's always me taking you out." Zengzeng would say, "Mom has the money—ask Mom for it," or "Money is in the bank, you

go get the money at the bank.” My younger one would say, “It’s your money that’s in the bank, I have no access to it.” And Zengzeng would tell her to ask me for the money.

On our days off, we would all go out together. My younger one would say, “Zengzeng, I am buying today, are you coming? I will take you out to eat.” Zengzeng would say, “Sure, I will pay you back when I get paid.” And my younger one would say, “I have never seen a single penny from your pay.” They like to joke with each other.

I gave birth to Zengzeng, but eventually her sister will have to take care of her. So my younger one has learnt from very early on to be very nice to Zengzeng. There are true stories of the younger sibling being mean to the older sibling, but it all depends on what kind of behaviors the parents encourage. I have always told my younger one, “Your sister is my child, so are you. You need to treat your sister as your equal.” Kids cannot do without education from the family, just like Zengzeng would have been having a hard time out there without help from society.

Q: Did your younger one have good friends among her own classmates?

Zhao’s mother: She did.

Q: Did they hang out?

Zhao’s mother: She brought them home to hang out sometimes.

Q: The two girls went to different schools. Was your younger one’s school far away?

Zhao’s mother: Not really, 15 min’ walking distance. Zengzeng’s school was farther away. Now that she has grown up, my younger one would recall, “On rainy days, everyone was picked up by either Dad or Mom. I had no umbrella and had to walk home on my own. Mom, I feel bad for myself when I think about it.”

Q: You couldn’t possibly have picked up both of them.

Zhao’s mother: I told her, “You are not the only one feeling bad. Mommy feels bad sometimes too. I feel like crying, but I can’t cry in front of you because that will make everyone sad. So many years have passed, and it’s too painful to always look back. So we should look forward, honey, and don’t dwell on things.”

I was only 33, with two kids, when their dad passed away. A lot of people nowadays are still single at that age. At the school my younger one was going to, when her dad was still alive, the teacher was super nice. Once he passed away and I had to work, the teacher would insult her by saying, “Your mom has taken off with someone and abandoned you.” My younger one would say whenever she looks back, “Why was the teacher so mean? She often made a point of telling me that my mom had abandoned me and she always had a long face for me.” If I couldn’t get away from work for the parent–teacher meeting, the teacher would take it out on my daughter the next day. My younger one said, “I didn’t know how to fight back because I was so young. Now I would probably talk back to the teacher.”

After graduating from vocational school, my younger one studied for an associate degree while working fulltime, and the school was right next door. She is mentally tough, not the attention-seeking type like some other kids. She often says that since there is no man in our house, the two of us will have to be the men and to rely on

ourselves. We have no relatives in Shanghai, so we have taken one step at a time and got to where we are today, all on our own.

Q: Were there fees for the vocational school and associate degree studies?

Zhao's mother: The government waived part of the fees because of the extreme financial hardship of our family.

Q: It must have been exhausting, working full time during the day and studying at night.

Zhao's mother: It was, but my younger one was determined.

Q: How does your family spend time together on your days off?

Zhao's mother: We all have weekends off, so Zengzeng will watch TV at home. She likes watching news, music, and TV series. She can memorize those cop shows from beginning to end. If I miss a couple of episodes, she can recount them to me. To tell you the truth, I forgot all about the reporters who had interviewed us. But if she sees some of them on TV, she can tell who is hosting what show and who is who. She remembers all and knows all.

If there's breaking news on TV, she would ask me to watch or brief me on it, like if someone was being totally ungrateful and killed his dad.

She will play board games or poker while watching TV. There are pens over there, so she writes sometimes or flips through books (there was a collection of novels on the table) and copies characters from the books. That calculator is hers too and she does addition on it sometimes. I would say to her, "Zengzeng, you are the government accountant. You have to do the books every day you come home and record my daily expenses."

(Looking for a notebook on the table).

Q: Does she punch random numbers into the calculator or numbers from the receipts of that day?

Zhao's mother: She just enters random numbers and writes down whatever shows up on the calculator. I would tell my younger one, "Look, Zengzeng is doing the books again. She is calculating our expenses from today and the expenses of your workplace as well." See, all of these were what she got on the calculator after she had entered her numbers.

Q (pointing at the notebook): This was probably a misspelling.

Zhao's mother: This notebook was especially bought for her. She was using her sister's notebook. Her sister wrote a lot of things in it at her workplace and diaries too, so she just turned the notebook over and wrote on it. Then we took her to the supermarket and asked her what kind of notebook she wanted. She wanted a big one and her sister said to just get her a big one. Look, she is running out of blank pages.

She keeps herself fully occupied at home on Saturdays and Sundays. I told her that she gets busier than when she is at work. She is trying to develop herself.

Q: I asked her the other day if the calculator on the table is for her to use. She said, "No, not for me. My sister uses it."

Zhao's mother: It's actually for her to use. Everything on this table including the board game and poker cards is for her to use. When she gets home at night, she will sit here with the TV on after her shower.

Q: During lunch break at the restaurant, Zengzeng carried her white bag to an empty VIP room to write. Do you know what she writes?

Zhao's mother: I do. She takes a book to the restaurant that her sister has finished reading at home and copies characters from it. Sometimes she would take an English book and copy the English.

Q: Does Zengzeng like dogs? How long has the dog been with you?

Zhao's mother: We have had the dog for 7 or 8 years. Both girls love it. Nowadays, both grownups and kids love pets, right? At first my younger one bought a Bichon Frise, but it got sick after 1 month and couldn't be saved, even after we spent more than 1,000 yuan at the pet hospital. My younger one was howling over its death, and Zengzeng cried too. So I had to tell my younger one to get another dog. My friend's dog happened to be breeding, so we got a puppy. Zengzeng walks the dog on her days off, in the little garden in the apartment complex. When she goes to work, I walk the dog, twice a day.

Q: Does Zengzeng play with the dog when she gets home from work?

Zhao's mother: We call the dog Feifei. So when Zengzeng gets home, she will say, "Feifei, your older sister is back." And when she goes to work, she will say, "Feifei, be good, your older sister is off to work."

Q: Does Zengzeng feed the dog?

Zhao's mother: She does. She will check if the bowls have water or food and refill them if she needs to. I have told her not to overfeed the dog but she is worried that it will starve.

Q: A lot of families buy pets for kids now to keep them company as they grow up.

Zhao's mother: Right, all of the kids like pets now.

Q: You have done a great job bringing up both your kids.

Zhao's mother: I wish I had done more for them and pampered them more, but I didn't have the financial ability or the time. When I talk to my younger one, I tell her, "I have given my all to bring you girls up, so don't get mad if there's anything I missed. Mommy wants a perfect happy family too, which would have been possible if your dad was still alive, right? But what can we do? This is the hand life has dealt us."

I am very satisfied now. Zengzeng has been to the Special Olympics World Games, and wherever she goes now, people like her and compliment me on having taught her good manners. When I went to the restaurant the other day, two co-workers told me that of all the young employees there, Zengzeng is the most talkative.

Zengzeng has really come a long way. She got lucky too, in that the Special Olympics World Games was held at the right time for her and was exactly what she needed to be inspired. She graduated from school after the games ended, and Papa John's hired her right away, so she got lucky there too. As parents, we have paid a heavy price. We have brought the kids into this world, and it's not their choice if they were born with disabilities. So parents need to find the courage to face it. If we can't do it and just keep the kids isolated at home, the kids will never have the courage to face the world.

Zengzeng has found the courage to face the world, but a lot of families haven't. Some of the parents simply don't want to lose face. I tell my younger one that

Zengzeng is my own child, and whatever her condition, she has already ventured into society and can be involved in it, so I am very proud of that. It's true that I have a child with disability, but I have accepted that. Kids are ours to keep, and if the parents can't be brave about it, they can't blame others for discrimination. There are so many kids like Zengzeng in the world now and they all need love and care. Society is more caring towards persons with disabilities now, so why keep the kids at home and shut out the world for them? Life will be different once you embrace it. We have found the courage ourselves, so we should help others do the same. That's why I liked the idea of this oral history as soon as I was made aware of it, because people need to know more about us. Zengzeng is where she is today because of the government and society. Society is making progress, so are the kids.

Interview with Zengzeng Zhao's Co-worker (I)

Interviewee: Ms. Qu, works in the dining area

Interviewers and writers: Mei Liao and Zian Li

Interview date: July 15, 2016

Interview place: Restaurant where Zengzeng Zhao works.

Q: How would you describe Zengzeng's work?

Ms. Qu: She listens well. She arrives early every day. Once she gets here, she will refill the sauce, clean up, refill the sanitizer, wash the mops, and separate them. The red mops are for the dining area and the green ones are for the non-dining area. She never mixes them up because she is so used to separating them. She is also the only one cleaning up our break room. When we get busy sometimes, we would ask her to help and tell her specifically what to do, and she can get a lot done like wiping the fridge doors and tables.

After she finishes everything, she will take a break and chat with someone. During the 1-h lunch break, she will go to a VIP room and sit there to write or to draw.

Q: Is there anything different about working with employees being cared for?

Ms. Qu: The co-workers have more pressure because they will have to watch the employees being cared for and lend a hand sometimes. Not even persons without disabilities can always do a perfect job, so it's normal for employees being cared for to make some mistakes.

Q: How does Zengzeng get along with her co-workers?

Ms. Qu: She had a good upbringing and has good manners, and always greets everyone. When she is in a good mood, she will snuggle up to me and kiss me and tell me she likes me. When she is in a bad mood, she will tell me to leave her alone. She is like a child.

Since you are here to interview her today, I am sure she will tell everyone all about it afterwards, like she got an interview today and what was said during the interview.

Q: Does Zengzeng often throw tantrums?

Ms. Qu (laughing): You go ask her that. She will tell you herself.

Kids like her, if you let her have her way, she will behave really well. We all have kids ourselves, so we understand and we do care about them.

The benefits are good in Shanghai. Where I come from, which is in Northeast China, kids like Zengzeng stay home and are supported by the families, since no one will hire them to work. Here the company takes care of them and pays into their social insurances so that they have something put aside for when they get old.

Translated by Cissy Zhao

Edited by Andy Boreham and Zijian Chen

Interview with Zengzeng Zhao's Co-worker (II)

Interviewee: Mr. Zhou, Manager on duty

Interviewers and writers: Mei Liao and Zian Li

Interview date: July 15, 2016

Interview place: Restaurant where Zengzeng Zhao works.

Q: How would you describe Zengzeng at work?

Mr. Zhou: I was the one who trained all of the employees being cared for. At first, Zengzeng was the most challenging one. There's a backdoor in this restaurant, and she would leave through that door and disappear whenever something upset her. So we had to immediately send someone to look for her. Luckily, she didn't walk fast and we could always find her within a 1.5-km radius. She has improved since then and won't leave the restaurant for no reason.

She used to usher in customers, but a lot of customers found it hard to accept, so we moved her to the non-dining area. She will finish everything she is assigned for that day, and take a break to practice writing or to sleep. Zengzeng has pretty severe intellectual disability, so we prefer not to give her other jobs in the kitchen, since there are ovens in the kitchen.

Q: Are ovens dangerous for employees being cared for?

Mr. Zhou: Unlike in some other restaurants, we don't have open fryers and the ovens are well sealed so they're relatively safe. We have been repeatedly telling the employees being cared for from day one that the ovens are hot. The most dangerous thing we have around here are the knives for cutting vegetables and salad. Everyone is careful, so we haven't had any injuries so far.

Q: Does Zengzeng go home by herself after work?

Mr. Zhou: Sometimes her uncle picks her up.

Q: I saw you talking to Zengzeng in front of the break room just now. Did Zengzeng...lose her temper?

Mr. Zhou: She did.

Q: What happened?

Q: You interviewed several employees today and chatted with us. So Zengzeng was unhappy about it. She said she is the celebrity and should be the only one to be interviewed. So I tried to reason with her and as we were talking, she pointed her

finger at me and said, “Let me warn you...” I had no choice but to scare her by saying that I would call her mom.

So I called her mom in front of her. I actually just told her mom that someone was interviewing Zengzeng today and asked whether she knew about it, since you have been here the whole day and we were obligated to let the parents know. Zengzeng believed that I had called to tell on her to her mom, so she was really scared and got unhappy. Then she left after work.

Q: They do show their emotions right away.

Mr. Zhou: Happy or unhappy, they don't hide it.

Interview with Zengzeng Zhao's Co-worker (III)

Interviewee: Ms. Zhou, Manager on duty

Interviewer and writer: Mei Liao

Interview date: March 16, 2018

Interview place: Restaurant where Zengzeng Zhao works.

Q: Do you still remember what it was like when Zengzeng Zhao joined the store?

Zhou: A lot of people from the Disabled Persons' Federation came with her and introduced her as the torchbearer for Special Olympics, which deeply impressed everyone. New hires at our store asked to have pictures taken with her because she was a celebrity and her pictures were put up everywhere at the subway stations 2 years ago.

Q: Did any customers ask to have pictures taken with her?

Zhou: Customers... She was greeting customers at the entrance for a long time, before all of the employees being cared for were moved to work in the non-dining area.

Q: What station does Zengzeng work at in the non-dining area?

Zhou: She mainly wraps plastic knives and forks.

Q: Does she work Monday through Friday?

Zhou: Right, and she gets weekends and holidays off. Her work hours are different from everyone else's.⁵

Q: During her interview, her mom said, “Leader means someone who leads you, so you must respect the leader.” Does Zengzeng get a little moody sometimes?

Zhou: She does. When she is in a good mood, you can tell her, “Zengzeng, we are running low, so can you wrap some more knives and forks since you have tomorrow off?” and she will happily agree. But when she is in a bad mood, she will just say, “Leave me alone.”

Her mom told her to listen to the leader, so it sounds like the manager on duty talked to her mom about her refusing to follow instructions and to do her job and throwing tantrums and things around. We have an older lady here who is from Northeast China.

⁵ Zengzeng Zhao has severe disabilities, so the restaurant gives her special treatment in arranging work hours. The other employees work varying shifts and have no fixed days off.

Whenever she feels that Zengzeng is being contrary, she will call her mom. Her mom will get mad at her when she gets home and she is scared of her mom getting mad, so she will apologize to the older lady when she comes to work the next morning. She even calls this older lady her “second Mom” and attaches herself to her as soon as she gets to the store. The older lady must have talked to her mom multiple times.

Q: Is the older lady in charge of Zengzeng?

Zhou: Not really. Zengzeng will misbehave at work and we will let it go, but the older lady won't and will want to talk to her parent.

Q: Oh, maybe the older lady feels like she has the responsibility of a mom. Zengzeng's mom said that one time Zengzeng used two more pieces of paper to wrap knives and forks.

Zhou: Our practice is to have one knife and one fork inside each bag, the knife and fork each wrapped in a piece of paper. We will give her two bags of paper every day and tell her, “Zengzeng, you will need to finish these two bags.” She feels that she can get off work early if she finishes early, so she will wrap two or three knives and forks in seven or eight pieces of paper which makes the bags so bulky. When we are not busy, we will unwrap what she has done. But when we get busy, we can't unwrap everything.

Q: Does the parent communicate with you a lot?

Zhou: Her mom mostly communicates with the store manager. When I am the manager on duty, I seldom contact her. One time, Zengzeng used the restroom at the supermarket next to us. When she opened the door coming out, she knocked down a very young girl. The girl bumped her head on the step and bled, and her grandma brought her to the store. That was the only time I contacted Zengzeng's mom and asked her to take the girl to the hospital.

Q: You hadn't interacted with employees being cared for before joining the store, had you?

Zhou: No. When I learned that there would be employees being cared for joining the store, I worried about what to do since I had never interacted with any before. I figured that the worst that could happen was to quit. Then the store manager reassured me that I should be able to get along with the employees being cared for and I asked whether it was because I have a loving nature and he said it was because there's not much difference between me and them. So the employees being cared for came and what do you know, I have been getting along fine with them ever since. (Laughing).

Q: When you have new regular employees joining the store, do you need to train them or remind them of how to get along with employees being cared for?

Zhou: We will tell them upfront that our store is a Caring Restaurant.⁶ That's one thing we must tell them when they join the store.

Q: When you are with the employees being cared for, do you feel relaxed or under pressure most of the time?

⁶¹ A Caring Restaurant (爱心餐厅) is a demo store for how Shanghai Papa John's is creating jobs for people with disabilities, and there is a large percentage of employees with disabilities at the store. Papa John's has two Caring Restaurants in Shanghai.

Zhou: When we are not busy, it's fun to see them goof around. But when we get busy, they can drive me crazy.

Q: What do you mean by "drive me crazy"?

Zhou: The orders are not being made and they look like it's none of their business. You are panicking whereas they are taking it easy and taking a break in between so many orders.

(Co-workers came to consult Ms. Zhou about work, and customers started arriving at the store, which brought the interview to an end).

Interview with Zengzeng Zhao

Interviewee: Zengzeng Zhao

Interviewers and writers: Mei Liao and Zian Li

Interview date: July 15, 2016

Interview place: Restaurant where Zengzeng Zhao works.

Q: How did you get to work this morning?

Zhao: By bus.

Q: You rode the bus by yourself?

Zhao: Right.

Q: Did you say "Hi" to anyone on the way here?

Zhao: No, I don't talk to anyone I don't know.

Q: How long did it take for you to get here?

Zhao: About 10 min.

Q: Just 10 min?

Zhao: Right.

Q: When did you leave the house?

Zhao: I...left at 9:15.

Q: When do you start work every day?

Zhao: I start at 10:30.

Q: 10:30?

Zhao: Right.

Q: So you arrived early today.

Zhao: I did, for work.

Q: Do you arrive early every day?

Zhao: I do.

Q: What did you do today at work?

Zhao: I refilled the ketchup and Thousand Islands salad dressing.

Q: Oh, you refilled them.

Zhao: Right.

Q: What did you do after that?

Zhao: After that...sanitizer.

Q: So you refilled the sanitizer.

Zhao: Right.

Q: And after that?

Zhao: I washed mops.

Q: You washed mops.

Zhao: Right.

Q: What did you do after that?

Zhao: Dinnerware.

Q: Did you wash them or collect them?

Zhao: I collected the dinnerware.

Q: You collected dinnerware.

Zhao: Right.

Q: Anything else?

Zhao: I greeted customers. I can do that too.

Q: So you greeted customers.

Zhao: Right, I welcomed them.

Q: Do you like coming to work?

Zhao: I do.

Q: What do you like to do most at work?

Zhao: Washing...I forgot.

Q: What job do you do best?

Zhao: Job...wiping tables, collecting dinnerware. Wiping tables...

Q: That's awesome, you are doing great.

Zhao: Yeah.

Q: Did the customers say good things about you?

Zhao: They did.

Q: What did they say?

Zhao: "Zengzeng Zhao, you listen very well."

Q: Who do you listen to?

Zhao: I listen to the manager on duty.

Q: Does he tell you what to do?

Zhao: He does.

Q: Do you do the same things every day?

Zhao: Right, the same every day.

Q: Do you ever forget how to do them?

Zhao: I don't forget.

(A co-worker walked past).

Zhao (introducing the co-worker politely): That is my co-worker.

Q: Oh.

Zhao: My co-worker is very nice to me.

Q: How is she nice?

Zhao: She really cares about me.

Q: Do you like everyone?

Zhao: I like my co-workers and the manager on duty. And Pan and Qu really care about me.

Q: How do you show them that you like them? Do you tell them?

Zhao: I tell them that I will behave.

Q: How will you behave?

Zhao: I will get things done, like wrapping knives and forks, and folding snack boxes.

Q: Your mom must be really happy to see you doing so well.

Zhao: My mom is happy. I don't have a dad anymore. My dad died of lung cancer. My parents and my sister all care very much about me. I have a younger sister and she works. My mom cares about me a lot.

Q: How does your mom care for you?

Zhao: She cares for me every day...My mom cried because she was sad about my dad. I went with my mom to Anhui...(inaudible) I went to Anhui. My dad went into a grave because he died.

Zhao: I don't have any grandparents left either.

Q: So it's just your mom and you girls.

Zhao: Right, just my mom, me and my sister.

Q: How do you usually play with your sister?

Zhao: Usually...My sister gets mad and hits me.

Q: She must have been kidding around with you.

Zhao: She was.

Q: Why did your sister hit you?

Zhao: When I was young, I threw things around. I also hit my co-workers from behind.

Q: Do you still do it?

Zhao: Not anymore. Now I behave. The manager told me to be good and to listen well to Pan. My mom said I am good and took me with her when she had a meeting at the company.

Q: So both your mom and your co-workers said you are doing great.

Zhao: Right, my co-workers say good things about me. And Zheng cares about me too.

Q: So you don't get mad now. What do you do if you get upset?

Zhao: They call my mom if I get upset.

Q: Did your mom come?

Zhao: She did.

Q: But not often, right?

Zhao: Not often. My mom has to work and she has no time.

Q: You have days off. What do you do on Sundays?

Zhao: On Sundays, I take it easy at home, watch TV, and go out for fun or to eat. On my mom's birthday, I took her out to eat.

Q: You took your mom out to eat?

Zhao: Right.

Q: Then who picked the place to eat?

Zhao: My sister picked the place.

Q: Is the calculator on the table at home for you to use?

Zhao: No, not for me. My sister uses it.

Q: Where do you like to go for fun?

Zhao: Parks. My mom tells me to go out for fun, which means she cares for me. I must support my mom.

Q: What do you do when you are with your sister?

Zhao: I don't have good memory...I can't remember.

Q: Thank you. That's all for today. You probably need to go back to work.

Zhao: It's okay. Why don't you have some water.

(After the lunch break, Zengzeng Zhao came out of the VIP room and sat down to chat with the observers. She cuddled against the older observer and rubbed the observer's arm).

Q: Do you write every day during lunch break?

Zhao: Yes.

Q: Do you like doing it?

Zhao: Yeah, I like writing.

Q: What do you write?

Zhao: You won't get it.

Q: Does your mom not look at what you write?

Zhao: Neither my mom nor my sister look at it. My mom uses the Internet. My sister uses the Internet, watches TV shows, and listens to music.

Q: So you write for your eyes only?

Zhao: Right.

Q: What kind of music do you like listening to?

Zhao (rubbing the older observer's arm): All kinds. You must be tired. I am very touched that you came for the interview. You are a busy person.

Q: I came today specifically to see you and your co-workers.

Zhao: Our manager on duty is arriving soon.

Q: The lady in black this morning must be the manager on duty.

Zhao: Right. There is another manager, Mr. Zhou. He will be here anytime now.

Q: How do you know?

Zhao: He comes to work at 3:30. We are getting busy now. It gets very busy at night.

(After the day's work and before clocking out, Zengzeng Zhao sat next to the observers and held onto the older observer's arm while nestling against her).

Zhao (looking wronged): The manager was mad at me.⁷

Q: Why? What did you do to make the manager mad at you?

Zhao: He got mad at me and that was mean.

Q: Was there a reason?

Zhao: I (inaudible)...I was mopping the floor.

Q: You were mopping the floor and the manager got mad at you?

Zhao: Right. Nothing happened and he just got mad at me.

Q: I see.

Zhao: Then the manager called my family and talked to my mom.

⁷Zengzeng Zhao had expressed her displeasure to the manager on duty about the observer interviewing other employees at the store. But at this time, the observer was as yet unaware of it.

Q: What did your mom tell you?

Zhao: My mom didn't tell me anything.

Q: Did you finish everything you needed to do?

Zhao: I did.

Q: How about doing something extra next time?

Zhao: Okay.

Q: You are very capable. I saw you mopping the floor and taking out the trash. You are the only one cleaning the break room. Do you have to wipe all of the tables, chairs, and the door?

Zhao: All of them. And the backdoor too.

Q: Have you had dinner yet?

Zhao: I have. I had lunch and dinner in one meal.

Q: Will you have dinner again after you get home?

Zhao: Not after I get home.

Q: You don't have to work now?

Zhao: I will keep you company. I don't have any work to do now.

Q: No work? Thank you. In the morning, I saw you taking out a packet with a knife and fork. What's that for?

Zhao: For a delivery order.

Q: You wrapped so many packets. Were they all used today?

Zhao: Yes.

Q: So you will wrap more tomorrow?

Zhao: Tomorrow is my day off.

Q (laughing): Right, tomorrow is your day off.

Q: How many days a week do you have off?

Zhao: Two days.

Zhao: I want to keep you company.

Q: But you are getting off work soon.

Zhao: Not yet. I get off at 7:30, so I still have 1 h.
(It was close to 7:20 at that time).

Q: How do you know what time it is?

Zhao: The time is over there.

Q: I don't see it. Where's the clock?

Zhao: There's a clock.

Q: What sauce did you refill this morning?

Zhao: The yellow sauce.

Q (pointing to the sauces on the table): Is there a yellow sauce among the three sauces here?

Zhao: There is.

Q: In which bottle?

Zhao: The farthest one contains the yellow sauce.

Q: So the garlic sauce is called yellow sauce, right?

Zhao: Right.

Q: Thank you for teaching me.

Zhao (laughing): I can call you "elder sister".

Q (laughing): I am auntie to you. You can clock out now.

Zhao: Right.

Q (checking time on cell phone): Yeah you can, it's 7:30 already.

Zhao: 7:30 already. (Hurrying to get up and leave).

Q: Bye.

Observation of Zengzeng Zhao at Work

Observation date: 10:30–19:30, July 15, 2016

Observation place: Restaurant where Zengzeng works

Observers and writers: Mei Liao and Zian Li

Time	What Zengzeng Zhao did	Remarks
10:07	Refilled sauces	The observers arrived at 10:07. Zengzeng was already at work. Zengzeng opened big cans of ketchup and Thousand Islands salad dressing and transferred them to big buckets and sauce bottles
	Talked with co-workers Left the snack station to look for work badge Didn't find badge and returned to snack station to continue working Refilled sanitizer	A co-worker realized that Zengzeng wasn't wearing her badge Co-worker: Where's your badge? Zhao: I can't find it Co-worker: Let's make another one for you Zhao: I don't want to pay for it. (It's actually free.)
10:16	Delivered sanitizer to the dining area	Passed the observers and said politely, "Please wait a bit and I will get some water for you."
	Returned to the non-dining area and carried water to the dining area	Delivered the glasses of water to the observers with both hands and said, "Please have some water."
10:18	Returned to the non-dining area, took out small sauce boxes for takeout orders, filled the boxes with sauces, closed the boxes and put them aside. Work speed was an average 10s per box	
10:24	A co-worker found her badge and put it on for her	
10:38	Finished work for the morning and was interviewed	Tidied up before leaving the non-dining area, while a co-worker straightened her apron for her, smiling and apparently in a good mood

(continued)

(continued)

Time	What Zengzeng Zhao did	Remarks
11:03	Returned to the non-dining area to wrap disposable knives and forks before putting them in a plastic box and delivering the box to the dining area	
11:28	Continued wrapping disposable knives and forks in the non-dining area	
11:32	Put the wrapped knives and forks in a plastic bag which was then delivered to the dining area	Dining area co-worker: Are you done with wrapping? Zhao: Yes Dining area co-worker: Please take them to the cashier in the front. Thank you
12:36	Went to the soda station to fetch a ketchup bottle for filling up sauce boxes for takeout orders	Passed the observers and said politely, "Please wait a bit" which was accompanied by a hand gesture
12:39	Used up the ketchup in the sauce bottle and fetched a big bucket to refill the bottle	As of that moment, she had finished all of her fixed work for that day. She would spend the rest of the day helping out co-workers or resting
15:25	Lunch break	Carried a white bag into the VIP room, took out paper and started writing with head tilted. Wrote two to three lines on each piece of paper Observers: Are you practicing writing? Zhao: I am Observers: What are you writing? Zhao: I don't know. I don't want to tell you
16:02	Organized her bag and left the VIP room. Sat next to the observers and leaned against the older observer with an intimate air	Spoke first, then only spoke by way of answering questions
16:10	Returned to the non-dining area	
16:35	Talked to the manager on duty in front of the break room while several co-workers looked on	Everyone looked serious and Zengzeng Zhao didn't look happy
17:58	Found the floor mop and got ready to mop the floor in the break room	
19:02	Took out trash from the break room	
19:15	Sat next to the observers and held onto the arm of the older observer with an intimate air	Spoke first, then only spoke by way of answering questions
19:30	Left for the day	

*Translated by Cissy Zhao**Edited by Andy Boreham and Zijian Chen*

Open Access This chapter is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits any noncommercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if you modified the licensed material. You do not have permission under this license to share adapted material derived from this chapter or parts of it.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.



A Compilation of Aid Policies for Persons with Intellectual Disabilities in Shanghai City



Mei Liao

Definition and Classification of Intellectual Disability (ID)

The classifying criteria for intellectual disability in practice vary from organization to organization, or specialization to specialization.

Intellectual disabilities comprise intellectual developmental disorder and dementia. In accordance with the *China Classification and Diagnosis Criteria for Mental Disorders 3rd Edition* (CCMD-3), intellectual developmental disorder refers to some syndromes of mental deficiency or retardation. Persons with the disorder tend to behave at a low grade of average intelligence and with a certain level of difficulty in social adaptation. The disability develops before the age of maturity at 18, and its syndromes either occur singularly or with complications such as intellectual disorders or physical diseases. Their intelligence grades, by the standardized approach to intelligence testing and assessment, are found to be lower than normal.

In reference to standardized IQ values, intellectual disability can be scaled as shown in Table 1.

Moreover, in accordance with the *National Standard of Disability Classification and Scales for Disabled Persons* (GB/T26341-2010), disabled children aged 0–6 years are classified into several scales of intellectual disability in reference to their developmental quotients (DQ) and adaptive behaviors. Developmental quotients are referred to for children in the DQ range of less than 72, whereas for those in the DQ range of 72–75, their adaptive behavior is referred to. For children aged 7 years or older, their disabilities are scaled by their IQ values and their adaptive

Mei Liao is the compiler of this chapter.

M. Liao (✉)

Shanghai Shida Public Welfare Foundation, 29F, 999 Middle Huaihai Ro., Shanghai 200031, China

e-mail: mliao23@vip.sina.com

Table 1 Descriptions of intellectual disability and related IQ ranges

Scale description	IQ range
Marginal intelligence	70–86
Mild intellectual disability	50–69
Moderate intellectual disability	34–49
Severe intellectual disability	20–40
Profound intellectual disability ^a	<20

^aChinese Society of Medicine Psychiatry Branch (compiler), *China Classification of Mental Disorders* 3rd Edition, “Intellectual Developmental Disability and Mental Developmental Disorders for Children and Teenagers”, Jinan: Shandong Science and Technology Press, 2001

Table 2 Scales of intellectual disability

Scales	Intelligence development grade		Social adaptability	
	Developmental quotient (DQ) for ages 0–6	Intelligence quotient (IQ) for ages 7+	Adaptive Behavior (AB)	WHO-DASII value for ages 18+
Scale 1	≤25	<20	Profound	≥116
Scale 2	26–39	20–34	Severe	106–115
Scale 3	40–54	35–49	Moderate	96–105
Scale 4	55–75	50–69	Mild	52–95

behavior. If the two are not scored at the same grade, the later reference is preferred. Their ID can be scaled as shown in the Table 2.¹

Dementia refers to a case of intelligence deficiency due to causal factors such as physical, chemical, or virus-induced injury to the originally normal brain.

Persons with intellectual disabilities interviewed for this book mainly refer to those with intellectual developmental disorder from the fetal or infant period.

Educational Policies

Children with Profound and Severe ID

Children with profound intellectual disability are unable to walk outdoors, and thus they may complete their compulsory education via access to direct approaches such as teaching at home.

¹General Administration of Quality Supervision, Inspection and Quarantine of the People’s Republic of China Standardization Administration of the People’s Republic of China, *Disability Classification and Scales for Disabled Persons* (GB/T26341-2010), implemented from 2011 onwards.

Children with Profound, Moderate, and Mild ID

Children with ID are admitted to special public kindergartens and special preschool classes. For mild cases, a special or general class of a public or private kindergarten where children with disabilities are funded by the government in the city applies. After completion of their preschool education, these children may go on to a special 9-year compulsory school. For mild cases, they are assigned to a general school special class, or a full-time general class of such a school together with their normally developing peers.

After their completion of their 9-year compulsory special education, students with ID may, at their own will and capacity through tests, be enrolled to study at elementary vocational and technical schools.

Persons with ID who are able and eligible for further study may attend general secondary specialized schools as well as institutions of higher learning.

Successively from 2004 onwards and across the country, free education has been provided to students with disabilities during their compulsory education. In Shanghai, students with disabilities enjoy free preschool education, compulsory primary up to junior high school education, and even senior high school education. For student with disabilities at senior high schools, apart from tuition waivers, free textbooks, and workbooks, they are also granted an annually sum of 4,000 yuan as a national stipend. For those at specialized secondary schools, they are offered tuition waivers, free textbooks, and workbooks, plus a sum of 2,000 yuan as a national stipend.²

Students with disabilities and children living with individuals with disabilities, who study at full-time institutions of higher learning with Shanghai registered permanent residences in financially disadvantaged families, are also eligible for a certain sum of grant-in-aid to cover part of their tuition: a grant of up to 6,500 yuan per academic year for higher vocational education, junior college up to undergraduate levels; 8,000 yuan for postgraduates per academic year; and 10,000 yuan per academic year for PhD candidates. The aforesaid sums are for the recipient's actual tuition settlements within the amount limits for each academic year.

Children living with disabled family and disabled students, who study at adult education institutions with Shanghai registered permanent residences in financially disadvantaged families, bear 10% of their adult education tuition. The rest (90%) is subsidized to students with disabilities receiving a secondary education with the disabled persons' employment security fund at sums of up to 3,600 yuan; those receiving their junior college education may be given a total of up to 9,000 yuan; those receiving their undergraduate education may receive 13,500 yuan.³

²Shanghai Municipal Education Commission, Shanghai Municipal Bureau of Finance and Shanghai Disabled Persons' Federation, *The Circular on Shanghai's Implementation of Free Education to Disabled Students for the Stage of Basic Education*. Shanghai Education and Finance Document [2015] No. 103.

³Shanghai Disabled Persons' Federation, Shanghai Municipal Bureau of Finance, Shanghai Municipal Education Commission and Shanghai Municipal Bureau of Civil Affairs, *The Circular on*

This policy may vary from region to region. In some districts or counties of Shanghai municipality, students with disabilities, who receive their secondary education, higher education, adult education, or vocational education, may have their full tuition amounts subsidized by the local government.

Policies on Social Relief and Aid

Minors with Disabilities

Subsidies for Rehabilitation Training to children with disabilities at specialized rehabilitation institutions designated by the Shanghai Disabled Persons' Federation are granted by the government in the sum of 15,000 yuan per year for each child with cerebral palsy and 3,000 yuan per year for each child with intellectual disability.⁴

Institutional Care Subsidies are available for persons with disabilities, financially disadvantaged children aged 8–16 years with a Disability Certificate of the People's Republic of China, who are unable to receive a compulsory education because of severe disability and live in a disabled persons caring institution designated by the Shanghai Disabled Persons' Federation. They are granted from the government a monthly sum of 1,000 yuan if eligible for the institutional care service through verification. The institutions that provide care to severely minors with disabilities are granted an additional subsidy of 500 yuan per bed each year. Individuals with disabilities, who receive such supportive policies, are no longer entitled, meanwhile, to the subsidies for rehabilitation training for the disabled aged 8–16 years.⁵

Shanghai's Adjustment of the Subsidy Standard for Disabled Students and Children Living with Poor Households, Shanghai Disabled Persons Federation Document [2016] No. 117.

⁴Shanghai Municipal Health Bureau, Shanghai Municipal Education Commission, Shanghai Municipal Bureau of Finance, and Shanghai Disabled Persons' Federation, *The Circular on 2007 Shanghai's Rehabilitation Aid Work Program for 2000 Disabled Children Aged below 7*. Shanghai Disabled Federation Document [2007] No. 57; Shanghai Disabled Persons' Federation, Shanghai Municipal Health Bureau, Shanghai Municipal Education Commission, and Shanghai Municipal Bureau of Finance, *The Circular on Subsidies to the City's Disabled Children and Minors aged 8–16 for Their Rehabilitation Training*. Shanghai Disabled Federation Document No. [2010] No. 81. Shanghai Municipal Health Bureau, Shanghai Municipal Education Commission, Shanghai Municipal Bureau of Finance, and Shanghai Disabled Persons' Federation, *The Circular on Adjustment of the Rehabilitation Aid Subsidies Standard for the City's Children and Minors with Cerebral Palsy and Autism*. Shanghai Disabled Federation Document [2012] No. 114.

⁵Shanghai Disabled Persons' Federation, Shanghai Municipal Bureau of Civil Affairs, and Shanghai Municipal Bureau of Finance, *The Circular on the City's Institutional Care Subsidies to the Severely Disabled and Impoverished Children and Minors Aged 8-16*. Shanghai Disabled Federation Document [2010] No. 80.

Adults with Disabilities

Living and Nursing Subsidies are available for unemployed disabled persons aged over 16 at the primary (disability Grade I), secondary (disability Grade II), or tertiary (disability Grade III) disability rating scales.

In 2017, for the unemployed and persons with severe disabilities in Shanghai, a sum of 1,270 yuan was granted as a living subsidy.

The living subsidies for financially disadvantaged persons with disabilities are divided into three categories: a monthly sum of 330 yuan to each unemployed person with a severe disability for his or her minimum living provision; 300 yuan for persons with disabilities living with a household receiving basic living allowances; and 200 yuan for persons with disabilities living in a low-income household. Meanwhile, any persons with a disability, who is eligible for any of these three categories, may apply for a higher category with a greater subsidy sum.

The Nursing Subsidies for Persons with Severe Disabilities are divided into two categories: a monthly sum of 300 yuan for each person with a disability rated at disability Grade I, and a monthly sum of 150 yuan for each person with ID rated at disability Grades II and III. Persons with disabilities who already enjoy nursing subsidies are also eligible to apply for access to institutional, household, and relevant nursing services.

The eligible persons with disabilities may also apply for Living Subsidies for Financially Disadvantaged Disabled Persons, as well as Nursing Subsidies for Severely Disabled Persons.⁶

Medical Insurance is raised by the government in full for urban and rural residents with severe disabilities, for which two-thirds of the premium is covered with the disabled persons' employment security fund at the regional or national level in Shanghai, and the remaining third is covered by the social welfare lottery public welfare fund.⁷

Medical Subsidies are granted to persons with severe disabilities insured against their outpatient emergency or household sickbed fees at a starting sum of 300 yuan. Any excess is covered with the medical insurance fund, of which a 70% payment of the fees from the fund applies to Grade I medical institution outpatient emergencies; a 60% payment at Grade II; and 50% at Grade III.

For their hospitalization or emergency room observation fees, the starting sum of payment varies: 50 yuan at Grade I medical institutions; 100 yuan at Grade II medical institutions; and 300 yuan at Grade III medical institutions. The excess is covered with the medical insurance fund, of which a 90% payment of the fees from

⁶Shanghai Municipal Bureau of Civil Affairs, Shanghai Municipal Bureau of Finance, and Shanghai Disabled Persons' Federation, *The Circular of Shanghai Municipal Bureau of Civil Affairs Print and Distribution for the Regulations on the Living Subsidies to the Financially Disadvantaged Disabled Persons and Nursing Subsidies to the Severely Disabled Persons*. Shanghai Civil Affairs and Welfare Document [2016] No. 1.

⁷*The Circular on the Subsidies to the Severely Disabled Persons' Urban and Rural Basic Medical Insurance in Shanghai*. Shanghai Disabled Federation Document [2015] No. 158.

the fund applies to the Grade I medical institution hospitalization; 80% at Grade II; and 70% at Grade III.

The entire fee for which a patient with severe disabilities must pay at their own expense for medical treatment, inclusive of outpatient expenses, is covered by the government via relief and subsidy.⁸

Institutional Nursing Subsidies are available for the eligible unemployed and persons with severe disabilities, who may apply to the government for access to institutional nursing services with these subsidies. From July 2011 onwards, each eligible person with a disability is subsidized a sum of 700 yuan directly transferred to the account of the nursing institution with any inadequate amount to be complemented by the applicant.

Each district and county in Shanghai, as the case may be, increases nursing subsidies of its own accord. For instance, in Jiading District, institutional care services have reached out to all persons with disabilities in need within the entire district, subsidizing up to a monthly sum of 400 yuan each to the non-severe, unemployed, institutionalized persons with disabilities with minimal assurance families; and up to a monthly sum of 200 yuan to each applicant with disabilities certified and eligible for nursing conditions through examination.⁹

In-Household Care applies to persons with severe disabilities, unemployed in the 16–59 years bracket, who have not yet received institutional nursing or daytime care subsidies. They are eligible to apply for government-funded in-household care services, for whom service workers go to the household of a person with a disability offering 1 h of nursing on a daily basis, such as housework and living care.¹⁰

Transport Subsidies apply to the certified person with disabilities at ages below 65 years (exclusive of 65) with a Shanghai registered permanent residence, at the monthly sum of 45 yuan each.¹¹

Grain and Cooking Oil Poverty-Relief Subsidies apply to persons with severe disabilities and unemployed persons living with a Shanghai urban or rural household receiving the minimal subsistence allowances, or their spouses and children. They are granted monthly grain and cooking oil cards and vouchers. The poverty-relief subsidy

⁸*The Circular of Shanghai Municipal People's Government's Print and Distribution for the Regulations of Shanghai City on the Urban and Rural Residents' Basic Medical Insurance*. Shanghai Government Document [2015] No. 57. *The Circular on the Adjustment and Update of the City's Medical Aid System and Enhancement of the Hospitalization Aids*. Shanghai Civil Affairs and Aids Document [2015] No. 43.

⁹Shanghai Jiading District, *The Opinions on Standardization of the Institutional Nursing Subsidies for Disabled Persons* (2012), See http://www.jiading.gov.cn/zwpd/zwdt/content_12633.

¹⁰*Shanghai City's Implementation Programme for the Disabled Persons' Home Care*, Shanghai Disabled Federation Document [2009] No. 39; *The Circular on the Adjustment of the City's Home Care for the Unemployed Severely Disabled Persons*, Shanghai Disabled Federation Document [2014] No. 175.

¹¹*The Circular of Print and Distribution on the Regulations on the Transport Subsidies to the Disabled Persons in Shanghai*, Shanghai Disabled Federation Document [2017] No. 12.

cards include 10 kg rice, 900 ml cooking oil, and 0.5 kg table sugar, convertible to a sum of 72 yuan; and 4 kg rice, convertible to 22 yuan.¹²

Training and Employment

Sunshine Home, one of the Shanghai Municipal Government's projects in operation in 2005, is a community aid-to-the-disabled training institution for persons with intellectual disabilities in the age bracket of 16–35 years. The home develops activities such as educational training, rehabilitation exercises, Special Olympic sports, and simple labor, helping persons with ID improve their capacity for self-care and social skills while promoting their chances to include themselves into society. The trainees at the home include mostly persons with moderate to severe ID.

The full-time training activity subsidy amounts to 250 yuan per person per month, in addition to the monthly meal subsidy of 150 yuan. The two subsidy categories are funded to the Sunshine Home for its purchase of activity-purposed supplies and consumables as well as for its provision of lunch, drinks, etc., for the trainees.¹³

At present, Shanghai has 241 such homes altogether in all its downtown street neighborhoods and towns. Institutions similar to Sunshine Homes are established across the country, although they may differ slightly in their institutional names.

The Sunshine Vocational Rehabilitation Aids Base, or Sunshine Base, Sunshine workshop, is one of the Shanghai Municipal Government's practical projects of 2010. Taking its communities as its units, it is an informal employment institution designed to organize relatively centralized vocational rehabilitation activities such as production and vocational training for persons with disabilities with employment difficulties. The subjects for aid are persons with mild to moderate disabilities of working age. Through labor and employment training, persons with disabilities gain a basic living provision and their inclusion into society is fostered.

The trainees' pension contributions as well as their medical and unemployment insurance are paid on their behalf; 40% of the Shanghai urban workers' minimal wages are granted to the trainees as employment subsidies; to those intending to purchase commercial insurance, such as group life accident insurance and additional group health insurance against accidental injury, at an annual subsidy of up to 80 yuan; to the eligible for their lunches, etc.; and to the Sunshine bases' purchase of

¹²Shanghai Municipal Bureau of Civil Affairs, Shanghai Municipal Bureau of Finance and Shanghai Municipal Bureau of Grain, *The Circular on Further Improvement of Shanghai's Grain and Oil Allowance to Poor Households*. Shanghai Civil Affairs Document [2016] No. 20.

¹³Shanghai Disabled Persons Federation and Shanghai Municipal Bureau of Finance, *The Circular on Improvement in the Fund Subsidy Allocation for the Sunshine Home*. Shanghai Disabled Federation Document [2014] No. 84.

tutorial materials and consumables, at a monthly training subsidy of 250 yuan, and a monthly meal subsidy of 150 yuan.¹⁴

So far, Shanghai City boasts 170 Sunshine bases, some of which have collaborated and merged with the Sunshine Home. Each trainee is entitled to choose one of these institutions.

The Off-Duty Register is a local practice by which workers with disabilities sign employment contracts with an employer although they do not actually work in the nominated job posts. However, the worker still receives full insurance, as the state stipulates, against the pension fund, medical treatment, unemployment, occupational injury, and child delivery, have their housing funds contributed, and receive a certain wage no less than the city's minimum.

According to the stipulations of the Shanghai Municipal Government, governmental organizations, enterprises, and public institutions shall employ persons with disabilities with the city's registered permanent residence in the proportion of 1.5% to the total number of on-the-job workers in the workplace in the previous year.¹⁵ Any workplace that fails to employ workers with disabilities on a pro-rata basis as stipulated shall pay into persons with disabilities employment security fund. After a worker with disabilities registers as off duty, the workplace is entitled to a waiver of the proportionate disabled persons' employment security fund. There are also some local enterprises that rent disability certificates just for exemption from contribution to the fund.

Taking Shanghai as a case in December 2017,¹⁶ the city provided that an employer must pay registered workers with disabilities (or those really employed) the minimum wage and contribute a minimum to the social insurance premium; thus, the employer shall pay each person with disabilities, actually, 3,927 yuan as a minimal monthly wage plus a contribution to the five types of social insurance premiums;¹⁷ if the

¹⁴Shanghai Disabled Persons' Federation and Shanghai Municipal Bureau of Finance. *The Circular on Improvement in Subsidies Grant for the Sunshine Vocational Rehabilitation Aids Base*. Shanghai Disabled Federation Document [2014] No. 85.

¹⁵Before 2017, employment of the disabled workers at the proportion of 1.6% to the average number of workers at each workplace in the previous year; from September 2017, changed to collection of the disabled persons' employment security fund at the proportion of 1.5% to the number of workers. See Shanghai Disabled Persons' Federation, *Guidebook to the Disabled Persons' Employment Security Fund in Shanghai*. <http://www.shdisabled.gov.cn/clwz/clwz/ggl/2017/09/04/4028fc765e3cca14015e4c2e1a5a21ad.html?tm=1504864907104>.

¹⁶From 1 April 2017, the minimal monthly wages standard for the workers in Shanghai was increased to 2,300 yuan. See the Shanghai Human Resources and Social Security Document [2017] No. 12, *The Circular on Adjustment of the City's Minimal Wages Standard*. http://www.12333sh.gov.cn/201412333/xxgk/fffg/gfxwj/ldbc/gzzl/201704/t20170406_1253536.shtml. Also from the same date, the Shanghai minimal social insurance premium benchmark was increased to 3,902 yuan. See http://www.12333sh.gov.cn/wsbs/wsbg/2007sbxx/201704/t20170407_1253571.shtml.

¹⁷ $2300 + 3902 \times 41.7\% = 3927.13$. Five types of insurance premium can be calculated on the basis of the sum of the pro-rata contribution by the workplace and that of the worker, multiplied by 41.7%, of which, the occupational insurance is calculated by the minimal standard, see 2017 Schedule

employer also contributes to the housing fund for workers with disabilities, each shall be paid at least an additional 306 yuan—thus the actual expenditure of the employer shall be 4,233 yuan.¹⁸ In the case that the employer does not employ any person with disabilities, but rather chooses to contribute to the employment security fund for persons with disabilities for the inadequate number of workers with disabilities less than 1.5% as required in proportion to the total number of workers, contributions shall be made through monthly payments of the disabled persons' employment security fund, at the sum of 3,902 yuan each.¹⁹ In other words, the expenditure on off-duty registration (or actual employment of workers with disabilities) is greater than that of the contribution of a business to the employment security fund for persons with disabilities.

In the beginning, local disabled persons federations and other relevant institutions assisted with persons with disabilities to find off-duty register workplaces. In recent years, in order to facilitate persons with disabilities on-the-job employment and inclusion, disabled persons' federations now do not advocate the off-duty register.

Translated by Chongshun Bai

of Insurance Premium Contribution for Various Insured Personnel via <http://www.12333sh.gov.cn/201712333/bmfw/bmwd/zccs/01/201711/P020171101490742853321.pdf>. Also, in reference to the Shanghai Human Resources and Social Security Document [2017] No. 12, *The Circular on Adjustment of the City's Minimal Wages Standard*, for the workers who are entitled to receipt of the minimum wage, the employer shall contribute social insurances premium and housing fund, hence the above 41.7% shall be assumed by the employer (workplace).

¹⁸*The Circular on 2017 Shanghai's Adjustment of Housing Fund Contribution Benchmark, Proportion and Monthly Contribution Minimum/Maximum*, Shanghai Provident und Management Committee Document [2017] No. 4. <http://www.shgjj.com/html/2017stzccwj/96358.html>.

¹⁹The equation for calculation of the disabled persons' employment security fund: the annual sum of the security fund contribution = (1.5%—disabled workers' proportion) × the sum of the employer's social insurance premium base in the previous year, see the *Guidebook to Collection of Disabled Persons' Employment Security Fund in Shanghai*. If the total number of workers at the employer is X , of which the number of disabled workers is Y , for every figure of unemployed disabled workers, the monthly employment security due to the employer is calculated as follows: monthly employment security fund for an unemployed disabled person = the employer's monthly contribution of the disabled persons' employment security fund/number of inadequate employment of the disabled = $\{(1.5\% - Y/X) \times 3902 \times X\} / \{(1.5\% - Y/X) \times X\} = 3,902$ yuan, equivalent to the social insurance premium base due in the same year.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits any noncommercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if you modified the licensed material. You do not have permission under this license to share adapted material derived from this chapter or parts of it.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

