

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.

