Giving Is More Rewarding Than Taking

Buyun Chen

Interview with Mr. S's Mother

S, male, born in 1992. The only child in the family. Grade IV intellectual disability. Graduated from a regular school (Shanghai Vocational School of Baoshan District). Started working at Shanghai Papa John's in 2015. Started working as a warehouse administrator at a 4S car shop in September 2017.

Interviewee: S's mother

Interviewer and writer: Buyun Chen

Interview dates: September 23 and December 10, 2016

Interview place: S's home

Where It All Started: Trying Time for a Loving Couple

Q: How and when did you and your husband meet and get married?

S's mother: We worked at the same place, that's how we knew each other. We got married in 1989.

Q: Did you work at Bao Steel?

S's mother: Yes, we worked at Bao Steel. Our bond was already very strong before we got married, and we got to know each other even better after we tied the knot. I often say that our emotional bond was key to bringing up and educating S. We were able to agree on how to educate him and what treatment to seek for him. That's one thing. Another thing is that even though we have been married for so many years, we have never had a fight. The conventional wisdom is that there are no husband and wife who don't fight, but it doesn't apply to us at all. We really don't fight. We would

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W. P. Alford et al. (eds.), *An Oral History of the Special Olympics in China Volume 3*, Economy and Social Inclusion,
https://doi.org/10.1007/978-981-15-5005-8_11

be mad at each other occasionally and not talk, but we never carry it overnight and always move on within 24 h.

Q: That's very rare.

S's mother: It is. And God has chosen to give me a child like S. He was by no means an easy child and we all suffered so much.

Q: How old were you and your husband when you got married?

S's mother: I am older. I was 36 when I got married, oh no, I was 35 when I got married.

Q: And your husband?

S's mother: He is 7 years younger. (Pausing) We couldn't conceive after we got married, and I figured it might be because of me. So I saw a lot of doctors and took a lot of medication. There was never any diagnosis. Then I got pregnant without knowing how it had happened. That was after we had been married for 3 years.

Diagnosis of Cerebral Palsy: A Crushing Blow

Q: So that was in 1992?

S's mother: Yes, in 1992. S was sick at birth, with pneumonia common in newborns. I had to go to great lengths to prevent premature birth. That in itself was not normal. And S has had poor health ever since he was born.

Q: What did you do to prevent premature birth?

S's mother: I took bed rest at home, and the doctor had to make house calls. I took all of the shots in bed, because I couldn't leave the bed at all. I was bleeding often and without bed rest, I would have miscarried. All of these could have had an effect on S's health. The doctor said that the fetus hadn't been developing well and miscarriage would have been a natural screening process. Because I went out of my way to keep the baby, something had to have gone wrong. It made some kind of sense.

As a baby, S seemed fine except that he had poor health and was always getting sick, but it was nothing alarming. When he was 7 months old, we took him to the hospital when he got sick. The doctor held him up and felt that even though he was already 7 months old, his feet had no strength whatsoever and his body sagged downwards like a bag of rice. The doctor told us there was something wrong with him and asked us to immediately take him to the children's hospital in the city. I asked what exactly was wrong, and the doctor said he couldn't tell but doctors at the children's hospital could, so I wasted no time in taking S to the children's hospital. The doctor saw that S's legs crisscrossed like scissors.

Q: Crisscrossed?

S's mother: Right, crisscrossed. S wouldn't be able to walk with such legs. The doctor said that as soon as he held S up, his legs crisscrossed showing that he had cerebral palsy. I had never heard of any child having cerebral palsy, so I had no idea what it was. But I blanked out at the words because they sounded so horrible. That day was beyond my worst nightmare.

We had had such high expectations for our child. We were doing pretty well ourselves, so we figured that our child should be healthy and smart, to say the very least. What would cerebral palsy mean to us? It was such a crushing blow. We had been a happy family, with the grandparents proud of having a beautiful grandson. It was... when I have time, I will show you pictures of S when he was young. He really had such good looks.

Q: Okay.

S's mother: We used to live close to Hongkou Park, in the house next to the old residence of Lu Xun. We would take S out for fresh air every day, and on the way to the park, passersby would comment on his looks. They would walk behind me and keep saying how beautiful S was. But the cerebral palsy destroyed everything that was beautiful.

I can't remember how I survived the first few days after learning the news. I just couldn't accept it. My husband was in a daze too. The grandparents took it the hardest and were so depressed. Grandpa was the saddest. Our neighbor had a child with disabilities, too—S would grow up to be like him. Raising such a child would be such a burden and so painful. But at the end of the day, I decided that my husband and I had to try our best to seek treatment for him. What happened then was that as soon as we heard about a good doctor or a good hospital, we would take S there.

Q: Had you ever considered having another child to make up for it all?

S's mother: Yeah, and I actually got pregnant again, but I had an abortion after struggling with it for a while. It was the most difficult time for us when I got pregnant, because we were spending so much on S's treatment. And even though he was the one getting the treatment, it was physically draining for us. We couldn't be at two places at the same time, so we had to hire help. I had severe reactions when I was pregnant with S and was constantly bleeding. When I was pregnant the second time around, my instinct was that the baby was very healthy and I wasn't feeling a thing, as if I wasn't even pregnant. So I felt that the baby must be a healthy one, because I remember the doctor telling me that miscarriage happens when the baby isn't developing well, and babies that are artificially kept alive in the womb will be born with this problem or that.

I was heart-broken over the abortion, but we really didn't have the time or the energy. After the abortion, all I had was a very small chicken. I said to my husband, "All you fed me was a chicken as small as a fist. That's it?" We didn't want to spare the money for anything better. I wish we had been in a better financial situation or our families had been able to chip in, but we had no choice. It's such a pity that I had to get rid of the second one.

Q: If he had been born, he might have been a great help to his brother later on in life.

S's mother: Right, right. But on the other hand, the second one would have had to take care of his brother, like I do. It might affect his life later on. For example, he would want to get married, and it would be no help when he has a brother to bring into the marriage. So we felt that we were dealing the second one an unfair hand even before he was born. Also, once he was born, we might shift attention away from S and be less willing to spend so much money on him, because we would need money

for the second one's education. So we went back and forth and eventually decided not to have the second one.

Forced to Move: To Make Matters Worse

S's mother: There was a *qigong* master who often went to People's Square and who said that that place was good for summoning the positive energy needed in *qigong*. We didn't exactly live close to People's Park, so we would get up very early in the morning to take S there, and people who knew *qigong* would give him massages. It must have helped, now that I think about it. After a while, the grandparents got mad and said we were too noisy.

Q: Too noisy?

S's mother: We had to get up very early to take S for the massages, and that affected the grandparents. They asked us to move out. They were very disappointed in us having a child like S, and having to spend money on treatment for him was one more thing that displeased them. So they decided that we should move out.

Back then, Bao Steel had a lot of apartments to assign to its employees. All we needed to do was to apply. But the company did ask, "You should have stayed in the city to seek treatment for your kid. Why would you move to Bao Steel? You have no place to stay in the city?" But it was really getting unpleasant living with the grandparents. Grandma was pulling a long face every day and giving so much pressure, so we ground our teeth and moved out. We spent only 1 month getting the apartment ready to move in. There wasn't even enough time to air it. As soon as the apartment was ready, we moved in. The walls still felt wet and there was a damp smell throughout the place. So it took us just 1 month, from getting the apartment to moving in.

Q: Which year was that?

S's mother: It was 1993 and S wasn't yet 12 months old. After we moved, it wasn't so easy to see doctors when S got sick, so we had a hard time adjusting. Healthcare services were very bad in Baoshan District. Less than 20 days after we moved there, S got sick and we had to take him to the hospital. Hospitals in our neighborhood were not as good as the children's hospital, but we had to live with that.

Also, kids like S couldn't go to preschool or anything else, so we had to keep him home, and if we couldn't handle it, we would have had to get a nanny. Just like that, our entire life was turned upside down by having a child like S.

And what followed was continuing to seek treatment for him which included physical therapy. It was really wearing us down.

We had to pay out of our pockets if we wanted to use the best drugs. Not a single penny would be reimbursed. Expenses covered by insurance weren't that high. The drugs we had to pay for ourselves were super expensive. I remember the doctor saying, "There's this drug, imported. Did you bring money? It's pretty expensive." And I would ask how expensive it was. What happened a lot of times was that we would get paid a lump sum, like several months' salary, and I would immediately

take all of the money to the hospital to get a certain drug. I don't even remember its name—it had a foreign name.

Q: What was the total amount of your medical expenses back then?

S's mother: Every time we saw the doctor, if it was just a check-up without any prescriptions to fill, we could totally afford that. What was draining us financially was when S had to take some imported drug and also physical therapy. When I had money, I would pay for physical therapy for him. When I didn't, I would stop it for a while. So there were many disruptions.

There was this drug... I can't recall the name... S was drooling before he took the drug and it got much better once we started him on that. We couldn't afford it for a long time, like 12 or 18 months, then I came into some money and bought a whole lot. It was taken twice a day, one in the morning and one in the evening. I asked the doctor if the drug would have any side effects if the dosage was increased. The doctor said it should be fine since S started taking it when he was already of a certain age. So I started giving him six pills a day. In retrospect, what kind of financial implication did that have? Six pills were probably equal to what I made per day... actually more than that. One pill equaled my salary per day. I had S take that drug for a long time, because I felt it worked the best.

S's mother: (Getting teary and pausing) It was such a hassle taking S for physical therapy. There was no light rail or elevated highways back then. We had to ride the bus which made so many stops, and it took us more than 5 h both ways. Because of his cerebral palsy, S couldn't walk well, so I had to carry him to take the bus. One time I passed out on the bus. It was in summer. S understood nothing, otherwise he would have tried standing on his own which he could do. It wasn't really about the money. I was literally putting my life on the line. (Crying and pausing) After I came to, I debated whether to go home or to continue onto the hospital. I decided that since we had already left the house, we might as well just go to the hospital.

Q: So you rode the bus?

S's mother: We took the bus. Sometimes we took the smaller bus for 5 yuan which was more than what the regular bus cost, but it made fewer stops and saved us some time. I didn't want to spend so much time on the bus since S needed to eat and to use the bathroom.

When we lived in the city, we only needed to take one bus to get to the hospital. After we moved to Baoshan, it became so inconvenient and tiring to go to the hospital. Since the physical therapy was only 1 h per day, S couldn't be admitted as an inpatient. So we had to bring him from Baoshan to West Beijing Road every day.

We had become such regulars at the hospital. One of the doctors was very nice and recommended enhanced external counterpulsation which worked wonders, according to him. He explained how the therapy worked, and as far as I understood, the patient was tied up from head to toe, the machine was turned on to apply pressure which pumped blood to the brain, and once the blood started flowing fast in the brain, the cerebral blood vessels would expand. So we prepaid for the therapy, like prepaying for public transportation. Money was deducted from our card after every visit.

Enhanced external counterpulsation was very painful and S would fuss and cry. If I couldn't take him to the therapy myself, I would pre-record a tape for him. I would

start by saying, “S, we are about to start your physical therapy.” I would keep talking to him on the tape, telling him stories and playing him a song. Because one session lasted an hour, I had to make up things to fill a 1-hour tape to help him through that session. The doctor said that S was very strong-willed and sometimes it took more than two doctors to hold him down. I kept the tapes for a while but had to get rid of them as old things started piling up.

Q: Parents weren’t allowed to stay for the therapy?

S’s mother: They could stay, but I couldn’t go sometimes myself. So I had to find someone to take him. It didn’t cost much to do that by today’s standards, just 30 yuan if I remember correctly. And we paid for transportation. But the person we found couldn’t hold him still for the therapy. S wouldn’t listen to him, he only listened to us. So we had to prepare the tapes and they had to be different every time. Even though it was costly in terms of money and energy, the therapy worked. But the hospital was just so far and we had difficulty getting help taking S there. The relatives found it a hassle. But then, if we had asked an elderly relative to help us, it probably would have been too much for him, so we didn’t continue.

Q: How long did the enhanced external counterpulsation last?

S’s mother: Three months. We prepaid for a 6-month regimen, but only used 3 months. We really had no choice. The hospital was too far, and we couldn’t find anyone to take him. Not everyone was willing to help. Once kids start making a racket, it got on people’s nerves, right?

Treatment and Therapy: Hope Means Not Giving up

S’s mother: S had been going to the children’s hospital for treatment from 7 months to 12 or 13 years old. Then the doctor said that he had outgrown the children’s hospital and had to seek treatment elsewhere. He referred us to a doctor specializing in mental development—he had his own treatment methods and was a very good doctor, too.

A lot of the doctors were really nice. I didn’t give up, and they would tell other parents that S’s parents were the best at not giving up, so S had improved the most. There was a parent who had the financial ability and his kid had been in better shape than S and had gone through physical therapy and speech therapy as well. But maybe the parent didn’t have the same energy as we did, since we were younger, so the kid didn’t improve as much as S did. A lot of parents with kids like S would call us back then, asking about S’s treatment and where he got it.

The treatment needed family support. It wasn’t convenient to go to the hospital and we had to pay out of our own pockets for so many items like physical exercises. The hospital charged an hourly rate for S to use its balance beam, slide, and other equipment. It was very advanced treatment and available only at Shanghai Children’s Hospital. So we tried to replicate it at home, to save money on one hand and to save us trips to the hospital on the other hand.

Q: How did you replicate the hospital’s therapy setup at home?

S's mother: We emptied one room of furniture except for carpet, and hung something from the ceiling. The most interesting thing we set up and I had kept for a long time was called the "single-legged stool." It had only one leg that was as thin as a 1-yuan coin, so you have to be really good at balancing to not fall over while sitting on it. Another thing was a board with an arc-shaped leg that could roll like a ball. You have to have good balance to stand on it. S would definitely fall if he stood there without anyone supporting him, and he was supposed to stand on it and bounce a ball. He couldn't do it, but we never gave up just because he couldn't do it. The two of us would exert ourselves to drag him onto the board. There was another funny device—it was a board with four wheels underneath it, and S was supposed to lie on top of it, face down, and to use his limbs to crawl along the floor, from left to right, like a turtle.

The most exhausting exercise was standing on his hands so that the blood would gush to his brain, which is good except for those with hypertension. I trained myself so well back then. S was no longer a kid and even his dad couldn't hold him straight upside down. I was the one who helped him.

Q: How did you help him stand on his hands?

S's mother: He couldn't understand verbal instructions, so I had to show him. At first I asked his dad to show him, but his dad said he was too old to do it. So I ended up teaching him. I was already in my forties then, but I did it, and I would stand on my hands too every time S did it. He couldn't hold himself up, so his dad had to support his legs. If I look at the positive side, I got a lot of exercise myself. If I dwell on the negative side, I get teary. I was no longer young and still jumping through hoops. Other people's kids seemed to have grown up on their own, whereas my kid had to go through so much. (Sobbing)

We took some pictures back then in which S was crying while laughing with tears covering his face. I was helping him with physical therapy, and some of the things I had to do caused great pain. His legs were deformed and twisted, so we had to straighten them out, otherwise he would walk bow-legged. He would cry from the pain, but would laugh too because we were teasing him to distract him from the crying. The pictures look awkward now, but they mean a lot.

We never stopped physical therapy for him. For example, one of his legs was skinnier than the other one, so he would walk with a limp. I just wrapped a sandbag around that leg and made sure he went to school with the sandbag on. It helped him balance his weight between two legs when he walked. Ever since first grade, he had carried his own school bag no matter how heavy it was. We never carried it for him and we never spoiled him in that way. In other areas, especially in seeking treatment, we spent more than any other parents. The two of us basically gave everything we had for his treatment. As soon as we came into some money, we would use it to see doctors even if the doctors were outside Shanghai.

Q: You even saw doctors outside Shanghai?

S's mother: Right, right, like in Suzhou and other places that are smaller than Shanghai. We really never spoiled him in any other way. For example, his middle school was pretty far from here, about two bus stops away, but we never dropped him off or picked him up. One time it rained really hard, and one of my co-workers

came over to talk to me about something. Afterwards this co-worker suggested that I pick S up because of the heavy rain, so we drove to pick him up. I let S do whatever he could do himself. Carrying his schoolbag was easy, doing well at school wasn't and that's something we had no control over.

Q: Physical therapy sounded so tough for him. Did he ever resist or want to quit?

S's mother: Not really. He would go through with it even while crying. Enhanced external counterpulsation was so painful and he cried during every session. But he laughed on his way to the hospital. So I believed that he could handle it all.

Q: So he understood.

S's mother: I couldn't really tell. Maybe he felt he had to go. For me, since I prepaid, I felt that we should go. S didn't exactly put up a fight about not going.

Helping Hand: Friends in Need, Friends Indeed

Q: Did you have financial difficulties at home back then?

S's mother: Yes, things were very tough for a while.

Q: Exactly how tough?

S's mother: We made everything ourselves. S had digestive problems and had to eat a lot of yogurt, so we would make the yogurt ourselves. We made our own bread too. He was slightly autistic, so we needed to take him out more like traveling. When we went on trips, we would bring our own food. Everything had two sides. We spent so much time making our own food and even brought the food with us when taking the train. But on the other hand, S became interested in cooking, which might have had an impact on how he got the current job later on.

Q: Because of your financial hardship, did you ever think about asking for help from relatives or friends?

S's mother: No, we never told anyone about our financial hardships. While we were living with the grandparents before we moved to Baoshan, my husband and I gave all our pay to them. We had to hire someone to help take care of S, and the cost was 90 yuan per month. It was in 1992 or 1991 and our pay was very low, just several hundred yuan per month. After we moved to Baoshan, we stopped giving our pay to Grandma. We had never asked for help from either Grandma or my own mom.

Q: Was it out of self-respect?

S's mother: We just felt that it was our own problem. If other people wanted to help, they would help. If we had to ask for help, we wouldn't feel comfortable even if we received help. My husband and I kept encouraging ourselves by saying that we should not rely on anyone else but ourselves.

Q: But there were still friends who helped, right?

S's mother: Right, right, a lot of friends. They didn't lend us money, but gave us a lot of mental support, like offering suggestions or looking for doctors for S. After all I've been through, I really appreciate society. I want to show appreciation whenever someone gives me even the slightest help. (Pausing and sobbing) We did receive a lot of help.

Q: Can you share with us how you received help?

S's mother: Sure, I will share some. The doctor told me that S had bad physical development and coordination, so sports would be good for him, but he couldn't do any sports. The doctor recommended swimming. We started off teaching him ourselves but failed, so we hired a private coach and that didn't work either.

Then a friend recommended a professional swimming school in Baoshan District. The coaching was excellent and the fee was 1,500 yuan per student. It was almost 20 years ago, so the fee was pretty high for us. But we figured it was both physical exercise and physical therapy, so we were willing to pay the fee. Once we took S there, the place saw that he was different and immediately returned the money to us, the reason being that there was no way S could be taught to swim. The 1,500 yuan covered ten lessons. The average kid would definitely be able to swim after ten lessons, but not our kid.

I had to disclose S's condition saying that the doctor recommended swimming for him. A coach overheard it and was very sympathetic, so he came up to me and said, "Take back your money, I will teach him for free—all you need to pay each time is the entrance fee." Later he said that it was very difficult to teach S and he didn't have all the time he needed during his work hours to teach him, so he mentioned this at a meeting for Communist Party members and enlisted everyone's help. He basically started the ball rolling and should be credited, before all other people, with S's being able to swim. I was really surprised to see S swimming faster than I do. He can do both breaststroke and freestyle and not even his dad can keep up with him now. I was so very touched.

Q: Did he learn alongside other kids?

S's mother: No, no. He had private lessons which were different from lessons for the other kids. One time the coach asked me to go watch. He felt bad for me and wanted to give me a pleasant surprise. So S was in the water and sinking. The coach used a very, very long pole and stretched it all the way across the pool to tap S under the tummy. As soon as he did that, S floated up and started swimming. That coach really knew how to teach and how to use the pole. I almost cried watching it, because I had never expected S to be able to swim.

Q: How long did it take for him to learn?

S's mother: A very long time. We went almost every day for about 2 or 3 months. It took the average kid eight or nine lessons, and the smart kids about five lessons, to learn to swim. I lost count of how many lessons S took. They went on from summer to winter. When he first started, it was very hot. By the time he completed all the lessons, it was very cold. We would go watch him, and my glasses would fog up when we entered the pool area.

Q: Was he willing to learn?

S's mother: He was very willing and he didn't care how hard it was or that he often choked on the pool water. He was very grateful that someone would teach him.

Q: So he was a very appreciative child.

S's mother: Right. He is very simple-minded and very kind-hearted. He may not always say the right things at the right times, but he really has a big heart and is willing to share. We have brought him up this way and ever since he was young, he

has been grateful for the help from society. (Getting teary) While he was growing up, he was discriminated against and a lot of kids bullied and hit him. But he was appreciative of even the smallest gesture of kindness. I have been with him since day one, so I feel the same as he does. (Crying hard)

Q: Can he show people that he is grateful?

S's mother: He can. There was this health teacher at middle school. S had bad physical coordination and was constantly falling, so he asked me what he should do when he fell. I said that there was a medical office at school and he should go to the health teacher there when he fell. So he was always going to the health teacher to fix him up whenever he fell.

The health teacher gave S a lot of help on a daily basis. On the occasion of the physical check-up for graduation, I visited him and talked to him. He said, "I am not his Chinese teacher or math teacher, so I can't tell how he is doing with schoolwork. All I see is a child seeking my help. He is the child with the best manners and the biggest heart."

Because of the kindness he had shown, S will visit him on every Teachers' Day.

In the Face of Bullying: I Could Only Change Him

S's mother: S is a very simple person, and simple people love and hate in simple ways. If he likes you, he will always remember you and try to make you happy. If he hates you, he won't hide it either.

Q: For example?

S's mother: For example, when he was in first grade, the homeroom teacher was a Chinese teacher. Maybe because he was a senior teacher, he had high expectations for his students. S was different from other kids—he wrote slowly and had other deficiencies. The teacher told me about it, and I had to tell him that S had some intellectual disability. The teacher said, "We are in a regular school here. I cannot make any exception for your child just because he has disability. You chose to send him to this school, so he must keep up with schoolwork." Maybe I had not been very effective in communicating with him, which was why I have been very careful in that respect ever since. I will never go to S's workplace to plead with his manager... (Pausing and sobbing)

That homeroom teacher started bullying S and was very malicious about it. One time, the school asked the kids to write about their own "happy family" after they had had a chance to watch something related to it on computer. S brought a disk to school and asked the teacher to make a copy for him. The teacher said, "What kind of happy family do you have? After your mom had you, your family stopped being a happy family." Even though S didn't completely understand it back then, it was very traumatizing for him. The teacher also said, "If you can't keep up with schoolwork, your dad will get laid off." S came back home and repeated to me what the teacher had said. He didn't know what "being laid off" meant, so he came home and told me that he cried hard at school because the teacher said his dad would be laid off. Even

though he didn't know what it exactly meant, he was scared and started crying in the classroom, and the teacher kicked him out.

S said later, "I hate him—I will kill him when I grow up." I was very shocked by what he said, because he had never said anything vicious before and I didn't understand why he would have this idea to kill anyone. What scared me even more was when he took a pair of scissors and cut the tablecloth. He continued to be so mad that he cut his own hair. I was very worried that he would end up with a distorted mind. It's okay if he is not as smart as some other people, but he cannot hate society. If he does harm to society or to our family, no one will be able to save him.

It hasn't been easy for me trying to nurture an outgoing personality in S. I gave him a lot of positive energy and made him believe that even though he isn't that smart, he has his own use and his self-confidence. My reasoning was that S's teachers and managers in the future could very well be kind-hearted people and they are not obligated to give S any special treatment because of his disability. I often tell S that he has to accept the fair or unfair ways other people treat him. It's not the smartest philosophy. I cannot change society, so I had to change him and make him mentally strong. If someone hits him, he should just put up with it. If S were not the way he is, I would have taught him to fight back whenever he is hit and not to put up with bullying. When he was in elementary school, there was this kid who would dump a trash can with trash inside onto S's head. There's nothing he wouldn't do to bully S, including slapping him on the face.

Q: Did S fight back?

S's mother: He didn't have the courage to, but he hated it. And I was scared of this hate, because it would affect him mentally on one hand, and on the other hand, it might make him a danger to society and to our family. Because I had the feeling that he would act out his hate somehow.

As a Student: Studying Hard to Make up for the Disability

Q: Did you ever consider sending him to a special education school?

S's mother: No.

Q: Did he start school at the normal age?

S's mother: He did, and it put a lot of pressure on him.

Q: On his first day of school, was the curriculum overwhelming for him?

S's mother: There wasn't much schoolwork during the first several days of school, but it was indeed overwhelming for him. He couldn't sit still or focus on what the teacher was saying like the other kids could. He just didn't seem to get it. It took him a long time to catch up, unlike in kindergarten where he could just keep up. School was indeed tough for him.

Q: Did you or his dad help him with his schoolwork?

S's mother: We did, especially when he was in first and second grade.

Q: How did you help him? Did you have difficulties helping him?

S's mother: No, there was no difficulty in elementary school. I remember one time when he was in the first semester of second grade. I was dropping him off at school and ran into the principal. The principal held me back to say, "S's mom, S's mom, S scored the highest on the test this time." I was so surprised that I couldn't move. I remember it being a math test and he answered all the questions correctly. I saw the test later. He actually made some minor mistakes, but the teacher didn't deduct any points, which was his way of encouraging S. And this kind of encouragement was, in my opinion, much more effective than scolding and yelling at him. For a while, he was in such a positive state of mind.

But he is different from other people, after all. He isn't as smart, so he had to do things repeatedly. Ever since he was young, he had to stay up very late to do homework. We managed his time pretty well and he did put in more effort than other kids. A teacher once asked me to go to school to give a presentation on how hard he studied. I didn't give up until later on when he just couldn't keep up. I figured that he couldn't exactly stay up all night to study, so if he couldn't do well at school, so be it.

He was doing well at physics and chemistry. There were two reasons for that. One, he had good teachers for those two subjects. Unlike the homeroom teacher, as long as you paid attention in class, the teachers would give you recognition. Another reason was that physics and chemistry were relatively simple when he first started middle school. Once they got difficult, he would struggle. Compared with people without disabilities, S tries harder. In simple things, he will do better as long as he tries hard. In difficult things, no matter how hard he tries, his intellectual ability will fail him.

One time I went to the parent-teacher meeting, and the teacher got mad at other parents, saying, "You all know that we have S in the class. Do you know how much S scored and how much your kids scored? Go home and check their scores." That's what the teacher said when I attended the parent-teacher meeting. So it's a kind of encouragement to S. But he started lagging behind as the schoolwork got more difficult.

Q: Approximately when was that?

S's mother: He failed the entrance exam to high school after graduating from middle school. He was failing in English, and Chinese too, because he didn't have good logic and couldn't write good essays. He might have got that from me, because I have bad logic and hated writing essays (laughing).

Q: He must have been staying up late for homework every day back then.

S's mother: Yes, he did stay up late. But I felt that he saw things getting too tough for him and started saying things like, "I really can't keep up."

Q: Did you ever try private tutoring for him?

S's mother: We did, we did, including a tutor from Fudan University. The tutor's last name is Wang and he's from Anhui. He liked S a lot. He came once a week and tutored two kids at the same time, and the other kid later went to school in Britain. I didn't expect him to think more highly of S than of the other kid. He said that even though S isn't that smart, he tried hard, whereas the other kid aimed higher than what he was capable of. Sometimes I wish things were different. Without the intellectual

disability, S would have been at least on par with everyone else. But fate has wanted it this way, as if to test how tough I am.

Exposure to the Outside World: A New Phase of Growth

Q: He must have made a lot of good friends at school.

S's mother: Right, he had a lot of good friends. Like the kid I just mentioned. They are of the same age and grew up together, even though they were going to different schools. That kid later went to Britain. He didn't mind the way S is, which I think was very kind of him. Also, S has a good mentality and can communicate with other people. He doesn't suffer low self-esteem like some other kids. When playing with other kids, he didn't feel that he was inferior. He knew that he was a little different, but not to such a degree that he couldn't be a part of everything.

There were also classmates from elementary school and middle school who lived nearby. One lived right across the street. He has graduated from college with a degree in computer science and has a good job now. Another kid lived in the same apartment complex as us and always hung out with S. He is graduating from college this year and will work as a physics teacher at Wusong High School. They were all good kids.

Kids like them were all nice and upbeat kids. Being with them was somehow inspiring for S and he learnt from them. I liked it because he could keep up with society through those kids. Sometimes he complained to me, "You won't let me watch this or that, and because of that, I have nothing to talk to other people about. I need to learn so that I can talk to people." I realized that he was so right, because he has to communicate with people without disabilities. If I forbid him from watching movies or going out, he wouldn't learn anything. So I support him to learn as much as he can.

Q: So he has had good exposure?

S's mother: He has.

Q: Did you and your husband create a lot of opportunities for him to gain exposure to the outside world?

S's mother: Yes, yes, we did. That's always been the way we've educated him. We believe that even though he wasn't doing well at school, he should be an outgoing and happy person. We have different expectations for our child than parents with healthy kids. As we are getting older ourselves, we don't want to see him having negative thoughts or holding grudges and feeling that people have treated him unfairly, because then he will live an unhappy life. He cannot change society, so it's better that he changes the way he lives and the way he thinks. He should take comfort in thinking, "I may not do well in this, but I can do well in other things."

Another thing we did was to nurture his interests so that he wouldn't idle away his time. I took him to learn dance and musical instruments. I also tried to get him to appreciate a lot of things. For example, I took him to the art museum and explained everything to him. We also took him to some historical sites. We would do our homework on those places first before we played tour guide to him. Even though he

was lacking in a lot of areas, I believe that he was on par with other kids in terms of interests and the ability to appreciate things.

For example, Shanghai Museum was giving a class on archeology and S was interested. One of his interests is history which we have helped him develop. We hoped that he could be exposed more to history, so we registered him for that class which included a trip to an out-of-town archeological site. He asked if we would allow him to go on this trip. People in the class were either adults or college students, whereas he was still a teenager and the only kid in the class. Still, he went on the trip with the class. He told me that they dug out a lot of things, but I forget exactly what they were. There was also a graduation certificate on completion of the class. It was a nice experience for him.

Another interest of his is opera. He likes pop music too, but he can appreciate things adults like us do, which has to do with the way we have brought him up.

I often tell him that because of his disability, if he does not dress neat and has body odor, people will shun away from him. His good friends are all college graduates with decent jobs. If he smells bad, they won't want to hang out with him. So he really pays attention to whether his clothes are clean. Doctors that we saw used to ask whether he was willing to shower or change clothes. S was happy to take showers and to change into clean clothes. The doctors wanted to make sure that S didn't have this affliction, because people with ID do not like to shower or change into clean clothes. Well, they don't exactly hate it, they just don't feel like doing it.

S would change into clean clothes without being asked to. Later on, I tried to figure out why and realized that it was because that's the way we are and the way we taught him. We always wash our hair or shower before we go out. If he gets out of bed with messy hair, I would ask him to wash it. He has to go to work on mornings lately, so I'm not asking him to wash his hair in the morning. He stays up late at night and is in a hurry getting up in the morning for work, so he doesn't have the time to wash his hair. I told him that unlike other people, he doesn't have ambition or the need to save his time for some difficult research. His life is about eating, sleeping, and going to work, so he has all the time to make himself presentable. That's how we have brought him up, because we want him to be able to settle down and to make himself presentable even when we are not with him.

Q: He needs to be presentable.

S's mother: Right, presentable. That's what we want for him, to have some quality of life.

Q: How old was he when he started taking care of himself, like brushing his teeth and dressing himself?

S's mother: Pretty early. He could brush his own teeth when he was about five or six. Before that, we had been doing it for him. He couldn't dress himself till much later.

Vocational School: Pursuing Knowledge and Struggling Along the Way

Q: You just mentioned that he failed the entrance exam to high school after graduating from middle school. What did he do then?

S's mother: He went to Baoshan District Vocational School and got into a cooking class. Originally, he didn't like that major which I had picked for him. He had wanted to study computer science. But I told him, "Computer science includes programming which is required for operating the computer. You will have to have an advanced degree, good English, and good logic, right? Otherwise your programming wouldn't make sense and no one will want you to do it. So I don't think you have the ability to even write the simplest program. Your best choice is cooking. You may end up not cooking as well as some other people and not being hired by any restaurant, but at least you will be able to cook at home, which is a set of skills, too."

At that school, he didn't do as well in cooking and baking as some other kids. But most of the kids there were struggling with schoolwork, so S outshone them there and even won scholarships. He had several good years at that school.

The only drawback with that school was that the kids there weren't exactly the best students and the overall culture wasn't ideal. S was always being bullied. We have taught him to be forgiving, to not harbor grudges or become confrontational. Once a classmate took his transportation card—the school was far from where we lived, so he had to walk more than 2 h home. Driving would take less than an hour. So he recalled the directions and walked home. I called his homeroom teacher about it afterwards.

Q: Did his classmates ever do anything really bad, like using violence?

S's mother: They didn't exactly hit him viciously. But they dumped a trash can over his head, took away his transportation card, took his glasses and threw them away, and did other similar things.

Q: How did he handle that?

S's mother: He wouldn't physically fight anyone.

Q: Would he seek help?

S's mother: No. He just walked home by himself. He wouldn't tell the teacher. If he had told the teacher, the teacher would have given him 2 yuan to take the bus home. But he wouldn't. I panicked that time he walked home, because he didn't have a cell phone. (Tearing up and not speaking.)

Q: And he wouldn't say anything either when he got home?

S's mother: I asked him when he got home, and he told me. Then I called the teacher.

Q: How old was he when he graduated from the vocational school?

S's mother: He was 20. He couldn't find a job after graduation. He worked at a supermarket for a while before being let go, because he had neither the physical strength nor the smarts to work there, according to the supermarket. So he worked there for less than a year.

Supporting Each Other in Despair

S's mother: For a while at home... my husband was sick for a while. Pressure had built up over time, and there were other contributing factors. So he suffered severe depression.

Q: What were his symptoms?

S's mother: He wouldn't talk or get out of bed. He believed that he had a terminal disease but that it was nothing mental. So he took all kinds of tests including EEG and ECG. He had himself checked everywhere and there was nothing wrong with him, but he just couldn't eat or sleep and was so depressed that he lost the will to live. He didn't exactly talk about taking his own life—he was thinking about it but wouldn't say it out loud. He couldn't work, which was scary. He was the chief engineer of a major project that was supposed to be exported once the design was finalized. The project was halfway through when he stopped going to work.

Q: He didn't take sick leave?

S's mother: He didn't. He just turned off his phone. People were looking for him, but he didn't want to talk to or see anyone. I was so scared back then. S had no job, I was retired already, and my husband was sick like that and not going to work. At that time... (sobbing), I was feeling almost as sad as when I first learned about S's cerebral palsy. I didn't think this family could survive... (sobbing and not able to continue). What made it worse was that I was disappointed at the government agencies.

Q: What do you mean?

S's mother: Things were getting so tough for our family, weren't they? I don't mean we were starving, but the whole family was unemployed, which wasn't normal. I had hoped that the Disabled Persons' Federation (DPF), or some other government agency, would do something for families like ours, with Dad not being able to work and Mom being retired. Someone should have stepped in and arranged a decent job for S as soon as possible.

We contacted the DPF and were told, "There are not many jobs available now and we can't just request that jobs be created just for you. We have so many people registered with us looking for a job and none of them have got one yet." I went to the office several times, and I didn't take rejection well. So after several times, I felt it was hopeless and just didn't feel brave enough to go again. The reception wasn't warm at all and I didn't feel good about it. Everyone pulled a long face at me and was icy cold towards me. Then I remembered someone telling me that the Women's Federation was nicer, so I visited that office immediately. I said that my husband had been suffering depression for many years without getting any better and had cancer later.

Q: Oh, when was that?

S's mother: In 2014. He had cancer, then surgery. I felt like the family was collapsing. My husband had been suffering depression for more than 10 years without getting any better. That was bad enough. Then he had cancer. S was the problem for him. He has a high IQ but low EQ, and he isn't very expressive. He can't see beyond

a certain point and has pressure at work too. I couldn't pinpoint the exact reasons. I asked him and he couldn't either. All he knew was that he was extremely unhappy.

So I went to the Women's Federation. There's a lady there who heard me out, but all she could say was that she couldn't get a job for S either. She suggested that I seek help from the radio station and maybe some caring companies would have the right job for him. (Sobbing and not being able to continue) I said that my son could work because his brain functions well, he can talk and he won't do silly things and that there had to be a suitable job for him. But she just said, "I really have no job for him." (Sobbing)

Q: So you sought help from many places?

S's mother: I did. (Crying non-stop)

Q: Did you try to get your husband to see a doctor for his depression?

S' mother: I didn't have to get him to see a doctor. Because of the depression, he couldn't go to work. I asked him if he was physically sick, and he said he was indeed sick and needed to have a check-up. So I didn't have to get him to see a doctor. At first, I went with him for all of the doctor visits. Later on, I would get his prescriptions refilled even without doctor visits.

Q: Things were getting impossible, and your husband was suffering depression to make it worse. Had you ever felt like you were going to have a mental breakdown?

S's mother: Yeah. I actually saw a doctor myself. Back then, I felt so bad about my family and asked myself why there was something wrong with everyone in the family. S has intellectual disability, his dad had depression, and I had to see a doctor myself. I was suicidal and for no reason at all, nothing meant anything to me. I had no way out. People say that there is always some way out, but I really had no way out. (Tearing up) So I saw a doctor under a pseudonym.

Q: Pseudonym?

S's mother: Right. I was worried about people saying, "Her whole family are nuts." Then everyone would stay away from us. That's what I thought back then.

Q: Like you said before, you want to be presentable.

S's mother: Right, right. Back then I wanted everything to be perfect and wanted things to improve, so I had pressure. I felt that however hard I tried, I couldn't change anything. So I was very discouraged. (Sobbing) Sometimes I was resentful towards society, because I felt that whichever government agency I talked to, no one would help me.

I told the Women's Federation that my husband had a terminal disease in addition to depression, and that the only thing that could save him was his son getting a job because that would give him hope and save him from driving himself into a corner. I was told that there's no workplace that would take S. I thought if only it would lend a helping hand, it would save my entire family. I didn't mention my suicidal thoughts. If I had, the government might have thought I was bluffing.

Q: How long were you suicidal?

S's mother: Not long.

Q: How did you get over it?

S's mother: I remember taking medication. I couldn't have gotten over it myself, however hard I tried. So you have to see a doctor for this kind of suffering. Don't avoid getting help. (Crying non-stop)

Q: How did you get over your resentment towards society? Did it ever come back?

S's mother: It would come back. I would take medication and try to get some more sleep. At that time, I was often exhausted and wondered if the exhaustion was caused by some disease. But what really happened was that I didn't sleep well and was unhealthy on the whole and my blood pressure was high. Then I started going out and talking to more people and taking medication, and I gradually got better.

What it really comes down to is this: If everything is okay with S and he is doing okay at work, I will feel peaceful. If one thing or another happens with him, I will get rattled and more anxious than he is. I try my best to control my emotions and not pass them on to him. My reasoning is that for anything wrong with my husband and me, we can take medication and try to get over it, but if something goes wrong with S, he will have a harder time getting over it, so we should try our best to train him to be resistant against frustrations.

Q: So you would never show any negative feelings in front of S?

S's mother: Never.

Q: How did you and your husband communicate and support each other if both of you felt like crashing?

S's mother: We communicate very well. It's very important for a couple to communicate. We think for each other, especially my husband. At first when he knew nothing about my mental struggles, he would tell me how he was not feeling well. Once he knew about my condition, he would downplay his own and not show his depression in front of me so as not to pass anything negative to me.

What really touched me was this: He was diagnosed with cancer twice. The night before his surgery, the two of us had a talk. He told me a lot of things including that he was prepared for the worst and had made plans for S's future. His cancer made his depression worse, but he behaved very strong. He comforted me by saying, "It's no big deal, and I will be okay as soon as this tumor is removed." He never showed any pain. I knew how much effort was involved, so I told him that I really appreciated what he was doing. (Sobbing uncontrollably) We survived. His follow-up check-ups were all good and the cancer didn't linger.

Q: So the early discovery helped.

S's mother: Yes, it did.

Q: That's very lucky. So your husband has gone back to work?

S's mother: He has. His work is lighter now and he seldom has to deal with customers. Bao Steel isn't doing very well.

Q: How is life for you and your husband now?

S's mother: It's a quiet life. We don't have a lot of expenses, and we don't touch S's money.

Giving up Free Money: One Can't Always Just Take

S's mother: (Sobbing) Sometimes I wonder if the government can issue more policies encouraging companies to hire people with disabilities. There are many kids with disabilities like S. There's a kid who goes to work every day at the senior housing and I heard that he works for no pay, because his parents realized that he shouldn't be unemployed and should have a place to attach himself to, so he needed a job but no salary. I think that S could have worked at the guardhouse of the senior housing, like receiving and distributing deliveries.

In my opinion, it would be really nice if the government could save some of those jobs for people with disabilities. I believe that there was some kind of movement in society for giving people with disabilities a chance to do what they can, but workplaces that can truly accept people with disabilities are rare. The common belief is that employees with disabilities are very troublesome, and workplaces would rather just pay them not to come to work. When I mentioned earlier "having a place to attach himself to," I meant registering with a workplace and receiving minimal pay and not having to go to work. Why would a workplace allow that? Because it receives certain subsidies and tax exemptions for hiring people with disabilities. What the workplace really thinks is, "I would have paid this much in taxes, but I would rather use the money to help people with disabilities than pay it in taxes to the government. But I would prefer that people with disabilities do not really come to work."¹

Q: How come S didn't have the choice of attaching himself to a workplace?

S's mother: We did have this choice. When our family was having a really tough time, I had a friend who helped us find a place doing research for his company. He said, "As long as I am working and in charge, I will have S attached to us." That was a paying job with social insurances.

But we talked it over at home and didn't feel comfortable just taking. S totally has the ability to work. Attaching himself to a workplace will give him the wrong idea that he doesn't need to work and can be paid for not doing anything, and he will become someone who only takes. If he only knows how to take, what will he do once the government stops helping him? I was seeking help everywhere and when I couldn't get any, I was heartbroken. What if the same thing happens to him? He would be so helpless. So we felt that working for pay is better than being paid for not working, and that S shouldn't expect free money. What will he do if the free money stops one day? Who will he turn to then, the government? So we decided that he should go out there and get a real job.

¹The regulations of the Shanghai Government state that all state organs, social groups, enterprises, public institutions, and private non-enterprises shall arrange for the employment of disabled people according to 1.5% of the average number of in-service employees of the employer in the previous year. If any employer fails to meet this required proportion, the employer must pay for disabled people's employment security fund. If disabled people are "attached" to an employer, the disabled people's employment security fund is exempted, and the employer can even enjoy other incentives. Therefore "attaching" has been once very widely applied. Currently, SDPF advocates discarding the practice of "attaching" in order to advance actual employment of disabled people.

So S did attach himself to a workplace and the pay and the benefits were great. But you have to have personal connections in order to do that. And we really owed that friend big time for having arranged that for S.

Work Experience: Opportunities and Struggles

Q: S started working at Papa John's in 2015, right?

S's mother: Right, right, he has been working there for more than 1 year now. A friend told us that a kid like S worked at Jinqiao Papa John's and was doing great, and he recommended that S try it too. So we contacted the headquarters of Papa John's, and a young supervisor there was very nice. He arranged for S to interview and later called us to have S start working close to Gonghexing Road. I asked for a closer store but there wasn't any opening. So S has been working at that store that is pretty far from where we live (See Fig. 1).

Q: Was there any test before S was hired?

S's mother: There was a trial period of 1 month. After 1 month, he was accepted and I received a call telling me that a formal contract would be signed after 6 months.

Q: What did he do once he started working there?

S's mother: He started off working in the dining area. The store is divided into the kitchen, where food including spaghetti is made, and the dining area, where you greet customers, clean up, and serve drinks.

Q: Where you provide services.

S's mother: Yeah, where services are provided. When he first started, S worked in the dining area and the job was simple. He didn't do well and the store manager wasn't very happy. Then a new manager came and moved S to the kitchen to work. The manager expected much more of S and had him learn some things, which was nice. But S is different from other people. He gets nervous when there are high expectations of him and will fail at what he does, which will then lead to... (hesitating and pausing)

Q: What about the manager?

S's mother: Well, the manager doesn't like it that S is so slow. That really bothers me. Maybe the manager had never dealt with kids who have special needs, and kids who have special needs are different from each other. Some of them may not speak well but can do things well. The manager said, "S can talk, but he doesn't do things the normal way."

I don't think this is the right job for S, but I am afraid of telling anyone this, because then I might be told, "He can go back home if this is not the right job for him." What kind of job can society give S that's right for him? Society didn't exactly give us any choice. This was the only opportunity and we cherish it a lot. I can honestly say that S has a tougher time at work than any employee at any workplace. I worked and his dad worked and everyone around us worked, and no one worked the same way S does. He works 14 h a day, two of which he has to idle away as lunch break.

Q: He is out there working 14 h a day?

Fig. 1 Mr. S at work

S's mother: Right. He leaves for work at a little after nine in the morning and comes home at a little before eleven at night. We have no choice, so even with such crazy work hours, we have never expressed any dissatisfaction.

Q: What did you mean by "idling away 2 h as lunch break"?

S's mother: For example, we worked 8 h a day with 30 min for lunch. He is given 2 h for lunch which makes his workday 10 h. Of those 2 h, he only spends 20 min eating and the other hour and half he spends sitting there and waiting.

Q: Why is it that way?

S's mother: That way S can work to cover both lunch and dinner at the restaurant. He goes to work at 11 a.m., and when customers come for lunch, he can work till after 1 p.m. He will then clean up before having his own lunch. There are no customers during the time right after S's own lunch, so it's counted as his own lunch break instead of work hour. He just has to kill that time. Then it gets busy around 5 p.m., so he is scheduled to work again till 9 p.m.

So his work hours are extended, aren't they? Even though he takes 2 h' lunch break, he stays out for a long time, so he doesn't have the time to eat properly. Ever since he started working, he has lost a lot of weight. He dropped more than 10 lb from 140 to 120.

Q: What about the other employees? Do they cover only lunch or only dinner?

S's mother: An older employee at the restaurant told me that she works longer hours than S but she gets paid for all hours. Most of them take 1 h for lunch break, and only a few take 1.5 h. Only S is given 2 h for lunch break.

What I don't like is that he is given too much time for lunch break, which overextends his workday. He really just needs 1 h for lunch so that he can clock out 1 h earlier. Coming home 1 h late causes a lot of problems. It deprives him of sleep and it's too late and too dark when he comes home from work. He said, "Mom, I don't feel comfortable taking the shortcut home, because there are no streetlights and I can't see clearly." And I said, "Why don't you take the detour and walk on the bigger streets? You don't want to fall because you can't see clearly." But of course, we can never bring ourselves to request a shorter lunch break for him.

Q: So you have never requested it?

S's mother: Never. When he first started working, sometimes the manager would allow him to take his lunch break 1 h earlier and get back to work 1 h earlier, once a week. But it doesn't happen now.

Q: Are S's co-workers nice to him?

S's mother: Yes, they are all very nice. The older employee I just mentioned watches out for him. She said, "I am a mom myself, and I will naturally take care of kids like him." So I asked her to mentor S. I don't expect her to do his job for him because he will never learn that way. I don't spoil S at all. I just hope that he can live a normal life. We only want him to keep this job and to improve his life as a result. We have no expectations except that he can stay on this job till he retires. That will make us happy. And we also wish that the working conditions could be a little better.

Q: Is the relationship between him and the manager rigid? Or maybe he can handle it?

S's mother: He can't handle it, he can't. Whenever the manager jokes with him like patting him, he will come back and tell me about it saying that the manager has said this or that. He is very sensitive about this. Because he's told me about this quite a few times, I couldn't help but say to the manager, "I probably haven't done a good job educating S. He had a physics teacher who encouraged him a lot." I didn't elaborate. I just said that there was a teacher who used positive education and whether we could follow suit. I just hoped that the manager could give S more acknowledgement. The manager said I was spoiling him, so I couldn't say any more. I guess everyone has his way of doing things and I can't force anyone's hands. I can only ask S to follow instructions, and that's basically my last resort. The manager is unhappy with him and already told him not to talk back (Sobbing non-stop).²

²Several months after the interview, the parents negotiated with the company and S was transferred to another location to work. The company had a talk with the manager about improving his way of working.

Q: How is the pay at Papa John's compared to when he was attached to a workplace?

S's mother: Exactly the same.

Q: You mean minimum pay at both places?

S's mother: Right. At first, he got paid less than when he was attached to a workplace. I had been asking for pay slips from Papa John's but never got any, and I had no idea why. He was paid a little over 1,000 yuan back then, whereas at the workplace where he was attached to, the monthly pay was 1,860 yuan, which is the government-mandated minimum, and he ended up getting paid 2,020 yuan as a matter of fact. But the pay at Papa John's was less than 2,000 yuan, and I didn't know what was going on. I asked S to ask for pay slips from the manager and he never got any, so I gave up.

There's something fishy here, because a workplace has to produce pay slips when asked for them, right? What if there's a labor dispute later on and I need the pay slips for my case? But the restaurant just wouldn't give them to me. We made inquiries afterwards at Papa John's headquarters and were told that the company doesn't send out physical pay slips but everything can be checked online. I have no idea about pay itemization and wonder if it is the same as stipulated under the contract. But it's fine, I don't want to know anymore.

Q: What does the contract say?

S's mother: The contract stipulates the signing of a new contract after S had worked for 6 months. Six months later, there was no new contract for him to sign. Six months earlier, I was told that this job position was paid this much and that job position was paid that much. But after S changed job position, we were never given a new contract to sign. All we have is still the original one.

Q: Have you tried filing a complaint?

S's mother: No, no. I asked around and was told that we should be happy with this job no matter what, because there are hardly any jobs available for people with disabilities. At Papa John's, at least the top management really cares about people with disabilities, and had it not been for that, S would still be unemployed. As for what kind of preferential treatment the company receives in return for hiring people with disabilities, I have no idea and I don't really care. Bottom line is that S has a job now, right? We wanted a job and Papa John's provided the right opportunity, so we should cherish it. There's a lot of room for improvement, but we shouldn't complain.

Dating and Marriage: Let Them Be

Q: Is S in his twenties?

S's mother: Yes, he's 25.

Q: Has he ever dated?

S's mother: He has. A classmate from school dated him. She is healthy without any ID.

Q: Which school?

S's mother: The vocational school. They dated for quite a while, more than 6 months actually. They met at the school. After graduation, she got a job and he didn't, but they went out for quite some time.

Q: What exactly did they do when they were dating?

S's mother: (Laughing) They were young and didn't know what they were doing. Sometimes S would tell me that she's a good girl. I asked if they were dating for real and he said that they were and that he would kiss her goodbye after their dates. I asked whether they had learnt it from watching TV. He is slow when it comes to matters of the heart. It was 4 years ago anyway, and he knew a little about dating but practically nothing about marriage. He would take her to the museum, to catch a movie, to drink coffee and to play with cats. I had the impression that they were happy together.

Q: It sounds very romantic.

S's mother: Right. He even brought her home. But he never went to the girl's place.

Q: Why not?

S's mother: I wouldn't let him. I told him, "When I am not home, you are not allowed to bring any girl home. And you can't for any reason go to the girl's place. If you go and there's no one else home, her parents will be mad when they come home to see you there. You have to remember this."

Q: Did he understand why you said that?

S's mother: He did. Nowadays kids are exposed to so much online and they can understand some of the things. He has some sense even though he doesn't understand everything all the time. Sometimes I would tell him, "I can't really explain this to you in so many words." And he would say, "I get it, I get it," which means that he does have some sense.

Q: Why did they break up then?

S's mother: He said that she was no fun.

Q: He said that?

S's mother: Right, he said that she was no fun and knew nothing. She didn't know how to have fun, so he had to teach her all the time which was no fun for him. One time he said, "If I avoid her and don't do things with her for fun, she might cry. What would I do then?" As he was saying that, he was tearing up himself. I felt at that moment that he does understand certain things. I had never felt that way before, but at least with regards to that matter, he did have some sense. He said, "I will be very upset if she cries, but she is really no fun to be with." He also said, "She is so mean sometimes and yells at me. I hate people who are mean. Say it nicely and I will do it."

Q: So he knows what true love should be like.

S's mother: Right.

Q: Does his intellectual disability get in the way of his finding love?

S's mother: Definitely. For example, when he hangs out with kids without disabilities, things would go well at first, because he expresses himself well. But after a while, the other kids would realize that he doesn't know how to handle things and would then stay away from him. He did hang out with several girls and it's funny

that it would look like they were dating. I asked him how he got the girl to date him so easy, and he said, “She is calling me intimate names already.” But those girls soon stopped hanging out with him, because of his intellectual disability. He has very low EQ and doesn’t know how to handle things.

Q: I just saw his picture. He is very good-looking.

S’s mother: Yeah, he is. (Laughing)

Q: Are you making plans for him to get married?

S’s mother: About that... (hesitating) I actually go back and forth. I want him to get married more than his dad does, because I am very selfish. I hope he will find someone without ID. Even someone with physical disabilities would be preferable. If the girl has a good brain, they can complement each other. There will be someone to manage the family because it wouldn’t work to have two muddled heads in the house. But his dad is of the opinion that people nowadays are just getting married and then divorced, and the two of us would have a tough time if S does the same thing (laughing).

We tell our friends that we neither support nor oppose him getting married. We won’t play matchmaker ourselves. If he finds the right girl, we will support him. Some friend suggested finding a countryside girl whose family has financial hardship and who might be willing to move to Shanghai if the family is paid a certain amount of money, but I am really afraid of this kind of marriage that is so orchestrated. The hypothetical girl has no feelings for S to start with, so how can the two of them live together if she develops negative feelings towards him? What if they start fighting and want a divorce?

Q: But do you still hope he finds a wife to take care of his daily life?

S’s mother: That’s too much to hope for. I would have loved it but it’s too difficult. That’s what’s killing me. I figure that even if he had a short marriage, at least he would have got to experience it. But we are worried that he might marry the wrong person. We wouldn’t exactly call that person a bad person, but why would she marry someone with ID? She must need something in exchange, and I cannot afford to give her what she wants. For example, her parents might say, “My daughter will marry your son, as long as she has co-ownership of their place and can take half of what it’s worth in case of a divorce.” I wouldn’t be able to accept that, so there would be no agreement. Maybe we over think, but we are really bothered by such thoughts. And we feel bad for him because he may never get married.

Q: Do you hope that he will carry on the family name?

S’s mother: No, no.

Q: So you really don’t put too much pressure on him.

S’s mother: Exactly. Everything has to happen by itself, and it would be ideal if the right girl can eventually come along.

Expectations for Society: Practical Help

Q: What kind of expectations do you have of the government for society?

S's mother: I have some personal wishes. A friend of mine has a kid with ID too. They live in Canada where the mom takes care of the kid and the government gives them subsidies. The government even subsidizes housing for families with real financial hardships.

That's probably not going to happen in China. So I just wish that there would be more jobs available for people with disabilities. People like S do things slowly, so fast food restaurants are not the place for them. I just wish there were other jobs. With regards to pay, even though it is supposed to be equal pay for equal labor, the reality is far from that. So I hope that the government can give people like them practical help so that they can have a decent life. S receives minimum pay now which is 2,100 yuan, and that doesn't even cover his personal expenses. If he gets married one day, he just won't have enough money. I hope that the government can step up efforts and provide people like us with real help so that S can be guaranteed at least a basic living. What we have been through is unimaginable for people who have never experienced it. (Sobbing)

As a matter of fact, we will be very grateful if the government just puts in a little bit more effort. We are just invisible and no one cares about us. When we were literally dying out there, no one offered a helping hand. No one. We powered through all on our own, because the only other choice was to die. I know only people with depression will constantly think about death, but both my husband and I suffered depression. (Sobbing uncontrollably) We had our resentment, especially when we couldn't get the help we asked for. This society is so unfair.

Q: Have you been staying at home ever since you retired?

S's mother: No. I work as a volunteer now. I am a community correctional volunteer helping disadvantaged groups. There are people who have committed minor crimes like drug use and fighting in public. They should have been sent to some correctional facility, but there's no such facility now. They need to get back into society, and community correctional centers are there to help them do that, finding jobs for them if they are unemployed and giving them monthly allowances if they have no money. They are people that society cannot give up on.

People like them can become liabilities to society, so we need to help them settle down by telling them, "If you have difficulties, let society know instead of doing harm to society." I like this volunteer job because I can help bring peace of mind to them. On the other hand, I feel even more strongly that society should care about disadvantaged groups like people with ID. They are not as radical as the small-time criminals, but they are in a worse situation. Let me put it this way: if you commit a crime, the Communist Party and the government will try to save you. If your only crime is having ID, the Party and the government won't do anything for you. Now that I have this volunteer job, I see this contrast more clearly and it breaks my heart. (Tearing up and not able to continue.)

Q: Does it help your own state of mind when you mentor those people?

S's mother: It doesn't really help my own state of mind, but I am happy and willing to do my job. Giving is more rewarding than taking. If someone needs to accept help from other people, he must be in pain. Just like S, he is in a lot of pain. Since I can help other people, I see it as my happiness. And I realize that there are people around us, including doctors, teachers and coaches, who helped us when we hit a rough patch. I have met so many good people, so I should give back to society. I hope for a stable society, so I will do my part to stop would-be criminals from doing harm to society.

We visit the jail at Tilanqiao. After every visit, there will be peace in the jail for a month, because the inmates will be calmer and not inclined to fight. I do what I can to help, and there must be people out there who will realize that people with disabilities like S need help, too, and who will do what they can to help. I have very limited abilities—government agencies could do so much more to help if only they'd want to. (Sobbing non-stop)

Q: There will be help. There will definitely be help.

Interview with S's Co-Worker

Interviewee: Mr. C

Interviewer and writer: Buyun Chen

Interview date: December 6, 2016

Interview place: Restaurant where S worked

Q: How's S at work?

C: Him? At work? There's not much to say about that, to be honest.

Q: What does that mean? So-so?

C: He is okay. Other people might have expected more of him. I like him a lot. When I first joined, he was working in the dining area. It turned out not to be the right job for him, so he was moved to the kitchen.

Q: Why wasn't it the right job for him?

C: He sometimes dropped the plates he was serving, you know. In the dining area, every table has a number and I sometimes mix up the numbers myself. For example, someone would write down a table as No. 17 but another person would write down the same table as No. 19. If you didn't take an order yourself, you will never remember which table and sometimes you serve to the wrong table. It gets confusing in the dining area and it's easy to make mistakes. So he might have made a lot of mistakes. With him working in the kitchen, there would be fewer mistakes. Anyway, I like him a lot. I see him every day and I feel happy to have Cute S³ around.

Q: So how is he doing after being moved to the kitchen?

C: He does okay. At least he does whatever you ask him to do. When you ask him to do something, he will never say that he doesn't have time. He will always

³Cute S: Nickname Mr. C has given S.

acknowledge the request. It's a different story, of course, whether he does the job well. But at least he has a positive attitude, so I have no problem with him.

Sometimes he will make something and when it's done, we will realize that an ingredient is missing. When we are not busy, we are okay with that and will just ask him to bake it again. But it's a hassle when we get busy. When we are not busy, we make one thing at a time before packing it. When we are busy, seven or eight items would be ready at the same time. The person packing them already has a hard time telling which is which and will find it overwhelming if something is missing. So to have S work on weekends is probably not ideal. Even employees without disabilities find it challenging to work on weekends, let alone S. But of course we need to be considerate. He is an employee being cared for, after all, and we shouldn't expect too much of him. If he can get something done, great. If not, we will just help him out when we have the time.

From Monday through Friday, he does a good job. Sometimes I will work in the kitchen. Because I don't work there often, I have to consult him. He has good rote memory which I really admire him for. He has memorized all the materials we have for making pizza dough. The manager once asked him to memorize ingredients for the appetizers we were launching. It's not easy. There are different quantities required for different ingredients. Sometimes seven are needed and sometimes eight are needed, and all those numbers are arbitrary. He remembered them all while I found it impossible. There are more than a dozen platters and I have a headache trying to memorize them. And it's so weird sometimes. For the same platter with the same name, the ingredients are different for dine-in and takeout orders. I would get everything mixed up whereas he would memorize everything.

Q: What are the work processes for S?

C: We will take orders in the dining area and the orders will show up on the computer in the kitchen. He will just make food according to the orders, whether they are takeout or dine-in. He mainly makes appetizers. He hasn't been in the kitchen that long, only about 6 months.

Q: How does he get along with the co-workers?

C: Speaking for myself, I like him a lot. I feel happy seeing him every day. I often joke with him and he is okay with that, and we just mess around with each other.

But he is an employee being cared for, after all. When he communicates verbally, his mind may not be able to follow. For example, we will be talking and he will wander off in his mind. His thoughts would be all over the place and he'll say something totally unrelated. The rest of us won't know how to continue and everyone will end up staring at him. It's not that we try to avoid talking to him. We do talk to him, but when he talks without sequence, we won't know what to say. But he's really nice. I see him working in the kitchen and smiling at me, and he is good-looking, so every day is a fun day for me. I like people smiling because it's preferable to coming to work with a frown.

Q: How is S's personality?

C: How should I put it? I personally think he is a little depressed. Sometimes he will come to talk to me but will run out of things to say after a while. I do believe he is a little depressed because after all, there are not many people who understand

him. Even though we are not prejudiced against him, he may not feel so good about himself. He never talks about going out for fun anywhere, so I fear that he is suffering in silence which is not good for him.

Q: Does he have a good temperament?

C: Look at how cute he is. Can you imagine him throwing tantrums? He has no temper. I have never seen him get mad. Sometimes I would say, "Had it been me with my personality, I would have raised hell." He really has such a nice personality. When people get mad at him, he won't talk back. That's when I feel his depression. Other times I think he's okay. It's actually quite depressing working in this restaurant. Look at what happened today—when the manager was around, he didn't utter a single sound. Once the manager was gone, he came alive.

Q: Does he not get along with the manager?

C: It's not exactly that. The manager has a huge responsibility. S is an employee being cared for, after all, and the chances of him making mistakes are very high, and the manager is held liable for those mistakes. And the manager we have now is still on trial period and not official yet. Every time mistakes are made, his official appointment will be pushed back. In that sense, an employee being cared for is a huge burden on him, so he is very tough with the employees being cared for. We don't mind it as much. On weekdays, we kill time here at work, but on weekends we just go full throttle. Sometimes I will bring S with me for deliveries just to get away for however long we can. Things are okay except when there's any run-ins with the manager.

Q: Does the manager give him a telling off?

C: Getting told off is all in a day's work. Some older co-workers will also get mad at him—even I have a word or two for him sometimes. For example, when it comes to playing on the phone, it's normal to do it and we do it too when we have nothing else occupying us. But you shouldn't play when we are crazy busy during dining hours. Sometimes he will have no order for appetizers while we are overwhelmed, and we will be mad seeing him playing on his phone. If the manager sees that, it would be much worse.

Q: What would happen?

C: He would have a talk with S. I can't reveal the details, but I am sure you can imagine for yourself. (Laughing)

Q: What goes through your mind when the manager is having a talk with S?

C: I don't over think. You have never worked in the kitchen of a restaurant and have no idea how hectic it can be back there. If I take an order for something that's very complicated to make, those in the kitchen will yell at me.

Sometimes I wanted to take him out and asked him if he wanted to come with me. He said he did, but the manager wouldn't give him time off. Other employees can get time off, but he can't.

Interview with Mr. S

Interviewee: Mr. S

Interviewer and writer: Buyun Chen

Interview date: December 6, 2016

Interview place: Restaurant where S worked

Childhood

Q: Let's start with your childhood. Do you remember doing physical therapy when you were young?

S: I don't remember as clearly now. Just that it wasn't pleasant.

Q: It's okay. How much can you recall?

S: I remember only a little. I was crying and refusing to go to the enhanced external counterpulsation, and my dad had to drag me there.

Q: Was it very uncomfortable doing that?

S: Yeah. You had to be tied up for it, and being tied up was uncomfortable.

Q: How long did you have to stay tied up?

S: Either 15 or 20 min. I can't recall. It's been so long.

Q: It's okay, you survived it. Do you remember anything about elementary school? Was the curriculum difficult?

S: I was doing very well in elementary school for a while. When I was in fourth grade, my grades were among the top 20 in the class. Then my grades just started dropping, I don't know why. (Laughing)

Q: Did you have to study really hard?

S: Yeah.

Q: Were your parents with you when you studied at home?

S: They were.

Q: Do you remember how late you had to stay up to study at home?

S: Pretty late. After homework, I had to do some extra questions.

Q: How did you get along with your classmates back then?

S: I got along well with some and didn't get along at all with others. There's someone from elementary school I hang out with even now, which means we have been friends for more than 10 years. His dad was my mom's co-worker, so the two of us have always been close. At elementary school... something happened, do you want to know what it was?

Q: Sure!

S: It was when I was in sixth grade, right before graduation. My dad had back problems and was resting at home after surgery. He fell off the bed one day when I was at school. My mom took him to the hospital and forgot about me and didn't realize I was still at school. I had no choice but to spend the night with the friend I

just told you about. It wasn't until the next morning that my mom thought about me and she had such a bad scare. (Laughing)

Q: Were you very scared?

S: I was. But I knew that classmate well and often went to eat at his place. My parents knew that, maybe that's why they didn't pick me up from school that day.

Q: Did you normally wait for your parents to pick you up after school?

S: Not after fourth grade. Our elementary school was across the street from home, so I just needed to walk one block to get home.

Q: So you went home by yourself?

S: Yeah. My mom would take time off in the afternoon to come home. Because I got out of school early, my mom was allowed to leave work at probably 3 p.m. so that I wouldn't need to bring a house key with me.

Q: So on that day, you got home, knocked on the door and no one answered.

S: Right.

Q: Then you went looking for your classmate.

S: Yeah.

Q: Did he live close to you?

S: One block away too. He lived right next to school.

Q: That's nice. Where is he now?

S: He works for the design department of a game company. The company is a Japanese one with a subsidiary in Shanghai. He makes more than 4,000 yuan a month.

Middle School

Q: Was the curriculum difficult for you in middle school?

S: A little. I could manage eighth grade, but ninth grade was too much for me, and I failed the entrance exam to high school. When I was in ninth grade, my grandpa got sick, so my parents had no time for me.

Q: What about the teachers?

S: The teacher who was nicest to me was the homeroom teacher in middle school. He's in poor health now and I can't find time to visit him. He is a middle school principal now.

Q: What did he do to make you feel that he was the nicest teacher?

S: He tutored me for free.

Q: Oh, what did he teach?

S: He taught math, so in the class, in chemistry, math, and physics, I was basically...

Q: Among the top ones?

S: Among the top ones. But I was lagging behind in Chinese and English. I didn't know how to write essays in Chinese, and I was just naturally not smart in English. I couldn't remember the words and always forgot them.

Q: What time did he use to tutor you?

S: After class hours. In ninth grade, we had to prepare for the high school entrance exam and got really busy. We all wanted to get into a good high school, so we would stay back voluntarily to be tutored. We would stay at school till 6 or even 7 p.m. sometimes, and we still had a lot of homework to do once we got home. I actually did pretty well in physics and chemistry on the high school entrance exam, but my Chinese and English dragged the overall score down.

Q: Do you remember your score?

S: I was short by... about 60 points, otherwise I could have got into a high school. My parents had no time for me, so I played like crazy, and I regretted it later. (Laughing)

Q: What did you play? Like hanging out with classmates?

S: I hung out with classmates and we played basketball and did things like that.

Q: Oh, you like playing basketball?

S: Or we would play games at a classmate's place. If I had tried harder, I could have got into a regular high school. I really regret wasting more than 3 months just playing.

Vocational School

Q: It's a good choice to go to a vocational school to acquire a skill set. I heard from your mom that you went to a culinary school?

S: I went to the culinary class at Baoshan Vocational School. There are many majors besides cooking at the school.

Q: I see. Why did you want to learn cooking?

S: ...

Q: Did you pick it yourself?

S: My mom picked it for me. I initially wanted to study computer science.

Q: Why did you want to study computer science?

S: Computer science would have been a little easier. I am pretty fast at typing on the computer.

Q: But you were okay learning cooking?

S: I didn't like it that much.

Q: Why not?

S: Because I was the worst in the class in chopping and stovetop cooking.

Q: I see. What exactly did you learn in the culinary class?

S: Chopping, for example. We chopped potatoes and ginger every day.

Q: Was it like that every day?

S: Yeah. We also stir fried on the stovetop. We had to prepare our own ingredients and chop them ourselves; the teachers wouldn't do that for us, which means...

Q: Oh, you had to chop the ingredients before you could use them.

S: Right, right.

Q: What else did you learn?

S: We also learnt making dim sum.

Q: What kind of dim sum?

S: Chinese dim sum, like steamed buns and pancakes.

Q: Did the teacher show you what to do in person?

S: There was only one demonstration. If you got it, you got it. If you didn't, then you didn't and it was too bad for you.

Q: Which subject do you think you did best at?

S: ...

Q: I mean, was there a subject that you really liked and that was easier to learn?

S: Making food with dough was easier to learn.

Q: You mean making bread and dim sum?

S: Making steamed buns and that, like I just mentioned.

Q: Do you also make dim sum at the restaurant now?

S: Here... not here. Here we make Western food including desserts, and I don't work in desserts.

Q: I see. How long were you in that culinary class?

S: Two and a half years, and the last 6 months were for internships.

Q: Where did you do the internships?

S: I didn't qualify for any restaurant internships, so I spent a year interning at a factory in Shanghai, working at the front desk and doing clerical work.

Q: What clerical work, like answering the phone?

S: No. I interned at the recreational center of the factory which was open only to employees. So I was in charge of swiping cards and making keys, and if people came over for swimming, I would tell them which lockers to use.

Q: So you mean you helped people store personal belongings.

S: Right, right. I gave people who came to swim keys with the number of the locker printed on them.

Q: So the job was relatively easy?

S: Yeah. But those who got to stay later had connections. I had no connections. But I was pretty happy working there.

Q: How did you get along with your co-workers?

S: We got along well because we were from the same school. I had two classmates who were later hired by that factory.

Q: You mean there were a number of your classmates who interned at that same factory?

S: Just two or three, because the best were grabbed by five-star places like Baolong and Marriott. The top four students.

Q: They were hired as chefs by those places?

S: Yeah, as chefs. One of them is getting married on January 1. He is the main chef in the bakery.

Q: Oh. Are you still in contact with your classmates?

S: Yes.

Q: Do you use WeChat or call them?

S: QQ.

Q: Do you often chat with them on QQ?

S: I do. I really envy those four, because they make so much money.

Q: You don't have to. You are doing very well yourself.

S: I am really good-tempered and very obedient. But the classmates at the vocational school were not very nice.

Q: How so?

S: They bullied me sometimes.

Q: Like how?

S: They asked me for money and hit me if I wouldn't give them any.

Q: Gosh. So what did you do when you were bullied?

S: I either told the teacher or I put up with it.

Q: Did you fight back when you were hit?

(S shaking his head.)

Q: Was it because you didn't want to or because your upbringing stopped you from fighting back?

S: I didn't want to. My closest friends all call me "Kitty", because I am as good-tempered as a kitten.

Q: Why were you unwilling to fight back?

S: I didn't want to make it worse for myself.

Q: Would you tell your parents about it?

S: I would.

Q: And what did they do?

S: They would call the teacher and the teacher would warn those classmates.

Q: Were you bullied often?

S: Quite often over those 3 years.

Employment with Papa John's

Q: When did you start working here?

S: Last year... After Chinese New Year last year, in early spring in March.

Q: Do you commute by public transportation?

S: I do.

Q: From Baoshan?

S: Yeah, it's a little far.

Q: Do you take the bus?

S: Yeah. I walk 15 min from home to the terminal and the bus ride takes more than 40 min.

Q: Oh... so you spend more than 1 h commuting every day.

S: Right, more than 2 h both ways.

Q: When do you have to leave for work every day?

S: Nine thirty. I usually get here at 10:45 but I am late sometimes.

Q: When do you get home at night?

S: I get home... it depends. On a good day, I get home at 10:10.

Q: What makes a bad day?

S: When there's traffic on the outer highway ring.

Q: So it mainly depends on traffic?

S: Right. Sometimes the bus doesn't run on time, then I will get home late.

Q: When do you usually get off work?

S: Nine at night.

Q: Nine at night is a fixed time?

S: Right, fixed time. Previously when we had another manager, I sometimes worked the evening shift in the dining area and the hours were longer.

Q: When did the evening shift end?

S: Ten at night.

Q: Oh. What do you normally do at work?

S: I work in appetizers. I make appetizers like chicken wings and spaghetti for the customers.

Q: How do you make appetizers?

S: Umm...

Q: For example, how do you make spaghetti?

S: Our spaghetti is put in boxes before being placed among the appetizers, and every box is pre-weighed. I would just take a pack of spaghetti, empty it into a bowl with the sauce, put it in microwave on high for 1 min and 20 s, take it out and stir it.

Q: Oh. Did you find it hard learning to make appetizers?

S: Because... how should I put it? I often stuff up the ingredients.

Q: For example?

S: For example, I might misread the orders and mix up the tables.

Q: Do you panic when that happens?

S: At first I did. But now, if that happens, I will just make another order.

Q: What will the manager do when that happens?

S: The manager will get mad.

Q: Is the manager normally strict?

S: Quite strict. Sometimes if I am slow or make mistakes, he will get impatient and say, "Hurry up, you need to hurry up." Sometimes there are too many orders and I can't read everything clearly and will bake the wrong food. The manager helps sometimes. When it gets too busy, he will help with distributing appetizers in the dining area.

Q: Have you thought about whether to stay long-term or to get a new job?

S: I don't know. I'm not sure.

Q: Right, it's better to live in the present.

(S getting up to get his own drink.)

Q: What's that?

S: Rose petal tea.

Q: Did you bring it from home in the morning?

S: I did.

Q: Did your mom make it for you?

S: I put in the tea myself.

Q: Oh. Do you bring food from home in the morning?

S: I do, I bring lunch. We don't get lunch here.

Q: When do you normally get busy here?

S: How should I put it... we get busy for lunch and dinner.

Q: So part of your job is to have everything set up before lunch, right?

S: I normally don't do the setup. Someone else will have had everything laid out by the time I start working at 11 a.m.

Q: How do you set up?

S: Laying out ingredients on the counters. There's a lot involved, and I don't understand it all.

Q: So what do you do first once you get here?

S: I clean up and replenish ingredients if they are running low.

Q: Is this restaurant open only for lunch and dinner?

S: It's open all day long, unlike some other restaurants.

Q: But it gets busier during lunch and dinner hours?

S: It depends. Like today, we got a little busy with dine-in which doesn't happen often.

Q: When do you take a lunch break?

S: Between three and five.

Q: What do you do during that time?

S: I have lunch and take a nap.

Q: There's no work during those hours?

S: No.

Q: Oh. How many days a week do you work here?

S: I work 5 days and take 2 days off. I normally have Tuesday and Thursday off. For this week, because you had planned to come on Tuesday, I took Monday off instead.

Q: What do you do on your 2 days off every week?

S: I chat with girls and shop online for clothes I like. If some girl asks me out, I will go out.

Budding Love

Q: Do girls often ask you out?

S: *Doctor Strange* was playing in theaters and I went to watch it with my girlfriend.

Q: That's nice. When did you start dating?

S: We have been dating for more than a year. She is leaving and she said she would introduce a girl to me before she leaves, which she did. That girl is really nice to me. Both girls are and I went out with the two of them yesterday.

Q: You just said that your girlfriend is leaving. Where is she going?

S: She is going to Japan. She is a Chinese-Japanese mix, with a Japanese mom. She had a very good upbringing.

Q: Is she moving back to Japan?

S: To go to school and to live there permanently.

Q: And she said she would introduce a new girlfriend to you?

S: Right. I met that girl yesterday.

Q: How do you feel?

S: Since we have been together for more than a year, we know what each other thinks. She knows that I am a very mild person, so the girl she introduced to me is unsophisticated.

Q: So you mean you like this new girl?

(S nodding.)

Q: Are you sad about parting ways with the girl you have been dating for more than a year?

S: A little sad. She said that when I visit Japan in the future, she will be my tour guide and that I have to remember to pay her for her services. (Laughing)

Q: Do you think you can handle a new girl becoming your girlfriend so soon?

S: It will take me at least a year to accept her. I mean we will just go out for now. If our personalities don't match, we will just break it off which won't hurt anyone.

Q: Right. Was that your first relationship?

(S nodding.)

Q: Oh. Where did you two usually go?

S: We would go shopping. I would look for clothes for myself and she would look for her own clothes.

Q: Did you tell your mom about you and her?

S: My mom knows, about both girls.

Q: Oh. Is she supportive?

S: She is okay as long as the girl has a good personality. The truth is that neither of the two girls have striking looks, but they both have such pleasant personalities.

Q: What kind of girl do you like?

S: Mild and willing to do things.

Q: Did the girlfriend help you in daily life?

(S nodding.)

Q: For example?

S: There was a time when I felt like quitting my job and I would spend time with her.

Q: To talk to her?

S: Right. You know what my girlfriend liked to do most? We would go to exhibitions, and when she got tired, she would sleep in my arms, which was really sweet.

Q: That's nice. So you found it sweet?

S: (Nodding) That's what made me happiest.

Q: How did you feel when she was in your arms?

S: It was very heart-warming as I realized that there's this girl who was really giving towards me and never doubted anything about me.

Q: Have you thought about having a family later on?

(S nodding.)

Q: What do you imagine the family to be like?

(S remaining silent.)

Interests and Friendships

Q: You must have a lot of good friends.

S: I do, because I like music, anime exhibitions, and opera. That means that I surround myself with good people.

Q: When did you start liking music and opera?

S: I was still young and watched *Phantom of the Opera* for the first time. Ever since then, I have been in love with classic opera, music, and orchestra. My two favorite musicians are both geniuses, Mozart and Mendelssohn.

Q: For classical music, do you buy CDs?

S: I have CDs. I also have it on my phone.

Q: So you like Japanese anime and go to anime exhibitions?

S: Right.

Q: What do you usually watch?

S: I usually watch the aesthetic kind with tragic endings. (Pausing as if pondering over something) You know my friends nicknamed me “Missy.”

Q: Why?

S: Because I am very mild, I speak with sincerity, my voice is very soft and soothing, and I like afternoon tea. I am like a young lady of noble blood. That’s why all my friends like me. I just have such a good temper, so much so that no one can ever get mad at me.

Q: Right. How come you have such a good temper?

S: ...

Q: So you never get mad?

S: (Shaking his head) That’s why I got this nickname. I made a lot of friends at an anime exhibition and that’s where the nickname was given.

Q: Oh. Are you often in contact with friends you made at anime exhibitions?

S: Yup.

Q: Do you go out with them?

S: I am not a homebody. The day after tomorrow, which is Thursday, they are going to afternoon tea and I said I would join them.

Q: Where do you usually go for afternoon tea?

S: They said they would go to a fancy place. I said they are setting me up because I just got paid but my pay doesn’t really cover my expenses. (Laughing)

Q: (Laughing) Will you pay for them?

S: We go Dutch. That’s the best way and no one will argue because it’s fair to everyone. Whenever we eat out and go to karaoke after an anime exhibition, we go Dutch. No one wants to leave after exhibitions, so a dozen of us who are closest will stay to sing and eat out.

Q: You seem to have a lot of activities.

S: Right. There’s another reason they call me “Missy,” because I often go to anime exhibitions in female costumes.

Q: Oh, you mean cosplay?⁴

⁴Cosplay: Role-playing. Fans of Japanese anime dress as roles they like at anime exhibitions.

(S nodding.)

Q: And you are often in female cos?⁵

S: Right. I am in male cos too but not as often.

Q: Why do you prefer female cos?

S: Because of my personality, which is too mild. And because of my voice. No one can tell whether it's male or female.

Q: Who applies makeup for you for the cosplay?

S: I always use the same makeup person.

Q: Oh. How did you meet this person?

S: We met at an anime exhibition. When I went to the anime exhibition for the first time, I let it be known that I was looking for a makeup person. The first one I got was new at it and ruined my makeup. Then my friend recommended the current one who is a girl. I couldn't take time off for the latest anime exhibition, so I didn't go. It was held on December 3, which was just several days ago.

Q: Interesting.

S: You know what? Several of my friends and I made a plan to spend New Year's Eve together and each of us will bring our girlfriend or boyfriend. What I mean is that we won't go home for the night. My mom has said that's okay. We won't go home till 3 p.m. on New Year's Day.

Q: Wow. So you will bring your girlfriend too?

S: Right. But my mom made me promise not to cross the line. (Laughing)

Q: (Laughing). Do you know what your mom meant?

S: Of course I do. (Laughing) Next time I will arrive earlier to help them cook.

Q: Oh right, you are the chef.

S: Just to lend a hand with the girls. Our chief said he will cook himself and I said I would help.

Q: That sounds great. Who is this chief?

S: He is the head of the anime association. He isn't someone you would want to mess with, because he is the national karate champion and champion of the college karate tournament. We sometimes put on commercial performances and get paid for them. So he will organize those performances and everyone gets a cut of the pay. We all have a great time. I don't have time to go. They have organized quite a few performances and the latest one was in Wuhan back in October. He said he was exhausted but he made a lot of money, more than 7,000 yuan over 2 days. This is actually his day job now.

Q: So what kind of organization is your anime association?

S: ...

Q: Did you meet at an anime exhibition and decide to establish the association?

S: Right, we all met at this or that anime exhibition. Sometimes we would go eat out together. Sometimes after an anime exhibition, seven or eight key members of the association would go out to eat and discuss work.

Q: Oh, what kind of work?

⁵Cos: Short for "cosplay."

S: Our work is the commercial performances. For example, someone can get paid 100 yuan a day to perform at an anime exhibition.

Q: Do you take this kind of work?

S: I am busy at the restaurant so I can't. If I was less busy, I would definitely have taken such work. It's easy and fun.

Observation of S at Work

Observation date: 10:30–21:00, December 6, 2016

Observation place: Restaurant where S worked

Observer and writer: Buyun Chen

Note: S worked in the kitchen of Papa John's Gongkang Store. The kitchen comprises three sections: the drink counter where drinks are made, the dough section where all the dough for baking is made, and the appetizer section where appetizers like baked chicken wings and spaghetti are made. S worked exclusively in the appetizer section and his main job was to make appetizers following orders taken in the dining area and printed at the appetizer counter, and to deliver them to the service window. Occasionally he would do some organization and cleaning. His work hours were 11:00–21:00 for 5 days a week. He normally takes Tuesday and Thursday off, but for this week, in order to make himself available for the observation, he took Monday off instead of Tuesday. He worked during both lunch and dinner hours, and took his lunch break between 15:00 and 17:00. S was later transferred out of this store and started working in the Jiangwan Store in January 2017.

Time	What S did	Remarks
10:42	Arrived at the store	
10:50	Changed into work clothes and made himself presentable	Work clothes included light green long-sleeved shirt, long brown pants, white apron with logo, and white cap with logo
10:56	Went to the kitchen and washed hands	Went to the farthest sink in the kitchen to wash hands. Got ready for work after washing hands
11:00	Punched card for work	
11:02	Checked and replenished ingredients	Checked level of contents in the ingredient boxes. Took new ingredients from the freezer, cut the bags open and poured the ingredients into matching boxes. Used a mop to clean up sauce spilled onto the counter or stuck to the box lids, and put the mop and scissors back

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Time	What S did	Remarks
11:20–12:04	Was busy reading orders and making appetizers	Made appetizers following orders printed at the appetizer counter, cut and placed the appetizers on platters, and delivered the platters to the service window
12:06	Mopped floor in the kitchen	
12:13	Washed hands	
12:15–13:20	Was busy reading orders and making appetizers	
13:30–14:00	Checked and replenished ingredients	
14:10	Washed hands	
14:15–14:45	Wiped down the ingredients counter	There were hardly any customers and no work to do
15:00	Punched card for lunch break	
15:00–15:50	Interviewed with the observer	
15:50–16:20	Ate the lunch brought from home	S's mom had made his lunch in the morning and packed it in a lunch box for S to bring to work. Today's lunch included white rice, chicken soup, and mushrooms
16:30–17:00	Rested	Checked his phone and closed eyes for a rest
17:00	Punched card to return to work	
17:02	Washed hand	
17:05–17:23	Checked and replenished ingredients	
17:25	Washed pans and bowls	
17:36–18:30	Was busy reading orders and making appetizers	Made a chicken wing platter: took out a number of chicken wings from the freezer, sprinkled spices, put them in the oven, took them out after a number of minutes, arranged them on a wooden platter in a concentric flower pattern, and attached a plate of dipping sauce
18:32	Washed hands	
18:35	Mopped floor in the kitchen	
18:42	Cleaned up tables in the dining area	After the customers had left, S brought used silverware back to the kitchen to hand over to the lady washing dishes. He was skillful at this
18:59	Wiped the partition boards	
19:12	Wiped nets, put away ingredient boards, and wiped down the counter	

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Time	What S did	Remarks
19:20	Used phone to order takeout	
19:25–19:50	Cleaned up in the kitchen	Wiped down counters at a leisurely pace
19:51	Ate his takeout	A dessert (mango with black sticky rice)
20:00	Went to the dining area	Took off cap and apron
20:04–20:15	Collected trash	Poured trash in small bins placed all over the dining area into a big bin, and took the trash in the big bin to outside the store
20:17	Returned to the kitchen to mop the floor	
20:20	Washed hands	
20:22–20:56	Shut down for the day	Worked with the manager on duty to clean up ingredients and put them back in the freezer
21:00	Punched out	
21:02	Changed into own clothes	
21:07	Left the store	

*Translated by Cissy Zhao**Edited by Andy Boreham and Zijian Chen*

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