

Autism in China

parents with autistic kids struggle for help

T014 Social Responsibility

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When Ms. Chen's daughter was diagnosed as having autism 14 years ago, Ms. Chen's life took a sudden turn: The submarine engineer decided to commit herself to helping children and parents who struggle to fight autism. At age 30, she started the first autism treatment center in the affluent city of Southern China's Hangzhou.

Looking back, the engineer turned the education professional, Ms. Chen said she simply had no other choice because of the limited resources for autistic people in Hangzhou. "I was anxious and searched Hangzhou all around but could not find any suitable school or training center for her."

Mainly for her daughter, in 2003, Ms. Ma sold her apartment and founded Hangzhou Carnation Children's Autism Treatment Center in Hangzhou. Now, there are now 60 autistic children like Miaomiao and 30 teachers in the center.

Ms. Ma's daughter Miaomiao He, 16, was first diagnosed as having autism in 2002. "Children usually start to communicate with people around them by words and sentences around two years old, but Miaomiao showed no attempt to communication," said Ms. Ma.

Miaomiao is one of the most fortunate autistic children whose families can afford the high medical costs for treating autism in China. Currently, there are over 2 million autistic children in China, but many of them lack financial means and don't receive professional treatments, according to a report on the Development of Autism Children in China published in 2014.



Ms. Ma was talking to her autistic child, Miaomiao. Photo provided by Chen Ma.

The Scarcity of Resources for Autism

According to Beijing Disabled Person’s Federation, 1.53% of children under 14 years old in Beijing have Autism, while another estimate by the U.S. Centers for Disease Control and Prevention shows the number could be as high as 6.54%.

“After diagnosis, many parents don’t know where to get professional help,” Ms. Ma said. “Although there are some resources on the internet, many of them are usually misleading.” Because the credentials of the training centers differ greatly, parents often have little idea about which center suits their children most.

For many parents with autistic children in China, it is common for them to travel long distance just to find suitable treatments that are not available in their home cities. “We go to Jinan regularly for the remedy of sleeping disorder. There is no such remedy for autistics in Hangzhou, so we have to travel from Southern China to the North,” said Ms. Ma on the train from Hangzhou to Jinan, a city in Northern China, with Miaomiao on July 31, 2016.

Ms. Ma said high costs can also be a burden for parents. “Every year we recruit about 10 teachers. However, after two or three years of training, only two or three teachers choose to stay.” said Ms. Ma. The salary of one teacher in the treatment center

per month is between 3000 to 4000 yuan, which is far below the average monthly salary of 4,831 yuan in Hangzhou.

Private treatment centers face the paradox between using high salaries to attract qualified professionals and keeping the tuition at a relatively low level. While a higher salary may keep the center's staff stay for longer periods, Ms. Ma said increasing operating costs will add to the already high education costs and discourage parents from getting professional help for their children.

“Even if they can gain access to an education center, it sometimes means that they have to wait two or three years before receiving the training due to the lack of qualified teacher and resources,” Ms. Ma said. As there are only four universities and vocational colleges have the major in special education, training centers often face the difficulty of recruiting qualified professionals.

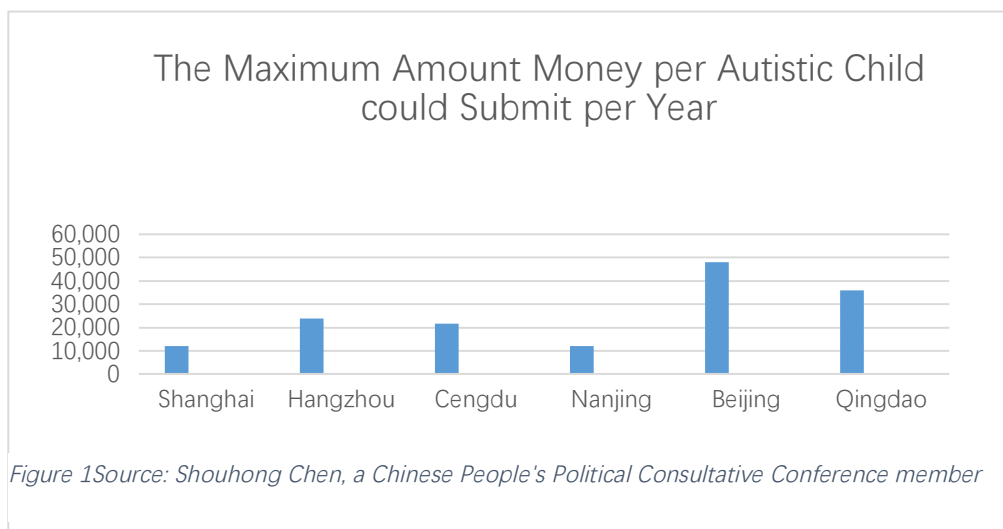
On the other hand, the public school system does not support the autistic children. Nearly 90% of the autistic children at preschool age could not receive proper treatment, according to China National Radio.

On April 6, 2016, the first public school that recruits autistic children in Guangzhou began to enroll students. However, it could only enroll 17 students for the first grade, while there are as many as 100,000 autistic children in Guangzhou. In order to get their children enrolled, some parents had to wait outside the school for three days, according to Yangcheng Evening News.

“Such scarcity of resources seriously affects the therapy's effect,” said Guoling Zhou, a doctor specialized in treating autism at Hangzhou No.7 Hospital, “The earlier the child starts to receive treatments, the better he or she would recover.”

Government and non-profit organizations: How helpful are they?

“Concerning the nature of autism, I am not optimistic about the future for autistics,” said Mr. Zhou. As autism is a genetic disease, there is no cure for it. “Our remedy now is specific to the symptoms but not to the root of the disease. This is why many cases take progression so slowly and parents can hardly insist to take treatment more than three or four years, both economically and psychologically,” Mr. Zhou said.



In Hangzhou, the Federation of Disabled Persons can cover up to medical costs of 24,000 yuan per year for families with autistic children. However, parents in Hangzhou still face significant financial burdens, as typical annual medical costs in a non-profit organization are often more than 50,000 yuan. Notably, not all cities in China have similar policies as Hangzhou, and many of them do not have any official subsidies for families with autistic children.

Many families also face the difficulty of balancing between time commitments for taking care of the autistic children and full-time jobs. In order to look after their children, some parents have to quit their full-time jobs to accompany their children's needs.

In the meantime, with the increasing attention paid to Autism, volunteer work like “Give the Mothers of Autistic Children a Spare Sunday” becomes more and more popular. However, as most of the volunteer lacks understandings of autistic children's need and cannot provide lasting and professional help, many of volunteers soon lose their interest in this kind of work.

The high turnover rate of volunteers makes it hard for volunteers to build trust among autistic children, because these children often need longer term time commitment from the volunteers, according to a research done by Professor Wang Wizen from Hangzhou Normal University in 2015.

It is hard for the autistic children to well communicate with someone whom, they think, “intrudes” their lives. Volunteers are often not effectively operating their work to help the teachers. They are easily disappointed.

“Although we visit the treatment center more than ten times, most of our group members are not familiar with how to communicate with those children,” said Mingchen Sun, one volunteer from the Attached High School of Nankai University.

The Future of Autistics and the Possible Solutions

Is inclusive education possible?

The answer is yes.

According to Report on the Development of Autism Children in China published in 2014, 95% of the disabled children from 6 to 21 years old attended normal schools. By contrast, there are only 10.43% of the autistic children in China could attend normal schools in the same year.

Miaomiao was rejected by primary schools, so she has to stay with the training center. Although more and more people get to know the concept of Autism, the society still don't have a healthy environment to provide sufficient tolerance for autistic children to blend into the mainstream society,” Ms. Miao said.

In the United States. Chamberlain and Harrick's research shows that most of the school faculty and students possess positive attitudes toward the autistic children and successfully build warm relationships with them.

In France, education concerning autism has been carried out for more than ten years. Every autistic children study in both treatment centers and normal schools, and their curriculum are personalized to suit their needs. The government has also financed over 500 education institutions for autistic children and 800 welfare institutions for autistic adults.

While in the U.S. and France inclusive education is widely implemented, autistic children in China are mostly prevented from taking classes with other students. “Although 9-year compulsory education is free to every Chinese child, autistic children are always rejected by the public schools,” Ms. Ma said. This makes it harder for these autistic children to feel inclusive in the society and to improve their communication abilities through day-to-day interactions with other children.

“Miaomiao is a typical type of autistic child — it’s hard to recognize her progress day by day. But thanks to my persistence, she now can communicate with strangers, do chores and control her mood.” The latest picture in Ms. Ma’s Moment in WeChat, a popular social media platform in China, shows Miaomiao smiles in front of the camera. “When she noticed that I was taking photos of her, she smiled at me and tried to make poses.”

Ms. Ma said her biggest hope is Miaomiao can take good care of herself. “As parents of autistics, we all share the same anxiety – what our children's lives will be like after we die.”