

Supporting special needs children Hands on help



By Greg Tantala

In June, Han Qunfeng, 37, was sentenced to five years imprisonment for the murder of her twin sons. In December last year Han gave her sons water laced with sleeping pills and drowned them in a bathtub before attempting to take her own life. As her sons were diagnosed with cerebral palsy, Han was given a lenient sentence because she had "an extremely complicated family background and motive," Dongguan City No.1 People's Court in Guangdong Province said. According to Han's husband, the family had exhausted all its finances on the twin's treatment.

"The mother lost confidence. As her sons grew, it became more difficult to care for them. She looked so hard for a cure, but her sons had a serious condition. She had no economic support and could not work. She needed more support. She needed psychological support," said Gao Yali, the founder of Shanghai Bo Ai Children's Rehabilitation Center, a non-profit organization that offers therapy and treatment for children with neurological disorders. For a parent like

Xuan Yongming, Bo Ai has been a godsend. Xuan Yongming's son, Xuan Yukai is 21. When Xuan Yukai was 5 months old, his parents noticed he was not developing normally and at 11 months old he was diagnosed with cerebral palsy. According to Xuan Yongming, fluid in his wife's womb became infected and Yukai

was born premature. His wife was 33 at the time. When Xuan first found out about his son's condition he felt like he was "struck by lightning." Immediately he looked for different forms of treatment. He took his son to a doctor at first and kept thinking to himself that the condition was not so serious and if he was treated, everything would be fine. After his son was 1 year old he realized that this would not be the case.

It is easy to see that Xuan Yongming is immensely proud of his son and the progress he has made at Bo Ai, where he has been receiving treatment since age 5. "He has an amazing memory," he said. His son can use a computer and has many interests including following the soccer team Manchester United, reading about cars and history and attending concerts. "When he was younger I would carry him everywhere. I've climbed mountains and the Great Wall with him," said Xuan Yongming, who added that he and his son have a very close relationship. They talk to each other like friends, telling each other secrets and sharing jokes.

First in Shanghai

Gao Yali is no stranger to cerebral palsy, an umbrella term that describes disorders or groups of disorders in the brain and nervous system that affect movement, learning, hearing, seeing and thinking. Gao's own son, who is now 21, was diagnosed with cerebral palsy when he was 10 months old. "At that time I had no idea how to treat the condition," said Gao.

As Gao had no training and no one told her what to do at home, Gao saw little progress in her son. "I wanted him to get better, but all I did was massage him. I didn't know he needed movement. No one told me. I saw a news report on an acupuncture specialist in North-east China, so I took a train there. I

was there for four months but saw no change in my son. Then I heard about a children's welfare organization in Nanjing. Two months later I went to Nanjing. It was the first time I saw a doctor do movement. I learned a lot and stayed there for five months. But then I had to go back to work in Shanghai, where there was no center for me to send him to. I tried to enroll him in a kindergarten but was rejected. I even offered to pay extra and have a full-time *ayi* there to take care of him, but I was still refused. So I had no choice but to start a center."

Nestled in a compound in the former French Concession, Bo Ai is the first center of its kind in Shanghai and depends almost entirely on donations. The center, which opened in 1996, also helps children with other disorders such as Down syndrome and autism. It employs 24 therapists. Bo Ai has two floors. The first floor is for children with physical disabilities and the second floor is for children with intellectual impairment.

However, most parents who have children with serious conditions continue to take them to hospitals for treatment. According to Gao, parents in China know little about cerebral palsy. They go to doctors for treatment and see that their child's condition is not improving and when they realize they need help it's too late. "It's the responsibility of doctors, the government and teachers to tell them their children need help," Gao said.

Gao and parents, whose children attend the center, stress the importance of such a facility in Shanghai. "In Western countries, kids (with disabilities) go to centers, not hospitals, especially kids with cerebral palsy. The kids need education and they need to learn daily tasks. Doctors can't teach that," said Gao.

According to Gao, there are around eight therapy centers in Shanghai. "Many parents insist that their children go to a normal school, but it's bad for them. They sit too much and teachers do not know what to do. Kids with cerebral palsy need constant movement," Gao said. "A center like this is more useful for people than a hospital. It's very convenient and doesn't need a lot of money. I really want to write a report for the government



At Shanghai Bo Ai Children's Rehabilitation Center children with both physical and intellectual needs receive training and therapy.



suggesting we have more centers." According to Gao, centers like hers offer more comprehensive treatment than hospitals and are cheaper for parents in the long run.

On a trip to Australia, Gao saw two children with cerebral palsy study in a normal school. However, a specialist would come in to help them twice a week. "In Australia there is an occupational therapy organization, but no such organization exists in China," Gao said. "In China, physiotherapy and occupational therapy are taught as the same major, but they are very different disciplines."

To help raise the standards of the therapists at her center, Gao receives volunteers from abroad. This month, occupational therapy students from Curtin University in Australia are volunteering at the center. "The students provide valuable training and support. We've had a 10-year relationship with the university," Gao said.

According to Gao most of her work at the center involves raising awareness of the work she is trying to do. "Most people assumed we were looking to make a profit for a long time," said Gao. The government then started to manage the NGO, but after a few years Gao was able to control the finances. "Marketing is a big part of what I do."

Students and grandparents

Most of the children who attend the center visit almost every day. Wang Jiaqi, 6, is one. Although he is not able to speak yet, his happy personality shone through as he warmed the room with his smile while lying on the floor receiving his treatment. He has been going to Bo Ai for the past four years. At first Wang used to receive acupuncture for his condition, but the treatment was not sufficient. Initially every joint in his body was tight and his limbs would coil up. Every day he receives a massage and then receives training to help him hold objects. He has made much improvement. Initially he could not stand, his head was tilted and he could only be carried in a rigid position on his mother's back as his spine is crooked.

Sun Xiufeng takes her 4-year-old grandson, Chen Zuihuang, to the center every day. However it depends on whether he is healthy or not. Because of his condition he catches colds



Wang Jiaqi (left) receives training from his therapist. Photos: Cai Xianmin/GT



The future

Lai Yungwong, an occupational therapist from the US who works at Olivia's Place Pediatric Therapy Center, a therapy center founded by expat parents who hoped to create an environment where their own child with special needs could

easily. According to Sun, before Chen was born, his mother's check-ups showed that he was in perfect health.

But when his mother was in labor, the doctor had to also tend to three other patients. As two of the patients were bleeding severely, no one paid any attention to Chen's mother, so Chen did not receive enough oxygen and they noticed that the child had an irregular heartbeat. Because of a lack of facilities in the hospital they did not deliver Chen in time. His problems now are severe. He has problems with his eyes and nervous system and spent his first month in hospital. While most of the children at Bo Ai show gradual improvement, Chen, unfortunately, loses valuable progress whenever he becomes ill.

"Every child needs a different type of treatment," said Xie Feng, a physiotherapy student who works at Bo Ai. Xie works with six children at the center and finds her job rewarding as she can put her theory into practice and establish relationships with people.

According to Gao many parents of special needs children rarely take their children out as they worry how the general public will react. Even today at Bo Ai a few neighbors ask Gao to leave, saying that they do not want to see these children. Gao replies that the children have the same rights as everyone. And it is this strength Gao tries to pass on to other parents. "I tell them, 'if you are weak, your child will be helpless.' We can be sad on our own, but facing people we must be strong and positive," she said.

thrive, told the Global Times that in the US, a child with developmental concerns is provided with a free evaluation. "Between birth and three years of age, the treatment is called 'early intervention.' The idea of early intervention is to help the child become independent," Lai said. "This benefits society too as the government won't need to care for them in the future. In Asia the attitude is 'is investing in a disabled kid worth it?' Long-term independence is not really a priority."

For Xuan Yongming, the long-term future of his son is a major concern. Sometimes it is difficult for Xuan and his family and they feel like giving up. But their love for their son gets them through the hard times. Xuan Yongming is grateful that his son can talk and express himself and Xuan Yukai's mother has sacrificed a lot for his education and didn't work for six years. Xuan Yongming feels that families like his need more help from society and there should be more platforms to offer help during his child's life. "He needs more support to become more independent and integrate into mainstream society. Right now, my wife and I do most of the work," he said.

According to Xuan, parents at the center support each other but it is limited. "If there was a society for parents to meet once a month and talk about their kids and their progress it would be great - especially for new parents," he said.

A director from the Shanghai Rehabilitation and Training Center for the Disabled, surnamed Shen, told the Global Times that starting from this year, Shanghai *hukou* holders under the age of 6 can rent cerebral palsy treatment facilities for free from the Shanghai Disabled Person's Federation. "Also every patient from birth to 6 with a Shanghai *hukou* can get up to 10,000 yuan (\$1,551) worth of medical treatment reimbursed every year from the 50 rehabilitation centers recognized by the federation," said Shen.

Ye Jun and Go Hui Zhen contributed to this story.

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