

Understanding Families with Children with Special Needs in China

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Abstract

There are an increasing dialogues and exchanges for special education programs between China and the rest of the world as the development continues in China. Policy makers, administrators, and educators need to keep in mind the historical and cultural backgrounds when working with families with children with special needs in China. Together, this collaborate effort can provide better services for these families.

Key words

Special education in China, China Ministry of Education, Chinese parents with children with disabilities.

Parenting is not an easy job, and raising a child with special needs takes parenting to a different level. “The boy’s uncle still hasn’t met the boy,” says a mom with a seven-year-old boy with autism. “I need to bring the baby to the other room when our neighbor comes by,” says a dad with a six-month-old infant with Down Syndrome (M. Liu, personal interview, April 8, 2012). “I am not going to send my son to the elementary school because they may not accept him -- he is a little slow,” says a mom with an eight-year-old son who is cognitively challenged (E. Wang, personal interview, June 12, 2012). These are some common comments from Chinese parents with children with special needs. These comments are often difficult for westerners to understand.

According to the China Ministry of Education, there were 1,706 special education schools across the country, with 425,613 students, at the end of 2010 (1). The China Disabled Persons’ Federation also cited 86,000 community therapy centers, with 314,000 therapists, in 1,823 cities across China in 2011 (2). The government’s 2010-2020 Education Reform act intends to achieve the goal of education equality for all (3). In addition to the above resources and intentions to assist families with children with special needs, people with disabilities are encouraged to participate in social benefits, various career options, sports, and internet social networks. However, many Chinese families with children with special needs still struggle. This can be seen through the parents’ reactions toward their children, and the decisions that parents make concerning their children’s education. There are three ideas to keep in

mind when working with Chinese families with children with special needs in China:

1) Chinese parents face social pressure due to having children with disabilities; 2) Chinese parents face financial stress in rearing children with special needs; and 3) Chinese special education and its support and networks are in the development stage.

1. Social Pressure

1.1 One Child policy

China's one child policy was introduced in 1978, and was first applied in 1979 (4). When married couples are considering having a child, they undergo the pressure of doing it right the first time, the last time, and the only time! Parents and extended families place all their dreams and expectations on this one child, and they also hope to secure a future retirement through this only child. Because of this one-child policy, some parents get an abortion when they discover genetic defects during pregnancy. Other parents abandon their child when they discover that the child has disabilities. These reactions are reflective of parents' fear that their hopes and dreams will not be fulfilled, and the uncertainty of the future due to raising a child with disabilities. Parents are allowed to have a second child if their first child has non-genetic disabilities (5). Since many Chinese parents have not seen or met children with special needs, they are not cognizant of what it takes to raise a child with special needs. Many parents with a child with disability decide out of fear that a second child will also have disabilities decide not to have a second child in fear of the possibility that the second child is also with disabilities. The development of the one-child policy will continue to affect the lives of many families in China.

1.2 Grieving Process

Parents who are raising their child with disabilities are on a journey facing a society and a system that is just beginning to become aware of children with special needs. Many Chinese children with disabilities are first diagnosed in hospitals. A few of these hospitals have a structured special education support system, such as early intervention specialists, therapists, or family liaisons to transition the parents to the next appropriate steps. But many do not. "The neurologist said there was no cure, and we felt like we were given a death sentence, and this terminal illness did not even have a treatment plan," says a dad whose son was diagnosed with autism at the age of four (B. Zhang, personal interview, October 18, 2010). "The doctor at the hospital

said there was nothing she could do, we could try therapies, and she told my husband and I to take care! My husband disappeared for two days after we came back from the hospital,” says a mom whose three-year-old son was diagnosed with cerebral palsy (J. Ding, personal interview, March 8, 2007). Many of these Chinese parents go through emotional trauma because of how the news of their child’s disability is announced to them, and because they are not given possible solutions concerning their child. Parents walk away from the diagnoses feeling hopeless and helpless. High level of stress can then begin to build up between the parents, starting with the question -- Who is responsible for the condition of the child? There are also differences in opinions as to how the parents should view their child -- Does my child have a condition that will be cured eventually, or does my child have a terminal disease? “My wife and I fought physically over the heated discussions concerning our son’s condition,” says a dad with a three-year-old son with autism (J. Jiang, personal interview, May 17, 2012). Some parents end up divorced because they are unable to resolve these differences in opinion about their child. Family counseling is recommended for parents to better cope with their situations and find solutions. Crisis management is sometimes needed for families who go through major violence and/or depression.

Some parents start going on the quest of answering the question -- Why me? Extended family members and close friends are usually involved in this quest. “You must have offended the ancestors, and brought down the curse!” is probably the most common answer from family members. “You are paying for the bad behaviors that you’ve lived in your younger years!” might be a comment from a close friend. Families and friends also try to give solutions such as, “Go down to the temple and give an offering!”, “Maybe try asking a fortune teller!”, “Try changing the name of the child, maybe it is not a lucky name!”, or “Change the arrangement of your house, it’s bad fengshui (the natural pattern of the wind and water)!” There are superstitions in Chinese culture underlying these reactions by families and friends.

Many parents begin to shut down emotionally when families and friends make too many of these comments. They are appreciative of the love, care, and concern, but no one seems to really understand, is able to answer their questions, or can give constructive suggestions regarding how to raise their child. Parents are on their own to reconcile and grieve with the thought, “My child will never be able to do this or that ever again!” Some parents channel their emotions constructively, while others

may not. “My husband often comes home drunk because he needs to work hard to provide for our sons,” says a mom with twin boys with cerebral palsy (J. Bai, personal interview, April 8, 2008). “My husband does not allow me to receive help from others because he does not want other people to feel sorry for our family,” says a mom with a nine-year-old daughter with Down Syndrome (T. Liu, personal interview, March 19, 2008). The Beijing Stars and Rain Education Research Center is founded by Ms. Tian whose son has autism. Mr. Cai, the author of the book, Daddy Loves Xihe, uses his gift as a writer to journal his thoughts and emotions on raising his son with autism. Together with many other parents who have children with autism, there has recently been a movement of autism awareness in Beijing (6). Spring 2012, the Water Cube had an exhibition of the artwork of children with autism to bring autism awareness to the general public.

1.3 Discrimination in the midst of Development

The 2008 Beijing Summer Paralympics initiated a high level of awareness of people with disabilities. Many special education schools watched the games and developed related lessons for their students, hoping to motivate them to continue striving forward. Our world of technology also brings many benefits for people with disabilities. Different computer software increases life functioning skills. The use of assistive technology helps many with their motor skills and other development. Scientists and researchers continue to develop technology to improve the quality of life for this population of people.

Internet social networks are one of the fastest growing channels to advocate for people with disabilities in China. Many non-profit foundations and several celebrities with disabilities have over ten thousand people following their Weibo (Chinese version of Twitter). They advocate, raise funds, and educate the general public about people with disabilities through these social medias.

But in the midst of the nation’s development, many parents with children with disabilities still face discrimination in their communities. “My neighbor disciplines her son saying that if he continues to be bad, he will end up stupid like my son!” says a mom with a ten-year-old son who is cognitively challenged (H. Chen, personal interview, April 9, 2009). “The customer hotline knows me already because I call so many times complaining about the buses not stopping for my son and I,” says a mom whose son uses a wheelchair (L. Hao, personal interview, November 18, 2008). “My

son likes the community, and I want to integrate. He knows it when he is not with his peers,” says a dad whose teenage son is cognitively challenged (E. Che, personal interview, April 20, 2012). Negative comments from the neighborhood disrupt the confidence of families with children with disabilities who want to integrate with their community. Due to the lack of integration, the community itself loses opportunities to understand these families and their lives.

Human beings are social beings, and Chinese parents love to get together and talk about their children. But many parents with children with special needs often do not feel comfortable in the usual social circles. “My friends like to talk about how their daughters or sons are perfecting in this or that in school, doing this or that with their grandparents at home. All I can think about is will my son be able to walk and feed himself, and who will take care of him when my husband and I leave this world?” says a mom with a teenage son with Down Syndrome (J. Chen, personal interview May 13, 2012). “My co-workers talk about what they will do when their children grow up, and when they will retire. All I can think about is will I have earned and saved enough money for my daughter for her to survive for the rest of her life?” says a dad with a teenage daughter who is blind (X. Qian, personal interview, May 17, 2012). The parents are unable to connect with others through conversation. As a result, they withdraw from their social settings.

Some parents have received unnecessary sympathy or help from others, and they feel disrespected. “‘Is your son getting better?’ is the first question my friends always ask me after their lengthy conversations updating the latest about their children,” says a mom with a five-year-old son who is blind (L. Miao, personal interview, September 20, 2006). “My friends are always giving me things that are passed down from their children because they know that my daughter has a high medical cost,” says a mom whose four-year-old daughter has a cleft palate (M. Lin, personal interview, April 28, 2007). Many parents with children with special needs yearn for acceptance and an equal opportunity to carry on conversations about the likes and interests of their children, just like everyone else. In a few cases, when they are constantly receiving help from others in raising their child with disabilities, parents develop learned-helplessness and an unhealthy dependence on others.

It’s important to continue raising the awareness of and educating the general public about families with children with special needs so that there is a healthy understanding and acceptance of this special group of families in the community. At

the same time, it is important for parents with children with special needs to form their own support groups, and intentionally reach out and integrate with their communities. Ultimately, there should be a mutual relationship between the community of families with children with special needs, and the community at large.

2. Financial Pressure

Families with children with special needs have higher financial expenses than average families. From early on, children with special needs require additional medical attentions and some disabilities require more than others. Children with cleft pallet need subsequent corrective surgeries as they age. Children who are vision-impaired need continual check-ups. These are just two examples of the continual medical care that children with disabilities require. Many families struggle to meet these medical costs. “My husband and I have almost gone bankrupt with our twin boys with cerebral palsy. We have sought all kinds of professionals since the boys were born,” says the mom (R. Lu, personal interview, October 20, 2010).

Children with special needs also require special therapy sessions and its related equipment in addition to cost of regular education. “My son’s physical therapy sessions are not like piano lessons parents can discontinue if the child is not interested anymore or it’s becoming too costly. If we stop the physical therapy, my son may not be able to walk on his own. It’s not an extra curricula activity, it’s a necessity,” says a dad (P. Hu, personal interview, June 5, 2011). In many cases, one of the parents, mostly the mothers, chooses to quit her job in order to raise her child full time. Some mothers volunteer at their child’s school or therapy center in exchange for a reduced cost for services. Another expense is that many special education schools and therapy centers are only located in the major cities in China. Families with children with special needs from rural areas need to travel to these cities, and pay room and board in order for their children to receive the special education and related support services that they require. All of these expenses accumulate as the child grows.

China’s social welfare system is developing, and non-profit organizations are expanding to support this population of families in China. But many Chinese parents still struggle emotionally regarding the future. “What’s going to happen to my son when he finishes junior high? He is not able to compete in the national exams for higher education. Will he be able to get a job?” asks a mother whose son has mild cerebral palsy (X. Deng, personal interview, December 7, 2011). “My son cannot hold

a job, how will he support himself in the future?” asks a mother whose son is seventeen years old and has autism (C. Wang, personal interview, December 10, 2011). Many parents try to earn and save money to leave behind for their children’s future expenses. The short term and long term financial requirements of children with disabilities all contribute to the financial pressure that families face.

3. Special Education Network and Resources in Development

3.1 Policies and Regulations

There is a nine-year mandatory education policy for all children in China (7). Special Education is one of the main focuses for the government’s 2010-2020 Education reform. Many policies are being implemented regarding so as to enable schools to better provide an education for children with disabilities. However, parents still struggle with educational decisions when their child with special needs is of school age.

Many parents are not aware of the changes in the special education laws and regulations that directly affect their children’s education. The school system has inclusions for children with special needs. In cities like Beijing, homeschooling is available when a child has severe disabilities. Parental manuals and newsletters at the local school districts level will help parents with children with disabilities be better informed regarding the latest special education policies and regulations.

3.2 Networking

Parents with children with disabilities often do not know where to go or who to ask concerning their child’s education. “Guanxi,” also known as relationship connection, is a vital aspect of the Chinese culture. Much of a person’s work and personal life is intertwined in these relationships. This is true in special education as well. Information and experiences are shared by word of mouth. Benefits come with these relationship connections. “One of my friends connected me to a person with position in the school district so that my son can receive advantage points for his junior high graduation exam,” explains a mom whose son has mild cerebral palsy (L. Liang, personal interview, March 3, 2010). “We came to know the four therapists that my daughter goes to through different people,” says a dad with a four-year-old daughter with cerebral palsy (Z. Cheng, personal interview, May 19, 2012).

But some parents are afraid to enroll their child in schools due to past personal experiences of discrimination. “I do not know if the school and people there will accept my child,” says a mom whose six-year-old son has behavioral issues (X. Lian, personal interview, May 18, 2012). “People warn me that I can send my son to school, but they will not take responsibility of his safety and academic learning,” says a mom with a seven-year-old son who uses crutches to walk (S. Lin, personal interview, April 22, 2008).

Networking among parents with children with disabilities will help facilitate the sharing of resources, the answering of questions that parents may have, and enable the support of one another in their journey together. Much of this can be done through parental support groups at schools or therapy centers. Internet social networks are another way to develop connections.

3.3 Parental Education

There are many private special education resource centers/schools across the country. These resource centers/schools provide services such as general education, physical therapy, speech therapy, counseling, etc. Many parents with children with special needs use these private resource centers/schools to support their children’s development. However, there are different philosophies, methods and styles between these resource centers/schools. Different disabilities require different support. Many Chinese parents have the tendency to bounce around from one resource center/school to another based on popularity, latest techniques, or quick results. “I am going to pull my son out of school because my friend recommends this other school that has a program from America, and their teachers have been trained by it,” says a mom with a three-year-old son with autism (D. Guo, personal interview, March 27, 2012). “My friend told me about this group in Shanghai. My husband and I are going there to have our daughter evaluated,” says a mom with a three-year old daughter who was born premature (F. Li, personal interview, May 12, 2011). The family lives in Beijing.

“My son was evaluated by a private special education group, but we never showed the report to the school that he is attending right now,” says a dad with a five-year-old son with autism (B. Yu, personal interview, June 23, 2012). A child’s progress reports and/or educational plans do not necessarily get passed on or followed up on when parents switch between resource centers/schools. As a result, disconnects take place in the overall development of many children. This is more of a

phenomenon with parents who are from rural areas or have lower educational backgrounds. Parents need to be better informed regarding different types of disabilities, child development in general, and how to develop connections between homes and schools.

4. Conclusion

There are many things to be considered when working with Chinese families with children with special needs. Many of these families face social pressure because there is a lack of social and emotional support, in addition to the discrimination that these families receive from the communities. Parents also face financial pressure in raising their child with disabilities. These children often require medical attention early on, and educational and related support services costs accumulate over time. As the social welfare system in China undergoes development, parents are concerned with planning and saving money in order to secure a future for their child with disabilities. China is going through education reform, and putting a major focus on special education, but, many parents with children with special needs still are not empowered to make educational decisions. Parental support groups and networks need to develop further in order for parents to find encouragement from one another, and share resources with each other. Many parents also need training and education so that they are better informed about the basic knowledge, methods, and assessments concerning their child's development. Children with disabilities need consistency and follow-up between the different educational and related support services that they receive in order for these to be good progress. There are more commonalities than differences across cultures in working with families with children with special needs. By keeping these things in mind, policy makers, educators, researchers and teachers will be able to better serve families with children with special needs in China.

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