

Parenting Stress in Chinese Parents of Children with Autism Spectrum Disorder

by

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Introduction

Raising a child with a neurodevelopmental disorder puts more strain on parenting skills than raising neurotypical children (Hayes & Watson, 2013). Children with autism spectrum disorder (ASD) normally have qualitative impairments in language, social interaction and eye contact, and repetitive behaviours or interests (DSM-5; American Psychiatric Association, 2013). In the United States, the Centers for Disease Control and Prevention (CDC) reported that the incidence rate of ASD was 6.7 per 1,000 in 2000, and 6.6 per 1,000 in 2002, equaling approximately 1 in 150 children during those years (CDC, 2000; CDC, 2002). In 2009, a different study from the United Kingdom found a percentage of 1 in 64 in that country (Baron-Cohen et al,2009). This shows that, over the years, the frequency of this syndrome has increased significantly in various countries, so much that autism spectrum disorder has now become the most common developmental disorder worldwide (Zaroff & Uhm, 2012).

The purpose of this study is to explore different stress sources of raising a child with autism in China, and evaluate how families respond to the challenges they face. Furthermore, a

more contextual understanding of life impact would help special educators and professionals to understand the complex experiences and extra burden on families.

Literature Review

Building on the extant literature review, this paper aims to explore the parenting stress of raising a child with ASD in China, and how parents respond to these challenges.

Research Question

This study aims to obtain further knowledge about parents of children with autism in China. The main question that this research is trying to explore, and possibly provide solutions for, is: what are the various types of stress that Chinese families experience while dealing with a child with autism?

Method

The present study uses both quantitative and qualitative investigation measures. I mainly used a qualitative method—grounded theory—to answer the central research question. Because there isn't a lot of research on this topic, I believed that the grounded theory method would be the most appropriate to apply at the beginning of this study, so that I could gather real-life experiences from Chinese parents. This method consisted of open-ended interviews made with

10 Chinese families of children with ASD. Without giving any hypothesis or themes, I started from collecting data in those formal interviews with 10 groups of Chinese families. As I collected and reviewed more data, elements of those interviews became apparent.

Analysis

The stress from the pre-diagnosis experience

In the pre-diagnosis stage, parents detected that something was wrong in their child's development, and began searching for answers from healthcare professionals (Altieri & Von Kluge, 2009; Hutton & Caron, 2005).

Searching for answers.

In this research, many parents have reported that, in the pre-diagnosis stage, they hadn't suspected that their child had autism at all, and this is a sign that ASD is not a well-known disease in China. Parent #3 described the first time she realised her son was behaving differently. She said: "*I didn't realize that his behavior was a problem; I thought he just had a different personality.*" Also, Parent #4 said: "*Before we got the diagnosis for my son, my husband and I felt very helpless about my son's emotional problems, but we didn't suspect he (son) had autism*". After atypical behaviors appeared, parents started searching for answers.

In Midence & O'Neil (1999), they revealed that American families would usually start searching for answers from family doctors. However, for the majority of Chinese parents in this study, the search for answers usually happened on the internet. Table 3 indicates the ways that Chinese parents used to try and understand their children's atypical behaviors when they first

noticed them. In Questionnaire 2, nearly 110 Chinese families sought answers from the internet, and only 25.58% (approximately 43 families) of parents went to professionals and clinics for help. Combining this with the interviews, Chinese parents revealed that they received stress from misinformation and lack of information in the pre-diagnosis stage. Parent #8 in this study said: *“I read books and checked information about autism on the Internet. I found out that the information about autism on the internet was overwhelming, and I didn’t know what kind of information was true, and which one was fake information.”* Also Parent #9 received the same stress resources in the pre-diagnosis stage, and she stated that: *“I was still frustrated with all kinds of information online, I was ignorant, I didn’t know what to do, and there were no people I could ask for help. There was lots of false information on the internet, so I didn’t know which institution I should choose for my child. My baseline is that my child must be safe and not try those messy methods on the internet.”* Besides the messy information online, Desai et al (2012) reported that parents also received misinformation from family members who believed that the child’s behavior was consistent with their family history.

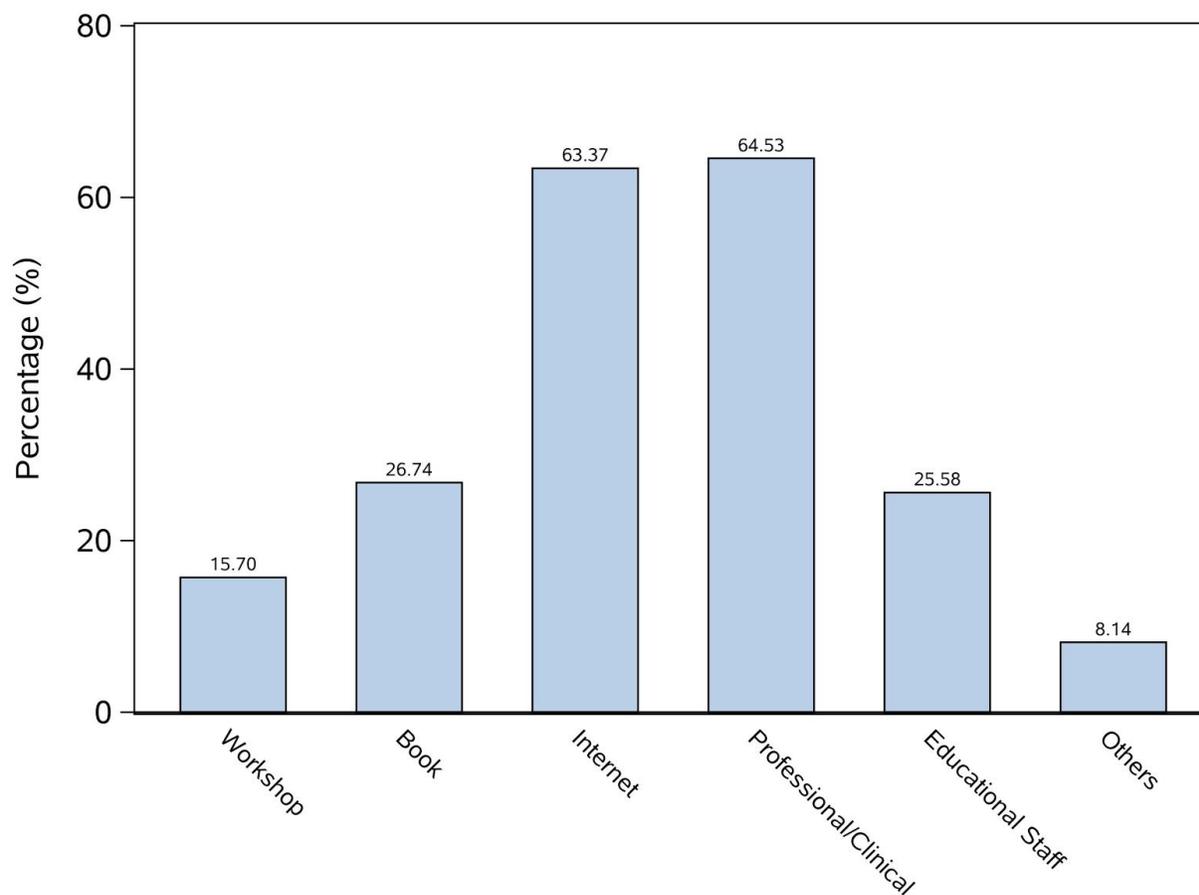


Table 3

The stress during the diagnosis

Lack of professionals and hospitals.

Lack of doctors/professionals is the most essential problem that Chinese parents face. Eight out of ten parents in this interview reported that the queueing lines of some professionals are too long. *“It is tough to see a doctor or professional in China. When I was searching for a*

hospital that could diagnose autism, the queueing line was too long in domestic hospitals. We had to go to an international hospital.” (Parent #4, Shanghai)

This situation could be considered as “lack of doctors/professionals”. In the online survey, 26.74% of parents in Table 4 filling Questionnaire 2 stated that they waited for their appointment for more than one month, while 33.14% of parents waited for one or two weeks. 29.65% of parents received an appointment from the doctor that was less than one week away. In contrast, still, 10.47% of parents waited for more than two months. Parent #7 in the research revealed that parents in China are not willing to believe the diagnosed results, and they always inquire about the best domestic hospitals. Therefore, several hospitals are very famous, and these doctors’ appointments are tough to book or queue for. Table 5, reporting still Questionnaire 2, shows that 51.74% of parents in this research didn't change hospital after receiving the diagnosis. However, the other half of Chinese parents changed hospitals after the diagnosis, therefore 27.91% of parents changed one hospital and 19.19% of parents switched between two to three hospitals. Surprisingly, 1.16% of parents in this research went to more than three hospitals. Furthermore, according to the data, doctors in the domestic psychiatric department are relatively weak in terms of medical knowledge, as it compares with other countries. Still, parents’ distrust of the results is another crucial factor in long queueing lines.

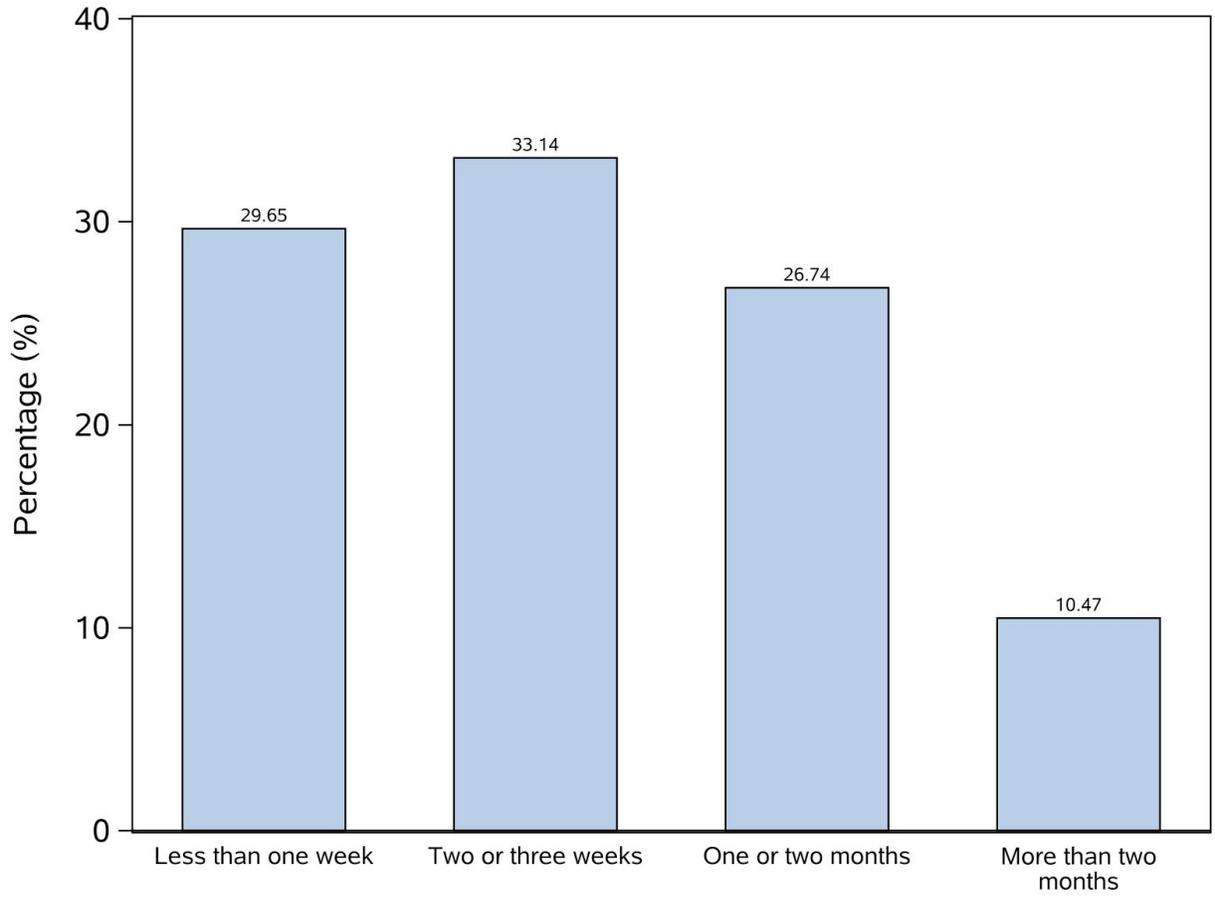


Table 4

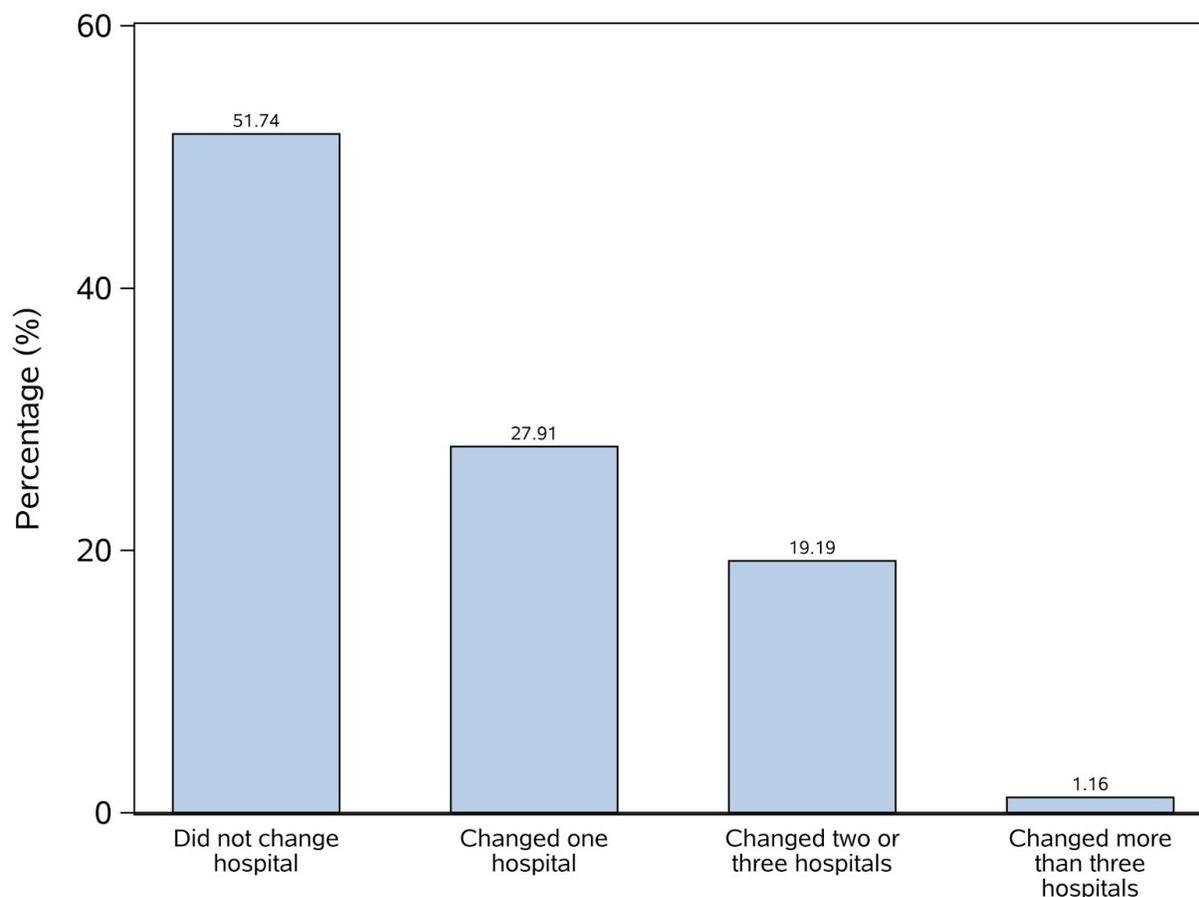


Table 5

Different diagnosed results.

McCabe (2009) revealed that parents in China sought multiple doctors to get a different diagnosis and identify varying cures and treatments. In this study, I also obtained a similar result proving that many Chinese parents went to different hospitals, and, every time, they received different results. *“We never got a definite diagnosis. When my son was 4, we went to the Seventh People’s Hospital of Hangzhou. The diagnosis was high-functioning autism. The doctor recommended going to an institution in Hangzhou for rehabilitation training. But I didn’t know*

what the difference between high functioning autism and Asperger Syndrome was.” (Parent #1, Shaoxing, Zhejiang Province). Another parent from Hangzhou, Zhejiang Province, also reported that they were very confused with various results from different hospitals. And they felt very anxious about their son's situation.

I went to hospitals three times in total. The first time my son was four years old...the doctors said that my son had no big problem, and he was just a little childish. Then, when he was five and a half years old, we went to another hospital.....the doctor felt that his performance was not consistent with the one of autistic children. Later, we went to the Zhejiang Children's hospital. The doctor suspected my child had autism, and he used the Autism Diagnostic Observation Schedule (ADOS) to diagnose my son. (Parent #5, Hangzhou, Zhejiang Province).

It is evident, at this point, that various results from different hospitals become one of the main stress sources to Chinese parents. I found out that hospitals in China use different methods to diagnose autism. Parents #1 and #2 said that the doctors use scale assessments and observations to make diagnoses, while Parent #4 received a diagnosis by doing ADOS in Shanghai (Autism Diagnostic Observation Schedule). Parent #7, also from Shanghai, had her son do ADOS, EEG and MRI. A doctor in Ningbo gave a diagnosis to Parent #8 by observation, parental assessment, and infant ability form. This demonstrates that Chinese clinics do not have a clear and standard method to diagnose ASD, and this causes that Chinese families receive more stress sources from the diagnosis period.

Response to diagnosis.

Previous research had already discovered data about stress resources related to diagnosis, including the mixed emotional responses reported by parents (Altiere & von Kluge, 2009, Gray, 2002, Hutton & Caron, 2005, Lin, Tsai, & Chang, 2008). Following the child's diagnosis, many parents described their feelings as devastation (DeGrace, 2004; Gray, 2003), guilt and blame (Lasser & Corley, 2008, Lutz et al, 2012). In the Zheng and Zheng research (2015), Chinese parents of children with ASD reported that they faced higher stigma and self-blame than parents in the West. In my research, most parents didn't receive a clear guideline for their child, thus they felt helpless, anxious about the diagnosis.

Parent #6 didn't believe the diagnosis, and said: "*Autism is a terrible word to my wife and me; we didn't believe our daughter had autism. After the second diagnosis...we first thought that the doctor had misdiagnosed. Even if he was right, my daughter might have slight autism (not severe)*" (Parent #6, Lianyun Gang). One mother related her work to her life in order to inform me about her psychological reactions after receiving the diagnosis of her daughter.

When I found out that my daughter had autism, I collapsed for two weeks, and I washed my face in tears every day. At the same time, I looked through all different kinds of information on the internet and searched for rehabilitation centers in Shanghai..... In the past six months, my mood has calmed down, but when the child does not behave well, I still feel terrible. (Parent #7, Shanghai).

In general, Chinese parents in this study reported that they felt that they needed to spend more time and energy on their child, so they had to give up on social activities. Parent #6 revealed that they have two children, but they spent most of the time with their older daughter,

who has autism: *“We have two daughters…… After we finish working every night, we only have half an hour to spend with the little sister, and the rest of the time, we need to look after our bigger kid, because she needs special care.”* (Parent #6, Lianyun Gang).

Due to the diagnosed results, many parents felt overwhelmed by family demands (Hutton & Caron, 2008). Doctors in China normally suggest that parents take their children to rehabilitation centers. In the research, some of the parents said that they travelled to different cities in order for their children to be able to take classes in the popular rehabilitation centers of China. Parent #2 took her son to the rehabilitation center in Nanjing, which is one of the most famous centers in China. She said: *After the training started, my life was completely different from my previous life. I used to be a school nurse who worked Monday to Friday, and my job was in Anhui. But after my son’s diagnosis, we were training in Nanjing. I needed to be there with him all the time, but I was so tired, I felt overwhelmed with the diagnosis results, and I felt helpless in general”* (Parent #2, Bengbu)

In addition, as described in Wang and Michaels (2009), Chinese families expressed the need for knowledge regarding their children’s disabilities and their own parenting skills, including how to manage their children’s challenging behavior. Participants in this study also reported a similar source of stress, coming from the fact that their children with ASD have limited access to professional help in China. Thus, this factor could be considered as one of the serious stress sources that affect Chinese families’ lives. Some parents in this study felt deeply lost during the first few months after the diagnosis. Specifically, Parent 6# commented that: *“Chinese government should set a clear guideline for parents, including more information about*

rehabilitation centers in the cities and further information about ASD, otherwise, parents like us would feel very hopeless after receiving the diagnosis result.”(Parent #6, Lianyun Gang).

The stress after the diagnosis

Hiding the Fact from Other Family Members.

Qian et al. (2002) suggested that the social attitudes and expectations of the Chinese population in general affected the families after the diagnosis. Traditionally, family issues remain within the family, and therefore, Chinese families try to resolve everything on their own. Some parents reported that they didn't have close contacts with other family members. Most parents reported that they didn't tell other family members (e.g. uncle, aunt) about autism, but only close family members (e.g. grandparents). Other parents, especially one father in this interview, expressed that telling other family members would give a special label to their son, and this would increase his own stress level.

Maybe not everyone realized that our son was autistic before, but if we told them, then everyone would think our son is a freak, then look at him in a different way. So we don't want our relatives and friends to know..... ((Parent#4, Shanghai)

Disclosure of disability within a family can result in “loss of face”, which may affect the entire family's prestige (Liu, 2001). Thus, families may adopt strategies to hide the existence of a disability, creating a source of additional stress.

Older Chinese Generations Believe in Traditional Chinese Medical Practices and Methods, and Overtrust Their Effects.

As aforementioned, Chinese families try to resolve everything within the family, and this leads to many older generations starting to search for methods to resolve the problem of the autism of their grandchildren. As my interviews confirmed, due to the lack of understanding of autism and the overwhelming amount of information about this spectrum on the internet, most grandparents still believe that traditional Chinese medicine can cure ASD. Parent #7 stated: “A large part of the old generation in Fujian (province) is very respectful of traditional Chinese medicine..... but many traditional Chinese methods are unscientific.” In addition, Yang et al (2015) conducted a research that revealed that the physiological mechanisms by which acupuncture, one of the Traditional Chinese Medicine methods, works for ASD seem to be very complicated, and still remain unclear. However, many private clinics and hospitals still utilize the inclination of Traditional Chinese Medicine (TCM) of the older generations, and lots of advertisements about acupuncture and other methods are diffused on the internet.

My son's grandparents started looking for various magical therapies after the diagnosis, and they wanted me to take my child to try them out.....Later, my son's grandparents found a private clinic in Nanchang, Jiangxi Province, saying that acupuncture and medication can be used to treat autism. (Parent#9, Xiamen)

Parent #9 in this research reported that she received a lot of stress from her child's grandparents (husband's side), and after her child was forced to have a catgut embedding therapy by his grandparents in a private hospital in Zhangzhou, the mum described her psychological response:

It was excruciating. When they brought my son back, my son slouched on me for more than one hour, and his body was very hot. I immediately checked the information about embedding therapy online, and I found that this treatment was more horrible than drinking Chinese medicine and acupuncture. I couldn't imagine how helpless my son was.
(Parent#9, Xiamen)

The conflict between Parent #9 and her child's grandparents came from a lack of understanding of ASD. After the diagnosis, most younger parents start looking at autism from a scientific perspective in China, and they are more likely to distinguish various information online. However, many grandparents or older-generation people are not familiar enough with the internet, and there is no other way for them to obtain reliable information from the right channels. This has led to many close-family relationships becoming a source of stress for many Chinese parents.

Education—High Rejection.

For many parents, one of the biggest obstacles was trying to fit their child within a rigid school system (Ho et al., 2018). McCabe (2008) investigated that regular public schools in China typically do not serve students with ASD, and this increased the level of stress in Chinese families. Despite the call for free public education for all children up to grade nine (Compulsory Education Law of the People's Republic of China, 1986), children with autism in China still receive high rejection from those public schools. In this research, parents received a high level of stress from three dimensions as they apply to education: 1. Searching for public schools; 2. High level of rejection of people with disabilities in public schools; and consequent 3. Hiding the fact

that the child has been diagnosed with ASD.

Looking for and finding a public school that is willing to accept a child with autism, and take good care of them, is very hard in China. Wang (2005) stated that public schools still exclude a significant percentage of children with autism. This high rejection may be due to the lack of trained professionals, curriculum, and facilities in public schools (McCabe & Tian, 2002). Parent 2 clearly stated that her son got rejected from public schools because of autism.

Before he (my son) attended a special school, I consulted the public elementary school near our house. Because there was no accompanying policy, he could not go to the public school in our city, so the integration of education for special children is almost non-existent. Public schools lack resources for special children and special teachers.(Parents #7, Bengbu)

The Protest from Neurotypical Students' Parents.

The cause of the high rejection levels is that the general education teachers worry that accepting students with disabilities will interfere with the achievements of other students (Mitchell, 1995), and so do the parents of neurotypical students. Participants in this interview revealed that the most worrying part of enrolling their children in public schools is other neurotypical students' parents. Parent #4 expressed her worries about her son's education:

There were single mums with an autistic boy who both committed suicide before. All kindergarten parents jointly boycotted the autistic boy from attending the school, because parents were worried that the autistic boy would interfere with the achievement of their children. So I am skeptical about the school's tolerance for children with special needs, I

am afraid to tell the school teachers! I am afraid that other parents will know! (Parent #4, Shanghai)

The most difficult part of implementing effective education for children of various achievement levels in one classroom is the very large class size of China (McCabe, 2008). The classroom usually contains forty to sixty students. If a general education teacher puts more attention on children with special needs, then the rest of the class would not receive enough support from that teacher, and therefore, many neurotypical students' parents would not accept students with autism or other special needs in public schools. Clearly, this could be another main factor causing stress in the Chinese families of autistic children.

Learning in Regular Classrooms (LRC)

I found out that four out of ten families' children with ASD attended schools in Beijing, Shanghai and Shaoxing, as an "audit"—the student doesn't participate in any exams or tests, but only listens and participates in class. Parent #3 from Beijing stated: *He (my son) is now in the second year of a public school in Beijing; his age is suitable for enrollment. But he is an "audit" instead of a normal student. The purpose is to not affect the performance of teachers and to reduce pressure for everyone. (Parent #3, Beijing)*, Also, Parent #1 from Shaoxing comments during the interview: *My son has been attending public school since kindergarten as an audit, and he barely has behavioral problems in school, except for interpersonal communication. Generally, it does not affect the school teaching. Therefore, there are no obstacles to attending a public school, but we lack professional support from special teachers. (Parent #1, Shaoxing)*

On the surface, LRC has decreased the stress level for many Chinese parents. However,

there are two limitations: 1. Learning in regular classes mainly exists in the larger cities, like Beijing or Shanghai; 2. The goal of the early trial sites has been to find out how to address the needs of students with disabilities without having a negative influence on the rest of the students (Chen, 1997), instead of how to better assess students with disabilities. Possible solutions to overcome these obstacles in order to effectively pursue inclusive education include better special educator training, increased number of special education professionals, and improved advocacy by parents.

Concerns for the Future.

In this study, I found out that all the participants have been worried about their child's future, and eight out of ten families had the same concern about their child's employment. They expressed to be terrified about their child's social skills because the interpersonal relationships in China are particularly important.

To be honest, I am under pressure because I compare my life experience to my child's. I am 40 years old this year, I have been working for almost 16 years. I graduated from a great university, but my work experience is very unsatisfactory. Thus, I feel a lot of pressure about his future job. First, he needs to learn social skills. Secondly, his professional skills need to be strong, better than other people, then he can have absolute advantages over many competitors..... (Parent #9, Xiamen)

Parent #9 started from her own experience and that, combined with the highly competitive social system in China, makes her worry about her child. Comparing with Parent #9, Parent #4 was more worried about limited job opportunities and choices that people with ASD have in China.

I highly doubt whether sheltered employment can provide a career that my son likes. In fact.....just like 50 years ago, the main occupations of Chinese people abroad were restaurants and laundry rooms. The occupations that the domestic ASD people can get are also primarily repetitive manual labor. I doubt the authenticity of those autistic children who say "I like this job very much" because, even though they don't like it, they don't have another choice. I think this area requires a lot of social innovation to promote systemic social change. (Parent#4, Shanghai)

In one of Helen McCabe's (2003) studies, she conducted research on one case of employment for an individual with autism in a Chinese city, and she discovered that, in China, there is often a concern that if something goes wrong, no one wants to take responsibility for that. Thus, there is hesitancy towards hiring people who may need extensive support, such as people with ASD or other special needs, and this results in a very low employment rate and a very high rate of people who are actually forced to stay at home because of the low employment rate. In this study, Parent #10 made a comment on her son's unemployment situation, and she wondered what would happen to her son with ASD after her husband and her pass away, if no company is willing to hire her son.

Our expectations for him (my son) are not very high. My husband and I only hope that he can grow up happily and get a simple job. This year, he is already 36 years old, he does

not have a job, and I started to realise that he can not stay with us forever. One day, if we passed away, who can take care of him? And can he survive in society? This is the biggest stress for us. (Parent #10, Shenzhen)

Despite the Chinese government published policies ensuring employment opportunities for disabled people, Pierini, Pearson & Wong (2010) still found that many companies are unwilling to hire individuals with disabilities even with tax incentives offered to them. In the case of such high unemployment, I am concerned that the unemployment of a large number of autistic people will cause a burden on all parents, and further increase the burden on the whole society.

Discussion

The main cause of stress in the during-the-diagnosis period seems to be the fact that Chinese parents hardly ever receive the same diagnosis from different doctors. They reported that many doctors in their cities' local hospitals are not specialized in diagnosing ASD, and thus cannot identify the problem properly. Therefore, the parents had to go to other mental health professionals in bigger cities, working in more popular hospitals in Nanjing, Beijing, Shanghai. The result is that many parents received high levels of stress from queueing for appointments with reliable professionals..

I would consider the absence of comprehensive guidelines for parents to adjust themselves and obtain detailed information about ASD as a stress source in this study. I argue that there is a need for informative handbooks for parents after they receive the diagnosed results. Doctors or other health-care professionals could be the ones providing those handbooks. By using this sort of guiding handbook, parents could gain knowledge regarding their children's

disabilities and their own parenting skills. I believe that this would effectively reduce the stress levels in a lot of parents.

The last major stress factors happen after the diagnosis. When parents face the long-term effects of autism, more multiple sources of stress emerge from many different aspects. One of them, the stress from their relationship with other family members, might not be so different from Western countries. However, in China, the attitude towards disabilities is far more negative than in other countries (Yang & Pearson, 2002). This is due to the unique family planning policies in China, where most families are only allowed to have one child (Attane, 2002). After the birth of the first child, family members put all their hopes into him or her. Thus, the shock of having a child diagnosed with ASD is more dramatic than in countries where parents are allowed to have more than one. This has led to two additional sources of stress in Chinese parents. One is that parents regard ASD as a special label, and try to hide it from other family members: telling the truth to other family members can result in "loss of face", and affect the entire family's prestige. The other one is that the older family members, such as the child's grandparents, may attempt to cure autism in a way that they trust (e.g. acupuncture, catgut embedding therapy), but that does not have any scientific support. The significant stigma put on individuals with a mental disorder in the Chinese culture exacerbates the lack of acceptance that these families experience (Ben-Porath, 2002). Therefore, due to the diffused ignorance and societal stigma related to autism, Chinese parents are seeking acceptance and recognition from the society, just like the parents in other countries, but in a country that makes acceptance and recognition harder to achieve with a child with ASD. I would argue that government programs not only need to improve the lives of children with autism and provide services to those children's families, but

they also need to spread information about autism to the public so that people's acceptance and acknowledgement of ASD and other disabilities would improve.

Another one of the most salient discoveries in this current study is that education has a direct impact as a source of stress in Chinese families with children with ASD. Many parents reported that public schools in China generally have a low acceptance rate of students with ASD. There are many reasons behind this, such as the lack of special educators, paraprofessionals or other resources, and these factors have become excuses to justify the public schools' rejection of autistic students. Although the laws on the protection of Persons with Disabilities in 1990 called for an improvement in education and other protections for individuals with disabilities (National People's Congress, 1990), Chinese parents are still worried about schooling possibilities nowadays, and have received a considerable amount of stress from the limited opportunities in the general education system.

Additionally, I also found out that the protests from other neurotypical student's parents—NT—is another serious stress factor that increases the stress and fear of parents with children with ASD. Due to the lack of awareness of autism in the Chinese society, many parents reported that people usually misunderstand ASD and other mental illnesses. This leads to the fact that many NT parents worry that their children might receive bad influence from autistic students, and unfair treatment from public schools. In order to improve the education of autistic students, and to reduce the pressure and stress on parents in education, the Chinese Bureau of Education should apply further measures to protect those students' rights.

The last salient finding regarding parents' increased stress, and ongoing feelings of anxiety, is the uncertainty about their children's future, which was not a surprising finding. In a similar statement provided by one of O'Brien's (2007) researches, parents reported that they had difficulty adjusting their expectations for their child because they did not know what to expect from their child's future after the diagnosis. The last family was the older participant, and they stated that older Chinese parents have the same anxiety because they fear that, once they die, their children will not be able to live alone. Then, the same should quickly make adjustments in the current employment situation for people with ASD and people with other special needs. This move could greatly reduce the pressure on Chinese families of children with autism.