

Experiences of Chinese Parents of Children with Autism Spectrum Disorder Advocating for Inclusive Education

Hui Zhang¹, Xueqin Qian², George HS Singer¹

¹ Department of Education, University of California, Santa Barbara, USA

² Lawrence Free State High School, Lawrence, Kansas, USA

HOW TO CITE:

Zhang, H., Qian, X.,
Singer, G. (2022).
Experiences of Chinese Parents
of Children with Autism Spectrum
Disorder Advocating
for Inclusive Education.
*International Journal
of Special Education*, 37(1), 62-74

CORRESPONDING AUTHOR:

Hui Zhang;
hui_zhang@ucsb.edu

DOI:

<https://doi.org/10.52291/ijse.2022.37.27>

ABSTRACT:

The purpose of this study is to gain an understanding of Chinese parents' experiences advocating for their children with autism spectrum disorder to be educated in a regular classroom setting. Sixteen parents of children with ASD in China were interviewed to understand their experiences with the 'learning in the regular classroom policy' (LRC) and its implementation. Our findings revealed three themes: (a) *guanxi* (social capital) is critical for parental advocacy, (b) Parents' commentary on educational rights features a self-deprecating tone, and (c) parents indicate they accept and even agree with the stigma attached to children with ASD. The interpretive phenomenological analysis approach is used to gain insight into the policy implementation of inclusive education in China from the perspective of parents. This study demonstrates the toll that social stigma takes on parents when they interact with the Chinese school system within the context of LRC.

COPYRIGHT STATEMENT:

Copyright: © 2022 Authors.
Open access publication under
the terms and conditions
of the Creative Commons
Attribution (CC BY)
license (<http://creativecommons.org/licenses/by/4.0/>).

Keywords: autism; parent perspective; learning in the regular classroom; inclusion; China

INTRODUCTION

Since the 1980s, the paradigm of placing children with disabilities in regular education settings, or 'learning in the regular classroom' model (LRC), has required public schools in China to integrate students with disabilities in mainstream classes (Cui, 2016; Ge & Zhang, 2019). The LRC is widely regarded as the founding document of inclusive education in China (Xu et al., 2018) and serves as the primary model for a series of rules aimed at ensuring educational services to children with a variety of disabilities, including autism spectrum disorder (ASD) (Su et al., 2020; Xu & Zhu, 2016).

However, students with disabilities in China still do not have enough access to inclusive education due to either a lack of resources or lack of acceptance of students with disabilities (Cui, 2016; Su et al., 2020). One study showed that in 2017, only 45% of school-age children with disabilities received some form of education (Su et al., 2020). Out of all the children with disabilities who applied to public schools, only 72% were admitted (Su et al., 2020). Moreover, although the number of students with special needs has been increasing, the enrollment rate under LRC has been decreasing, suggesting that a large proportion of students are being served in separate segregated schools and classrooms (Su et al., 2020).

Researchers identified a number of barriers to inclusive education in China, including a shortage of special education teachers, a lack of leadership support, and social discrimination against children with disabilities and their families (Huang et al., 2013; Ochoa et al., 2017; Xu & Zhu, 2016). Despite parents' crucial role as advocates for inclusive education, previous research on LRC has mostly focused on the perspectives of other stakeholders, most notably teachers' attitudes about inclusive education (Hu, 2020; Malinen et al., 2012). Few studies have been conducted just on parents' perspectives and experience under LRC.

Among a handful of studies focusing on parents of children with ASD in China, McCabe (2007) interviewed 43 families of children with ASD to investigate parental advocacy for educational assistance in general but did not explicitly examine LRC implementation in general education settings from parents' perspectives. The author discussed the primary issues families face as primary caregivers of their children and suggested that, despite parents' willingness to make sacrifices and changes in their lives for their children, they were impacted and stigmatized by traditional Chinese beliefs about family and disability. Similarly, Hu (2018) investigated

how Chinese parents perceive the value and feasibility of high-quality pre-school inclusion. In this study, 83 parents of children without disabilities and 125 parents of children with disabilities completed the survey and the author concluded that while Chinese parents of children with disabilities recognized the importance of inclusion, they did not believe it was viable in China due to a lack of public financing and professional resources.

Additionally, McCabe's (2007) study revealed that parents frequently had to rely on informal personal relationships with administrators to acquire educational resources for their children with ASD. As suggested by researchers, Chinese residents frequently rely on informal social capital and secret, out-of-sight negotiations with government and company managers to accomplish their objectives (Hwang, 2004). This is partly a response to a longstanding tradition rooted in Confucianism, which emphasizes the importance of social harmony, saving face, and respect for authority. There is a substantial body of literature about *guanxi* practice in China (e.g., Hwang et al., 2009; Gold et al., 2002). *Guanxi* is a broad term that refers to social relationships in the Chinese cultural environment. Personal connections and an individual's social capital may be far more influential than formal standardized rules and processes in a child's educational placement. Social capital leads to benefits like other forms of capital (e.g., human capital) can lead to tremendous benefits and has been proposed to explain educational inequality (Coleman et al., 1988; Small et al., 2009).

While these studies give insight on the problems parents confront while campaigning for their children with ASD's educational rights, few of them focus exclusively on parents' experiences under the LRC. Studies conducted in the U.S. have shown that parents play a critical role in advancing the implementation of special education laws or policies and ensuring their child's educational rights (Lindsay & Dockrell, 2004). Further, research shows that parents' voices are an essential source to understand disability policies (Collier et al., 2015; Cui, 2016; Ferguson, 2008). Furthermore, studies have shown that parents have faced numerous challenges when advocating for their children. For example, Fish (2006) interviewed seven parents of children with ASD regarding their experiences participating in IEP (Individualized Education Program) meetings and found that professionals often accused parents as being unreasonable as to their demands from schools. Moreover, parents were often blamed for their child's academic and behavioral problems. In one case, a teacher asked a parent the invasive question of whether she had drunk alcohol during her pregnancy. Given the lack of awareness of

autism and stigma beliefs toward ASD in Chinese society (Yu et al., 2020), parents in China are very likely to face similar or more severe challenges. Moreover, the absence of formal due process procedures and the informal structures of Guanxi may mean that Chinese parents must deal with these obstacles to inclusion in ways that are likely different than what is seen in US advocacy processes..

As such, this study aims to understand parents' perspectives and their advocacy experiences on LRC implementation regarding its effectiveness and challenges to implementation across regions, backgrounds, and contexts in China as they advocate for their child to be educated in inclusive settings. Regarding advocacy, we defined it as any actions that "*influence public attitudes and enact and implement laws and public policies*" (Holcomb-McCoy & Bryan, 2010; p. 263). In the context of parent advocacy, it may consist of obtaining services for their child, fighting for policy changes, or educating friends, family members or school staff about their child's disability.

METHOD

As Crotty (1998) proposed, a researcher's ontological and epistemological positions are inherently linked because the construction of meaning is composed of portray and interpretation of reality, the purpose of this study is to gain a meaningful understanding of the phenomenon of parental advocacy from the perspective of Chinese parents of children with ASD and to answer research questions about the subjective experiences of participants. When conducting this qualitative research study, the interpretative phenomenological analysis (IPA) method was employed (Alase, 2017; Noon, 2018). Other qualitative methods, such as focus groups, have rigidly defined procedures, and impose prior theory lenses on participants. In contrast, IPA foster a close bond between researchers and participants and require researchers to refrain from theorizing about participants' experiences prior to engaging in dialogue with interviewees. This study, rather than developing a new theory to explain how parents deal with school bullies who target their children with ASD (grounded theory) or examining the experiences of a single parent or a group of parents (case study), listened to parents' experiences advocating for their children's right to education and interpreting the meanings of LRC from parents' perspectives.

Participants

To illustrate, all 16 parents (15 females and 1 male) are from provinces that rank among the top ten in terms of GDP per capita in 2020, as shown in Table 1. In addition,

80 percent of participants claimed having a bachelor's degree or more, and each participant reported an annual household income that was greater than the average annual household income in China in 2020 (National Bureau of Statistics of China, 2021).

Recruitment

Following the IPA recommendation that researchers purposefully select participants who have experienced similar phenomena and expressed their willingness to share their experiences in an audio-recorded interview (Alase, 2017; Sohn et al., 2017), the first author advertised for recruits in two online Chinese anonymous parent groups to which she belonged, and parents contacted the first author to express interest in participating in this study.

When selecting participants for this study, two criteria were used to ensure a homogeneous sample of people who had similar experiences of advocating for their children with ASD (Alase, 2017): (1) parents who advocated for their children's inclusion in general education classrooms and (2) parents of school-aged children with ASD. The criterion would ensure that we found the parents who had gone through the same experience as we had been identified: lobbying for the provision of educational services for their children with ASD in China. Sixteen parents volunteered to participate in this study after being selected, as stated in Table 1.

Procedures

After gaining approval from the university's institutional review board (IRB), a demographic questionnaire was provided to participants and returned to the first author before conducting interviews. There were eleven items on the questionnaire, and they dealt with information on both parents and children with ASD. Age, gender, employment, education, marital status, household income, number of children, grades of children, type of school, gender, and age of children with autism were all obtained from the parents, and the results are reported in Table 1. Because these items were not included in the questionnaire, we were able to gather information on the participants' occupation and place of residence through interviews.

Using Weixin (We-shin), one of the most popular instant messaging software systems in China, semi-structured interviews with parent participants were conducted. As advised in prior research employing semi-structured interviews, interviews were performed in the form of one-on-one audio conferences using the Weixin platform, with each interview lasting roughly one hour. All interviews were conducted in Mandarin, which was the native language of

Table 1. Participants (parents) characteristics (Authors et al., 2021)

Parent Number	Gender of Parent	Age of Parent	Location (Province)	Education Level	Age of Child with Autism	Gender of Child with Autism	Type of School	Employment	Family Annual Income (RMB)
1	Female	30-39	Hubei	College	10	Male	Public School	Unemployed	100,000-200,000
2	Female	30-39	Hubei	College	8	Male	Public School	Part-Time job not mentioned	500,000-600,000
3	Female	30-39	Jiangsu	Bachelor's degree	8	Female	Public School	Part-Time Job job not mentioned	200,000-300,000
4	Female	30-39	Jiangsu	Bachelor's degree	7	Male	Public School	Full-Time Employed: Schoolteacher	100,000-200,000
5	Female	30-39	Jiangsu	College	10	Male	Private School	Full-Time Employed: job not mentioned	100,000-200,000
6	Female	30-39	Anhui	Bachelor's degree	7	Male	Homeschooling	Full-Time Employed: Entrepreneur	50,000-100,000
7	Female	30-39	Jiangsu	Master's degree	11	Male	Public School	Part-Time job not mentioned	500,000-1,000,000
8	Female	30-39	Jiangsu	Master's degree	6	Male	Public School	Full-Time Employed: job not mentioned	400,000-500,000
9	Female	30-39	Jiangsu	Doctoral Degree	8	Male	Public School	Full-Time Employed: teacher	400,000-500,000
10	Female	40-49	Jiangsu	Master's degree	13	Male	Homeschooling	Full-Time Employed: job not mentioned	300,000-400,000
11	Female	30-39	Zhejiang	Bachelor's degree	8	Male	Private School	Unemployed	400,000-500,000
12	Male	40-49	Jiangsu	College	11	Male	Special School	Full-Time Employed: job not mentioned	100,000-200,000
13	Female	40-49	Jiangsu	Master's degree	14	Male	Public School	Full-Time Employed, teacher	300,000-400,000
14	Female	30-39	Jiangsu	College	10	Female	Public School	Unemployed	100,000-200,000
15	Female	30-39	Jiangsu	Master's degree	7	Male	Public School	Unemployed	100,000-200,000
16	Female	40-49	Jiangsu	Doctoral Degree	5 and 13	Female and Male	Special School	Full-Time Employed, job not mentioned	300,000-400,000

the participants. Questionnaire questions were delivered in simplified Chinese, and permission was acquired from all participants to record the conversations on audiotape.

The semi-structured interviews were designed to elicit responses to the research questions and were modified to incorporate findings from earlier pilot research. In semi-structured interviews, questions on parents' overall experiences before and after school, as well as their school expectations, were asked first, followed by a range of probing questions in response to each participant's responses to grand-tour questions. "Could you please tell me what concerns you have about your child's development?" and "Could you please explain the most critical events you believe are important for your child to enter school?" are two examples of interview questions.

Data Analysis

Instead of developing a new theory explaining how Chinese parents interpreting their advocacy experiences for their children with ASD, this is a study aiming at unfolding meanings hidden underneath the narratives of participants' experiences (Sohn et al., 2017). Researchers proposed that under IPA method, researchers are supposed to utilize open-ended interview methods to elicit descriptions of participants' life experiences without relying on pre-set values (Kirn et al., 2014).

When employing IPA as a theoretical technique for a qualitative study, researchers are encouraged to adjust modular approaches in accordance with their research objectives and goals (Alase, 2017; Pietkiewicz & Smith, 2012;). Consequently, the authors followed the four-step process detailed in the following section. The first step was to read the original texts and make marginal notes. In the second step, memo writing was carried out, which functioned as a building block for all following steps of developing higher-level codes. Concentrated coding was the third phase, which meant that, after comparing initial notetaking and memo writing, codes with equivalent implications were synthesized based on the codes synthesized from the coded texts. The fourth step was to identify integration codes and to create themes. This involved deciding if themes or patterns could be created through the combination of and identification of codes that fall into the same categories and interpret the same issues. The theme forming process is as indicated on Table 2.

FINDINGS

Three primary findings emerged from our analysis: (a) guanxi plays a vital role in parental advocacy, and (b)

parents' commentary on educational rights features a self-deprecating and demoting tone, and (c) parents indicate they accept and even agree with the stigma attached to children with ASD.

Guanxi Plays a Vital Role in Parental Advocacy

When asked about their experiences enrolling their children in public schools under LRC, parents stated that their various online social networks serve as key sources of information about the implementation of LRC at various schools around the country.

We found that parents did not receive information from their children's school about inclusive education, such as eligibility requirements and expectations; instead, they relied on informal private discussions between parents on social media to obtain the information they required for their children.

'...we parents talked a lot with each other, for things like where could they go for school, which school are more inclusive and which teachers are more accepting, etc....' (Parent 2, mother of an 8-year-old boy)

'...there are a many local online parents' groups here, and we exchanged information with each other about schools, and this is important...like in our school, we have another boy with autism as well, and the teachers are kind to us...I met parents who didn't research school, and they ended up having difficulties to sign their kids up...' (Parent 3, mother of an 8-year-old girl)

Moreover, according to the findings of this study, inclusive education is most closely associated with the attitudes of school administrators, particularly those of principals, toward inclusion. From the descriptions of parents, two distinct viewpoints on principals emerge: accepting with conditions and rejecting without exceptions.

'...and the principal came to me and asked me to go to school with my son, and he said if I could do this, my son will be allowed to stay at the school...' (Parent 1, mother of a 10-year-old boy)

'...the principal was newly appointed, and he was cautious because there was a kid with autism at the school and that kid once ran away from school...no matter how I promised him my son would not be that way...he just seemed did not want to get involved with any trouble and he turned us down....' (Parent 10, mother of a 13-year-old boy)

About principals' attitudes toward inclusive education, the data revealed that guanxi played a role in whether child with disability was admitted into public school or denied admission altogether. Parents whose social network included school principals appeared to be more likely to

Table 2. Themes and Codes

Themes	Focused Codes	Texts
Theme 1: Guanxi Plays a Vital Role in Parental Advocacy	<p>Online parents' groups are a valuable source of information for parents.</p> <p>School principals have a critical role in determining the educational placement of students with ASD.</p> <p>Parents are aware of the critical role of social capital (guanxi) in determining their children's school placement and have taken proactive steps to get one.</p>	<p>"...we parents talked a lot with each other, for things like where could they go for school, which school are more inclusive and which teachers are more accepting, etc...." (Parent 2, mother of an 8-year-old boy)</p> <p>"...there are a many local online parents' groups here, and we exchanged information with each other about schools, and this is important...like in our school, we have another boy with autism as well, and the teachers are kind to us...I met parents who didn't research school, and they ended up having difficulties to sign their kids up..." (Parent 3, mother of an 8-year-old girl)</p> <p>"...and the principal came to me and asked me to go to school with my son, and he said if I could do this, my son will be allowed to stay at the school..." (Parent 1, mother of a 10-year-old boy)</p> <p>"...the principal was newly appointed, and he was cautious because there was a kid with autism at the school and that kid once ran away from school...no matter how I promised him my son would not be that way...he just seemed did not want to get involved with any trouble and he turned us down...." (Parent 10, mother of a 13-year-old boy)</p> <p>"...if you don't live in this school district, you need to find a guanxi, you know, as we Chinese say, a guanxi matters most..." (Parent 3, mother of an 8-year-old girl)</p> <p>"...it is because I worked in that school, so it was convenient for me to arrange for him for schooling..." (Parent 5, mother of a 10-year-old boy).</p> <p>"...you just asked me why I could get him into that school? Well, I guess that has something to do with our social status. ...the principal and I graduated from the same university, and I know he does not help just any parent who asked for help...I heard that another boy with autism whose dad is a famous surgeon get admitted by them..." (Parent 9, mother of an 8-year-old boy).</p>
Theme 2: Parents' Commentary on Educational Rights Features a Self-Deprecating and Demoting Tone	<p>Parents believe that educational rights are conditional on an individual's capacity to learn.</p>	<p>"...I believe that educational right is a human right to everyone, but there is a hierarchy as to what education one gets...I mean his stay in the classroom impedes others from learning, that would be unfair to other children, too...other children in the classroom are also flowers of our country..." (Parent 1, mother of a 10-year-old boy)</p> <p>"...I am quite supportive to say that it is a human right...and it depends on the abilities of the kid...if they lack the abilities to sit and study as other children do, they will interfere with the study of others, and in that case, it would be better to place them under special institutions..." (Parent 11, mother of an 8-year-old boy)</p>

	<p>Parents stressed the necessity of adhering to the group's rules and refraining from interfering with others.</p> <p>While parents expressed varying attitudes on academic success, they were concerned about the negative effects of falling behind in academic performance.</p>	<p>"...I feel that if a person didn't do as most people do, that would make them annoying, and I just wish he could hide well among regular people... and other people would just look at him as a weirdo and point fingers at us as bad parents..." (Parent 6, mother of a 7-year-old boy)</p> <p>"...you should not interfere with others, I mean if you were falling back in academics, they might be okay with it, but if you interfere with the class, they won't be tolerating with you anymore..." (Parent 12, father of a 11-year-old boy)</p> <p>"...I am worried about his academic performances...what will happen if he just keeps falling behind from the class?" (Parent 1, mother of a 10-year-old boy)</p> <p>"...I don't care about his academic progress at all, but I am afraid of the damages it will bring to his confidence and self-esteem because of the poor performances of academics under the current regular public school..." (Parent 5, mother of a 10-year-old boy)</p>
<p>Theme 3: Parents Indicate They Accept and Even Agree with the Stigma Attached to Children With ASD</p>	<p>Bullies from different stakeholders happened at school to both parents and their children with ASD</p> <p>Parents chose to explain and rationalize school bullies as a character-training process.</p> <p>Parents indicated a understanding of the discrimination and stigma associated with children with ASD.</p>	<p>"...the teachers, they resist implementing the policy (learning in the regular classroom policy) ...they wish us could exist in the classroom like a garbage can and not make any noise or make any trouble so they could tolerate us in the classroom..." (Parent 16, mother of a 5-year-old girl and a 13-year-old boy both diagnosed with ASD)</p> <p>"...the other day there was a little girl came up to me and asked, "what is wrong with your son? My mom wants to know what kind of disease he has got..." (Parent 16, mother of a 5-year-old girl and a 13-year-old boy both diagnosed with ASD)</p> <p>"...I think it is not the right mindset to worry about bullies all the time because it always happens, and it is all right if it happens...his ability will be improved in handling things like this..." (Parent 4, mother of a 7-year-old boy)</p> <p>"...there is no real bullies, I mean there are kids in his class and they called him stupid and weird, that's all about it ..." (Parent 11, mother of a 8-year-old boy)</p> <p>"...I mean it [perspective on educational right] depends on where you stand, like, I am a mom of a child with ASD, I sure wish he could stay in the regular classroom no matter what...but if I were a mom of a typical kid, I would not wish them to have classmates who have ASD..." (Parent 8, mother of a 6-year-old boy)</p> <p>"...you can't expect tolerance from others without limits...if other parents view him as a source of bad impacts to their children, surely they would go against us and want us to leave..." (Parent 10, mother of a 13-year-old boy)</p>

enroll their children in public schools, according to the findings. When it comes to the successful implementation of inclusive education, which is defined as the identification of children with disabilities in public schools, the term “guanxi” has been used to refer to informal networks of people rather than explicit written criteria in policy.

‘...if you don’t live in this school district, you need to find a guanxi, you know, as we Chinese say, a guanxi matters most...’ (Parent 3, mother of an 8-year-old girl)

‘...it is because I worked in that school, so it was convenient for me to arrange for him for schooling...’ (Parent 5, mother of a 10-year-old boy).

According to the information shown above, the right to an education is not equally available to all children in China. It suggests that parents of children with ASD may consider using their social capital to gain access to regular education classrooms for their children with autism from principals and instructors, according to the study.

Parents’ Commentary on Educational Right Features a Self-Deprecating and Demoting Tone

A similar thinking emerged among majority parents (14 out of 16 parents) who took part in this study when asked about their thoughts on the right to education: it is a human right, but it is subject to some restrictions and limitations. They were particularly anxious about the prospect that their children would be regarded as interfering with other people’s educational opportunities.

‘...I believe that educational right is a human right to everyone, but there is a hierarchy as to what education one gets...I mean his stay in the classroom impedes others from learning, that would be unfair to other children, too...other children in the classroom are also flowers of our country...’ (Parent 1, mother of a 10-year-old boy)

‘...I am quite supportive to say that it is a human right...and it depends on the abilities of the kid...if they lack the abilities to sit and study as other children do, they will interfere with the study of others, and in that case, it would be better to place them under special institutions...’ (Parent 11, mother of an 8-year-old boy)

When asked about the possible benefit of their children in the classroom, parents expressed that they understood the value of not interfering with others’ learning and their children might benefit from the class if they followed the class rules as their classmates did. This could be because academic success is viewed as more essential for typically developing students.

‘...I am worried about his academic performances... what will happen if he just keeps falling behind from the class?’ (Parent 1, mother of a 10-year-old boy)

‘...I don’t care about his academic progress at all, but I am afraid of the damages it will bring to his confidence and self-esteem because of the poor performances of academics under the current regular public school...’ (Parent 5, mother of a 10-year-old boy)

Parents indicated their children’s academic ability was essential, however there was a lack of individualized accommodations and support provided by schools to meet the needs of their child with ASD. Low academic performance was regarded as a burden in the classroom and would deepen the stigma and discrimination against the students with ASD. Further, the fear of being accused of fault by others due to their child’s disruptive behaviors may cause parents to hesitate to pursue and advocate the service right of education to their children with ASD.

Parents Indicate They Accept and Even Agree with the Stigma Attached to Children with ASD

As a result, when parents were asked about their experiences advocating for the right to an education in public schools, they shared instances and events involving bullying and discrimination with their children and with themselves as parents.

‘...yes my major concern for her is that she will be bullied at school because it happened before...because she cannot defend herself when being blamed for things she didn’t do... there was a girl in her class who turned her into teachers and said my daughter stole her pen, I knew it is not her, but she could not defend for herself and did not seem care about it... so I dealt with this issue with that girl’s mom...’ (Parent 3, mother of an 8-year-old boy)

In the situations where parents are physically present in the classroom, it is often a source of embarrassment and makes them the targets of discrimination.

‘...the teachers, they resist implementing the policy (learning in the regular classroom policy) ...they wish us could exist in the classroom and not make any noise or make any trouble so they could tolerate us in the classroom...’ (Parent 16, mother of a 5-year-old girl and a 13-year-old boy both diagnosed with ASD)

Under these situations, parents expressed worries about incidents of bullying coming along with discrimination. However, 5 out of 16 parents showed a different attitude toward bullies at school. They seemed to adopt a kind of “tough love” attitude in which they constructed bullying as constituting necessary life lessons for their children.

‘...I think it is not the right mindset to worry about bullies all the time because it always happens, and it is all right if it happens...his ability will be improved in handling

things like this... (Parent 4, mother of a 7-year-old boy) (Author et al., 2021)

As an example of how parents seem to accept stigma, some parents indicated they not only understand why other parents of children do not want their children to stay in the same classroom but also that they would do the same thing if they were parents of typically developing children.

'...I mean it [perspective on educational right] depends on where you stand, like, I am a mom of a child with ASD, I sure wish he could stay in the regular classroom no matter what...but if I were a mom of a typical kid, I would not wish them to have classmates who have ASD...' (Parent 8, mother of a 6-year-old boy)

'...you can't expect tolerance from others without limits...if other parents view him as a source of bad impacts to their children, surely they would go against us and want us to leave...' (Parent 10, mother of a 13-year-old boy)

The data indicated that the absence of any help with behavior issues left parents more vulnerable and fearing for the possible results of being rejected by teachers or other parents due to safety concerns. Furthermore, parents are regarded as the only ones responsible for preventing and dealing with school problem behaviors. Several parents in this study reported volunteering extensive amounts of time to serve as aides to their children.

DISCUSSION

Understanding how special education is practiced in China requires listening to parents' voices, as they play a pivotal role in obtaining services and maintaining children in general education placements (Collier et al., 2015; Cui, 2016; Ferguson, 2008). Thus, in this study we interviewed 16 parents of children with ASD in China and several themes emerged: (a) *guanxi* is vital to parental advocacy, (b) parents' commentary on educational rights features a self-deprecating tone, and (c) parents indicate they accept and even agree with the stigma attached to children with ASD. These findings furthered the understanding of Chinese parents' advocacy experiences in several ways.

The Vital Role of Guanxi in Relation to Parental Advocacy

Regarding parental advocacy, we found that many parents rely on their social networks or '*guanxi*' to ensure their children receives an inclusive education. This finding is not surprising given that the ambiguity of LRC and the lack of accommodation to children with ASD

at public school (McCabe, 2007; Xiao et al., 2014; Xu et al., 2018). The LRC policy is not a formal system of legal entitlement and dispute resolution mechanism as in IDEA. It lacks accountability when schools refuse to have a child in regular school due to challenging behavior issues. Further, it does not have guidelines pertaining to formal procedures for determining placement nor educational services needed by students to succeed in least restrictive environments. Thus, in the absence of due process mandated by law, parents in China are left to rely on *guanxi* to enroll their child in public school and not to be placed in a segregated school. They had to rely on principals, who has extensive power and discretion to decide a child's placement, to allow their child to be educated with their peers without disabilities. For example, a principal may recommend a child with ASD to attend a segregated school due to the lack of resources.

Another finding regarding social network is that parents depend on their social network to obtain information, which is one of the benefits of social capital (Hill & Dunbar, 2003). When navigating the inclusive education resources, instead of looking for information formally released by school districts participants reported their reliance on "hearsay", or the second-hand information circulated in the parents' online groups shared by parents with similar experiences. This finding is consistent with prior research that indicated that, Chinese society tends to rely on "*guanxi*" (personal relationships) between parties for a potential transaction, rather than resorting to laws and law enforcement. This provides the basis for trust and is, therefore, a source of stability (Chen, 1999).

It is important to note that our sample was made up almost entirely of well-educated parents with middle to high income levels. Given the relatively high socio-economic status, these parents are more likely to have a large and powerful social network (Bourdieu, 1990). However, even given these advantages, they had considerable difficulty obtaining access to schooling and many had to devote considerable time and resources that went beyond what is normally expected of a parent. This finding suggests a future research direction needing to focus more on advocacy among parents from low social economic status and their experience advocating for their child with ASD.

Parents' Commentary on Educational Rights Features a Self-deprecating Tone

In this study, we found that parents are using a self-deprecating tone when asked about their perspectives on their children's right to education with ASD. In this study, 14 out of 16 participants indicated that they believed their

child's educational rights depended on their ability and the degree to which they were teachable in the absence of additional supports. With such a mindset, parents of children with ASD seemed to be more concerned about interfering with other students in the classroom than their child's own educational rights and benefits in an inclusive classroom. This attitude is in keeping with Chinese cultural values around placing paramount importance on the wellbeing of a group over that of an individual.

Parents in this study were concerned that their child may be interfering with others' learning. This finding shows that parental advocacy in China for children with ASD is different from the early parental advocacy movement in the U.S. In the U.S., parents formed local, regional, and national organizations such as the Association for Retarded Citizens (now the ARC) for applying organized legal and political pressure at the local, state, and federal levels. Parental advocacy development adopted a bottom-up and confrontational model where parent groups were critical in providing information and exerting pressure, first through the court system and subsequently on Congress to write and enact legislation (Yell et al., 1998). Education for children with disabilities was considered as a fundamental right. By contrast, parents in China take a cooperative path by achieving individual informal arrangements with schools via using their social connections "guanxi" and view their child's right to inclusive education to be dependent on the abilities of their child. Parents even mentioned that segregated setting may be a better placement due to challenging behavior and low cognitive ability.

Researchers suggested that what defines inclusion is not a physical space, but the social belongingness and such distinction has been also discussed in the literature as "physical inclusion" vs. "social inclusion" (Kirby, 2017). Without adequate support system from public schools and training of both special and general education teachers, it is reasonable for parents to think that segregated school is a better option despite of advantages associated with inclusive education (Amor et al., 2019). Future studies need to focus on understanding supported needed by students with ASD in public schools and address these needs in collaboration with parents, researchers, as well as general and special education teachers.

Parents' Internalization of Social Stigma Attached to ASD

The absence of a legal safeguard for the service right to inclusive education may also have resulted in parents internalizing the social stigma associated with ASD. Further-

more, parents may be in a vulnerable position in conflict resolution with schools because of the informal schooling agreement made via *guanxi*. In this study, parents indicated that they adopted a submissive strategy in dealing with matters concerning their children's education, which entails maximizing attempts at integration while avoiding conflict. In this case, parents have a diminished involvement in making or influencing any decision on their children's placement at school or school requests regarding their parental roles. We found that parents endure prejudice and stigma because of low acceptability toward ASD at school. Out of the 16 parents, 12 reported incidences of bullying at school directed towards their children and themselves as parents from a variety of stakeholders, including students without disabilities and their parents, schoolteachers, and school administrators. In this situation, some parents may have chosen to rationalize the mistreatment by perceiving it as a means of fostering adaptability or experiences that may prepare their growing children for adulthood when they will have to deal with social stigma. Future research needs to understand how parents cope with stigma, the reasons why they consider bullying as necessary life lessons for their children, and ways to reduce stigma toward individuals with ASD and their families.

CONCLUSIONS AND IMPLICATIONS

The purpose of this study was to examine parents' perceptions on their children's education in an inclusive classroom following the implementation of LRC and this study contributes to an empirical investigation of parental advocacy experiences in China. In the process of advocating for the educational rights of their children with ASD, parents have been found to face a few obstacles, ranging from a lack of trained specialists to inadequate and undeveloped legal safeguard. In response, parents sought assistance from personal ties and justified and internalized the stigma associated with ASD. It is necessary to comprehend parents' experiences to get insight into the current difficulties of inclusive education in China and to determine the path of future progress.

Regarding the implications for practice and policy of the present study, we propose the following: (1) Our results highlight the need of implementing measures to guarantee the LRC policy is carried out. This may include fostering cooperation between general education and special education instructors as well as boosting the number of special education teachers in public schools. It is not feasible to require a parent working full-time at

a school to provide services for their children. Training support staff, such as paraprofessionals, is critical to the educational achievement of kids with ASD; (2) Just as children with ASD need a great deal of help, their parents who advocate for their rights often experience tremendous stress. Consequently, it is important to guarantee that children with ASD have access to public education regardless of their parents' financial situation or the severity of their condition through legal mandates; and (3) Children with ASD continue to face social stigma attached to their disabilities. The stigmatization of ASD means a greater emphasis must be placed on ASD awareness education and more advocacy initiatives are needed in the public discourse.

LIMITATIONS

There are several limitations to this research. First, participants in this research were recruited from online parents' groups. This recruitment method may have excluded parents who have no access to online resources or are not interested in online networking. Therefore, the result may not be generalized to students in different family backgrounds. The second limitation is the small sample

pool (16 participants), which could be biased and limited due to the small sample size. Finally, all participants in this study have a college degree and have a household income that is above the average level. It is very likely that the experience of parents who are from more disadvantageous backgrounds may have even less support and may experience more helplessness compared to parents interviewed in this study.

DISCLOSURE STATEMENT

This article's authors have stated that they have no potential conflicts of interest related to the research, authorship, and/or publication of the piece.

ACKNOWLEDGEMENT

None.

DISCLOSURE STATEMENT

This article's authors have stated that they have no potential conflicts of interest related to the research, authorship, and/or publication of the piece..

FUNDING

None.

REFERENCES

- Amor, A. M., Hagiwara, M., Shogren, K. A., Thompson, J. R., Verdugo, M. Á., Burke, K. M., & Aguayo, V. (2019). International perspectives and trends in research on inclusive education: A systematic review. *International Journal of Inclusive Education*, 23(12), 1277-1295.
- Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education and Literacy Studies*, 5(2), 9. <https://doi.org/10.7575/aiac.ijels.v.5n.2p.9>
- Bourdieu, P., & Passeron, J. C. (1990). *Reproduction in education, society and culture* (Vol. 4). Sage.
- Chen, A. H. (1999). Toward a legal enlightenment: Discussions in contemporary China on the rule of law. *UCLA Pac. Basin LJ*, 17, 125.
- Coleman, J. S. (1988). Social capital in the creation of human capital. *American journal of sociology*, 94, S95-S120.
- Collier, M., Keefe, E. B., & Hirrel, L. A. (2015). Listening to Parents' Narratives: The Value of Authentic Experiences with Children with Disabilities and Their Families. *School Community Journal*, 25(2), 221-242.
- Cui, F. (2016). A good example of parent advocacy for rights in inclusive education in China. *Frontiers of Law in China*, 11(2), 323-338. <https://doi.org/10.3868/s050-005-016-0018-4>

- De Boer, A., Pijl, S. J., & Minnaert, A. (2010). Attitudes of parents towards inclusive education: A review of the literature. *European Journal of Special Needs Education, 25*(2), 165–181. <https://doi.org/10.1080/08856251003658694>
- Fish, W. W. (2006). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education, 127*(1), 56-68.
- Ferguson, P. M. (2008). The doubting dance: Contributions to a history of parent/professional interactions in early 20th century America. *Research and Practice for Persons with Severe Disabilities, 33*(1–2), 48–58. <https://doi.org/10.2511/rpsd.33.1-2.48>
- Ge, Z., & Zhang, Y. (2019). Disability status and student outcomes over time in regular classrooms: Evidence from a national panel survey in China. *Children and Youth Services Review, 105*(August), 104460. <https://doi.org/10.1016/j.childyouth.2019.104460>
- Gold, T., Gold, T. B., Guthrie, D., & Wank, D. (Eds.). (2002). *Social connections in China: Institutions, culture, and the changing nature of guanxi* (No. 21). Cambridge University Press.
- Holcomb-McCoy, C., & Bryan, J. (2010). Advocacy and empowerment in parent consultation: Implications for theory and practice. *Journal of Counseling & Development, 88*(3), 259-268. <https://doi.org/10.1002/j.1556-6678.2010.tb00021.x>
- Huang, A. X., Jia, M., & Wheeler, J. J. (2013). Children with autism in the People's Republic of China: Diagnosis, legal issues, and educational services. *Journal of Autism and Developmental Disorders, 43*(9), 1991-2001.
- Hu, B. Y., Mak, M. C. K., Zhang, C., Fan, X., & Zhu, J. (2018). Chinese parents' beliefs about the importance and feasibility of quality early childhood inclusion. *International Journal of Disability, Development and Education, 65*(2), 163-182.
- Hu, B. (2020). "Castles in the Air": Kindergarten Directors' Perspectives on Inclusion in China. *International Journal of Early Childhood Special Education, 12*, 289–301. <https://doi.org/10.9756/int-iecse/v12i1.2010011>
- Hwang, K. K. (2004). Social connections in China: Institutions, culture, and the changing nature of guanxi. *Contemporary Sociology, 33*(5), 572.
- Hwang, D. B., Golemon, P. L., Chen, Y., Wang, T. S., & Hung, W. S. (2009). Guanxi and business ethics in Confucian society today: An empirical case study in Taiwan. *Journal of Business Ethics, 89*(2), 235-250.
- Kirby, M. (2017). Implicit assumptions in special education policy: Promoting full inclusion for students with learning disabilities. In *Child & Youth Care Forum* (Vol. 46, No. 2, pp. 175-191). Springer US.
- Lindsay, G., & Dockrell, J. E. (2004). Whose Job Is It? Parents' Concerns About the Needs of Their Children with Language Problems. *Journal of Special Education, 37*(4), 225–235. <https://doi.org/10.1177/00224669040370040201>
- Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic inquiry, 289*(331), 289-327.
- Lipkin, P. H., & Okamoto, J. (2015). The individuals with disabilities education act (IDEA) for children with special educational needs. *Pediatrics, 136*(6), e1650–e1662. <https://doi.org/10.1542/peds.2015-3409>
- Malinen, O. P., Savolainen, H., & Xu, J. (2012). Beijing in-service teachers' self-efficacy and attitudes towards inclusive education. *Teaching and Teacher Education, 28*(4), 526-534. <https://doi.org/10.1016/j.tate.2011.12.004>
- Mayfair, Y. M. (2002). The Resilience of Guanxi and Its New Deployments : A Critique of Some New Guanxi Scholarship Author (s): Mayfair Mei-hui Yang Source : The China Quarterly , No . 170 (Jun . , 2002) , pp . 459-476 Published by : Cambridge University Press on behalf of th. *The China Quarterly, 170*(170), 459–476.
- Meng, D., & Zhiyong, Z. (2007). The Chinese" learning in a regular classroom" and Western inclusive education: comparison and exploration. *Chinese Education & Society, 40*(4), 21-32. <https://doi.org/10.2753/CED1061-1932400402>
- McCabe, H. (2003). The Beginnings of Inclusion in the People's Republic of China. *Research and Practice for Persons with Severe Disabilities, 28*(1), 16–22. <https://doi.org/10.2511/rpsd.28.1.16>
- McCabe, Helen. (2007). Parent Advocacy in the Face of Adversity: Autism and Families in the People's Republic of China. *Focus on Autism and Other Developmental Disabilities, 22*(1), 39–50. <https://doi.org/10.1177/10883576070220010501>
- McCabe, H., & Deng, G. (2018). "So They'll Have Somewhere to Go": Establishing Non-governmental Organizations (NGOs) for Children with Autism in the People's Republic of China. *Voluntas, 29*(5), 1019–1032. <https://doi.org/10.1007/s11266-017-9879-4>
- National Bureau of Statistics of China. (2021). Households' Income and Consumption Expenditure in 2020. http://www.stats.gov.cn/english/PressRelease/202101/t20210119_1812523.html
- Noon, E. J. (2018). Interpretive Phenomenological Analysis: An Appropriate Methodology for Educational Research? *Journal of Perspectives in Applied Academic Practice, 6*(1), 75–83. <https://doi.org/10.14297/jpaap.v6i1.304>
- Ochoa, T. A., Erden, E., Alhajeri, O., Hurley, E., Lee, K., Ogle, L., & Wang, T. (2017). Disability laws and special education provisions in China, Kuwait, South Korea, Turkey, and the United States. *International Journal of Special Education, 32*(2), 325–354.

- Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii. *Czasopismo Psychologiczne*, 18(2), 361-369.
- Sohn, B. K., Thomas, S. P., Greenberg, K. H., & Pollio, H. R. (2017). Hearing the Voices of Students and Teachers: A Phenomenological Approach to Educational Research. *Qualitative Research in Education*, 6(2), 121. <https://doi.org/10.17583/qre.2017.2374>
- Burke, M. M. (2013). Improving parental involvement: Training special education advocates. *Journal of Disability Policy Studies*, 23(4), 225-234.
- Small ML. (2009) *Unanticipated Gains: Origins of Network Inequality in Everyday Life*. Oxford University Press
- Su, X., Guo, J., & Wang, X. (2020). Different stakeholders' perspectives on inclusive education in China: parents of children with ASD, parents of typically developing children, and classroom teachers. *International Journal of Inclusive Education*, 24(9), 948-963. <https://doi.org/10.1080/13603116.2018.1502367>
- Trainer, A. A. (2010). Reexamining the Promise of Parent Participation in Special Education: An Analysis of Cultural and Social Capital. *Anthropology & Education Quarterly*, 41(3), 245-263. <https://doi.org/10.1111/j.1548-1492.2010.01086.x>
- Wang, X., & Woo, W. T. (2011). The size and distribution of hidden household income in China. *Asian Economic Papers*, 10(1), 1-26.
- Xiao, X., Liu, P., Chen, Z., & Zhang, D. (2014). A study on the development status and policy implementation of special children enrolled in LRC -- a case study of Guangzhou. *Journal of Educational Development*, 4, 22-26. <https://doi.org/10.16215/j.cnki.cn44-1371/g4.2014.04.031>
- Xie, A., & Postiglione, G. A. (2016). Guanxi and school success: an ethnographic inquiry of parental involvement in rural China. *British Journal of Sociology of Education*, 37(7), 1014-1033. <https://doi.org/10.1080/01425692.2014.1001061>
- Xu, S. Q., Cooper, P., & Sin, K. (2018). The 'Learning in Regular Classrooms' initiative for inclusive education in China. *International Journal of Inclusive Education*, 22(1), 54-73. <https://doi.org/10.1080/13603116.2017.1348547>
- Xu, Y., & Zhu, M. (2016). "Pain" and "Difficulty" of Integrated Education for Children with ASD in China. *Modern Special Education*, 19. <https://doi.org/10.3969/j.issn.1004-8014.2016.10.008>
- Yell, M., Rogers, D., (1998). The legal history of special education: What a long, strange trip it's been! *Journals.Sagepub.Com*. Retrieved July 20, 2019, <https://journals.sagepub.com/doi/abs/10.1177/074193259801900405>
- Yell, M. L. (2019). *Endrew F. v. Douglas County School District (2017): Implications for educating students with emotional and behavioral disorders*. *Behavioral Disorders*, 45(1), 53-62. <https://doi.org/10.1177/0198742919865454>
- Yu, L., Stronach, S., & Harrison, A. J. (2020). Public knowledge and stigma of autism spectrum disorder: Comparing China with the United States. *Autism*, 24(6), 1531-1545. <https://doi.org/10.1177/1362361319900839>
- Zhang, C. (2017). 'Nothing about us without us': the emerging disability movement and advocacy in China. *Disability & Society*, 32(7), 1096-1101. <https://doi.org/10.1080/09687599.2017.1321229>
- Zhang, S., Liu, W., & Liu, X. (2012). *Investigating the Relationship Between Protestant Work Ethic and Confucian Dynamism: An Empirical Test in Mainland China*. <https://doi.org/10.1007/s10551-011-0993-8>
- Zhao, B., & Jiang, X. (2014). 'The Problems and Relevant Countermeasures in Qualified Teacher Training for Disabled Children and Juveniles' Learning in Regular Classes in China'. *Journal of Suihua University*, 34(4), 5-9. <http://www.cqvip.com/qk/97851a/201404/49087609.html>
- Zhou, B., Xu, Q., Li, H., Zhang, Y., Wang, Y., Rogers, S. J., & Xu, X. (2018). Effects of parent-implemented Early Start Denver Model intervention on Chinese Toddlers with autism spectrum disorder: A non-randomized controlled trial. *Autism Research*, 11(4), 654-666. <https://doi.org/10.1002/aur.1917>