

# Understanding the experiences and needs in autism education: A semi-structured interview among Chinese American parents of autistic children

Autism & Developmental Language Impairments  
Volume 8: 1–16  
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DOI: 10.1177/23969415231217191  
journals.sagepub.com/home/dli



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## Abstract

**Background and Aims:** The diversity of the autistic population seeking professional services and education in the United States has increased. As the diagnosis of autism increases among the Chinese American immigrant population, there is also an increasing need to learn about this population and provide appropriate intervention and education for this group. However, current education and intervention provided for autistic individuals tend to be culturally blind. Gaps were found in our understanding of the cultural context and its relationship with the education mechanisms among Chinese American autistic families. The current study intends to investigate how Chinese American parents perceive the education materials and intervention strategies received by their autistic children as well as their experiences and needs in the education process.

**Method:** Semi-structured interviews were conducted among 10 Chinese American parents (one father and nine mothers) online. They all had children who had a formal diagnosis of autism spectrum disorder and received some intervention or education. Thematic analysis was used to analyse the results.

**Results:** The study suggested that most Chinese American parents were satisfied with the current education materials and intervention strategies provided to their autistic children. Due to cultural-related stigma, parents differ in their perceptions of children's autism diagnosis and characteristics as well as their expectations of children's culturally sensitive education. A theoretical model was created to provide culture-centered interpretation of the interconnected relationship between their pre- and post-immigration contexts and parenting attitudes.

**Conclusions:** Culture plays a critical role in understanding Chinese American parents' experiences, needs, and expectations of culturally sensitive education for their autistic children. Interconnected relationships were found between contexts and parenting attitudes, which were largely influenced by cultural-related stigma.

**Implications:** Suggestions and implications were provided for institutions and professionals working with Chinese American families and children. It is critical for them to learn about the experiences, needs, and attitudes of Chinese American parents to provide Chinese American autistic children with more appropriate and culturally sensitive education.

## Keywords

Autism spectrum disorder, Chinese American parents, cultural sensitivity, online interview, theoretical model

## Introduction

Autism spectrum disorder is a neurological diagnosis characterised by persistent differences in social communication and

interaction as well as restrictive and repetitive behaviours, interests, or activities (American Psychiatric Association, 2013). However, cross-cultural research has illustrated that there are broad differences in cultural beliefs about

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the cause, diagnosis, and characteristics of autism. Characteristics of autism may appear similarly across groups but can be reported and interpreted differently by various culture groups (La Roche et al., 2018; Matson et al., 2011). Many community-based studies showed that both cultural and structural factors can influence families' perceptions of developmental disabilities, and immigrant families' understanding of autism is often connected with their native culture (Baker et al., 2010; Kang-Yi et al., 2018).

However, for immigrant communities in the United States, they are often underserved when it comes to education for their autistic children. Stress and concerns are expressed by parents due to inability to find appropriate education services for their autistic children, especially in Asian American families (DeLambo et al., 2011; Sakai et al., 2019). At the same time, current interventions provided to autistic children tend to be culturally blind (Kang-Yi et al., 2018). Training for professionals who provided education for autistic children often lacked consideration of cultural sensitivity in the United States (Grinker et al., 2015; Wilder et al., 2004). More emphasis was put on children's autistic traits rather than their cultural needs in inclusion practices (Bolourian et al., 2022). For immigrant families in particular, mismatch was found between the intervention provided and families' requests (Kang-Yi et al., 2018). Because minority immigrant parents' perceptions of autism may differ from the White community, conflicts and misunderstandings exist between these parents and the service providers, which can influence autistic children's education process and deprive them of accessible education opportunities (Chiang, 2014; Jaimes, 2022).

More often, the interpretation of autistic characteristics differs across cultural groups and will be subject to changes according to the contexts (Kang-Yi et al., 2018). Acculturation refers to the process through which individuals from one culture change in their cultural awareness and understanding after long-term contact with another culture (Tosi, 2015). For instance, depending on the levels of acculturation, immigrant families in the United States may change their perceptions of autism and their choices of intervention and treatment for their children can also vary. For example, Asian American parents worried less about the social communication skills in general compared with the majority of White parents during autism intervention (Choi & Wynne, 2000). Overall, to fully understand the perceptions of autism within a cultural group, it is important to take their cultural context into consideration.

Persistent influences were found among immigrant communities when the education lacked the consideration of cultural context. The American Psychiatric Association recommends children between 18 and 24 months get screened for autism, therefore, intervention for autism can begin very early in life (La Roche et al., 2018). The increasing number and the younger age trend of the diagnosis has

led to a higher demand for educational services. Many of the services need to be continuously provided to autistic children through adulthood and therefore, access to education for these children can profoundly impact their lives (Nydén et al., 2008; St. Amant et al., 2018). As a result, to reflect cultural diversity, intervention methods and educational materials should be culturally sensitive and appropriate for autistic children (Davenport et al., 2018). Additionally, partnership and cooperation between parents and education institutions will lead the best education outcomes for autistic children, especially in special education schools (Glueck & Reschly, 2014; Miller, 2019). However, for immigrant parents, communication with school institutions might be limited due to difficulties like language barriers and cultural differences (St. Amant et al., 2018). For example, the values and definitions of academic success as well as parental involvement in children's education may vary across cultural groups, hindering parent-school communication.

Within the immigrant population, the number of Chinese Americans increased significantly over the past 10 years (US Census Bureau, 2017, 2020). Despite the increasing number, they have experienced limited access to information about education services for their autistic children due to language barriers and the stereotypes held by the community (Tosi, 2015; Tu et al., 2008; Xu et al., 2023). As a result, there is a critical need for professionals and institutions to understand Chinese American parents' needs and experiences to better serve their autistic children in the education process. However, the cultural context of Chinese American families is of importance but understudied and often misunderstood, due to the stigma embedded in cultural beliefs (Sakai et al., 2019; Tosi, 2015). From the traditional and theoretical Chinese philosophy, disability is considered as a retribution of past life and therefore should elicit negative reactions from individuals and their family (Li & Kimble, 2015). The ancient perspectives remain influential to current Chinese American society in their attitudes and beliefs towards autism and some families with autistic children still have feelings of shame due to the diagnosis. In general, compared with the White American population, Chinese Americans have a unique understanding of autism, which is largely influenced by the stigma and stereotypes attached to the disability and rooted in ancient Chinese culture.

Very few studies consider the cultural context of Chinese Americans with autistic children. In fact, many studies in this area are based on the perspectives of providers instead of parents themselves. The limited number of studies that explored the parents' expectations for autism education either targets a large population from a variety of cultural backgrounds, which does not help us understand specific cultural adaptations we could make, or focusing on a specific program or method, making generalising cultural sensitivity recommendations for this population difficult (Li & Kimble, 2015; Matson et al., 2011).

The integration of context, culture, and developmental domains is captured visually by Mistry et al. (2016) (see Figure 1). The interconnection reflects how a child and family's experience with the education system can be shaped. The current study focused on understanding the education experiences of Chinese American parents with autistic children, as well as their attitudes towards education. Contexts that interact with Chinese American families with autistic children could impact families' attitudes towards autism, therefore, rooting our interview questions in Mistry's adapted framework (2016) helps integrate both social and family contexts to give a more complete picture of what is happening in a family's life (Bronfenbrenner, 1979). For this study, Mistry's original model was adapted to reflect the important role of parents, with "Parenting attitudes" substituted in for "Development domains" (Mistry et al., 2016; Ozturk et al., 2014).

The study addressed the following questions:

1. How do Chinese American parents perceive the education materials and intervention strategies provided to their autistic children?
2. What are some of their experiences pre- and post-immigration that may influence their understanding of the diagnosis and needs in education?
3. What improvements do parents identify for their autistic children's education?

## Method

### Procedures

Potential participants for the study were recruited via flyers posted on social media (i.e., Facebook) and email to



**Figure 1.** Integrated conceptual framework for Asian American children and youth (Mistry et al., 2016).

providers and cultural centres. Based on the information from the flyers, parents first completed a screening questionnaire online with basic demographic information of the family and their autistic children. Then, a semi-structured interview using online meetings via Zoom was scheduled. All interviews were conducted in Mandarin, the native language of participants, by the researcher, a native speaker of Mandarin. The interview was recorded, and consent was obtained verbally. Each participant was compensated with a \$20 gift card. All interviews were transcribed verbatim into Chinese and then translated into English by bilingual research assistants who were fluent in both languages. All data were also proofread and back-translated into Chinese by an experienced bilingual transcriber. To protect the privacy and the confidentiality of the participants, all the names were replaced with pseudonyms and identifying information was removed from the transcription. All procedures of the study were approved by the Tufts University, Social, Behavioral & Educational Research Institutional Review Board (SBER IRB).

### Participants

Participants were parents born in China and then moved to the United States afterwards. They all had children with a formal diagnosis of autism and received some intervention or education. Thirteen parents completed the screening questionnaire. Based on the results of the screening questionnaires, two of them were not from China and one had children without autism diagnosis. They were all excluded from the study. A total of 10 Chinese American parents, one father and nine mothers, participated in the interviews. According to Hennink and Kaiser (2022), 9–17 participants are usually sufficient for a qualitative interview. The new information threshold was below 5% after nine interviews with three interviews as base size and two as run length (Guest et al., 2020). Therefore, 10 participants were sufficient to achieve data saturation for the study. Demographics are summarised in Table 1.

### Data collection tools

**Screening questionnaire.** The screening questionnaire was used to get basic demographic information about Chinese American parents, including name, birthplace, occupation, education levels and length of time they lived in the United States. The information provided backgrounds in participants' experiences in the United States, which indicated their engagement into the U.S. culture. The questionnaire also asked parents information about their autistic child, including age, gender, birth order, number of siblings, diagnostic history for their children (e.g., when and where their children were diagnosed with autism), and autistic-related services received by the child (Supplementary Appendix A). As it could be hard to get authentic information

**Table 1.** Descriptive statistics for parents and autistic children ( $n = 10$ ).

Child characteristics	M	SD	Range
Current child age (years:months)	8:2	2:5	4:0–11:3
Age of diagnosis (years:months)	3:8	4:2	1:9–8:6
Birthplace			N (%)
China			4 (40)
United States			6 (60)
Child gender (identified by parents)			
Male			7 (70)
Female			3 (30)
Education			
Speech therapy			10 (100)
Special education program			10 (100)
Clinical therapy			6 (60)
Behavioural therapy			6 (60)
With IEP			9 (90)
With 504			1 (10)
Parent characteristics	M	SD	Range
Year in the United States (years: months)	7:5	2:8	2:1–11:0
Education levels			N (%)
Associate			3 (30)
Master			6 (60)
PhD			1 (10)
Occupations			
Dinning services			1 (10)
Self-employed			4 (40)
Manager			1 (10)
Unemployed			2 (20)
Not disclosed			2 (20)
Current family characteristics			
Family size			
Parent + child			1 (10)
Parent + child + one sibling			8 (80)
Grandparent + parent + child			1 (10)
Child rearing			
Mother as primary caregiver			9 (90)
Grandparent + mother as caregivers			1 (10)
Disclose autism diagnosis			
To immediate family (grandparents)			6 (60)
To extended family (aunts)			7 (70)

directly from Chinese American autistic children, information collected from parents provided supplementary information about their family contexts.

**Interview protocol.** A semi-structured interview was developed specifically for this study and comprised of four sections (Supplementary Appendix B):

1. *Perceptions of Educational Materials and Intervention.* This section included two major questions that asked parents to share the educational materials and intervention their children received at school and then to

comment on the cultural sensitivity. It intended to answer the first research question about parents' perceptions. The main questions included "Tell me what types of intervention strategies your child receives at school and how do you think the intervention strategies take into account your family beliefs, traditions, and culture?" and "What kinds/type of materials are provided to you to better understand or support your child by therapists or teachers? In what ways could the materials better reflect your family's beliefs, traditions, and culture?" The two questions reflected parents' understanding of education materials and strategies separately. Participants were encouraged to give examples.

2. *Expectations for Education.* This section aimed to understand the expected cultural-related education of Chinese American parents for their autistic children and give potential clinical implications and guidance for special educational programs in their curriculum design. It included one major question "What kinds of traditions or beliefs related to your culture that you wish your child were learning at school?" with follow-up question: "Are there other improvements you think need to be made?" The answers from parents showed the improvements parents identified for their autistic children's education in the last research question.
3. *Experiences and Attitudes.* This section asked about parents' understanding and explanation of their children's autistic characteristics as well as their experiences of autism diagnosis and intervention over time to answer the second research question. Five major questions were included in this section. Participants were first asked to share their children's diagnostic experiences and then a question like "Can you describe your reaction and feelings to the diagnosis?" was asked to learn about parents' acceptance of their children's diagnosis. More detailed questions about family environment were asked, such as changes of family members caring the autistic child. The questions provided rationale and background for the following questions about pre- and post-immigration context. "Have you disclosed your child's autism to your immediate or extended family, such as your parents?" was used to learn about their experiences within the family. "Do you think being Chinese ever made your child get treated differently by teachers at schools/educators in the programs/other clinicians?" and "Have you or your child ever felt discomfort with intervention processes or materials used in their learning process due to their identity as Chinese?" were used to learn about their experiences in children's education process outside family.
4. *Other Thoughts and Sharing.* This section includes only one question asking for other thoughts from parents.

Due to the uniqueness of the current study that targeted Chinese American parents about their needs and

experiences in diagnosing and educating autistic children, the questions were designed specifically for this study and have not been applied elsewhere.

### **Data analysis**

All interviews were analysed using six phases of thematic analysis approach as recommended by Braun and Clarke (2006). Six phases of this approach were followed to analyse the data: (1) Familiarisation with the Data: the first author actively read the data to immerse themselves in the data. (2) Generating Initial Codes: the first author started to generate initial coding in this phase and separated them into sections. Both the response and attitudes of parents, their reporting of the responses from their autistic children, and their restatement of the words from educational institutions were developed under each section and were coded separately. A codebook was generated at the end of this phase. (3) Searching for Themes: potential themes were identified through sorting the codes. (4) Reviewing Themes: During this phase, the authors refined themes so that both data within each theme correspond with each other in a meaningful way and there were clear and distinguishable differences between themes (Braun & Clarke, 2006; Patton, 1990). (5) Defining and Naming Themes: After creating the final thematic map, the authors started to name each theme and sub-theme in a concise and conclusive way. (6) Producing the Report: In this final phase, all themes were gathered at this phase to report the results.

All themes identified were largely related to the responses of parents with an inductive approach to capture the diverse attitudes and suggestions from participants because the study had no pre-existing coding frame and preconceptions. A few decisions were made in the analysis process. Given that the current study had a limited sample size in representation of Chinese American parents with autistic children, the consideration of themes was not limited by the quantifiable factor (e.g., more frequent appearance of related codes did not necessarily mean the themes were more important). Codes were not excluded only because they appeared less frequently if they were relevant to the research questions. In addition, the analysis focused on an in-depth and detailed interpretation of a particular group of themes rather than a rich thematic description of the entire dataset. Themes identified were largely related to the responses of parents at both semantic/explicit level and latent/interpretive level (Braun & Clarke, 2006). For this study, both the direct responses, the latent themes, and the underlying meaning, ideas, and assumptions made by parents were important elements to consider and were identified in the analysis.

### **Authors' positionality**

We understand the privileges we possess from our educational and professional backgrounds. The first author was

born in China and stayed in the United States for approximately 9 years for education and had experiences working with autistic children and families both in Chinese and U.S. education institutions. The experiences provided cultural background as well as bias for the author to understand both pre- and post-immigration environment of Chinese American families. The author might be more critical of Chinese practices around education on autistic children and focused more on stigmatised perspectives when analysing the data. Questions asked in the interview related to families' experiences with diagnosis and education pre- and post-immigration were based on the author's previous working experiences interacting with different Chinese American family members in the education institutions. The author's previous experiences and familiarity with the Chinese culture helped them to avoid asking potential offending questions in the questionnaires and interviews and misinterpreting the data because of cultural differences.

Also, both authors were trained in special education settings and have worked with autistic children and their families from Chinese American communities. However, although with shared cultural background and the knowledge related to autism diagnosis, we need to acknowledge that there were diversities in our socio-economic background and education experiences compared with the participants' that may compromise the reliability and trustworthiness of the results. In particular, the second author is not Chinese, a third-generation American, and did not personally experience the special education system as a student or parent; her lack of lived experience with the examples provided by participants likely limited her deeper understanding of how stigma, stereotypes, and cultural factors impact a family's ability to advocate for certain educational goals.

## **Results**

The subsections below are organised based on the research questions, with the last two subsections summarising participants' expectations and suggestions. Themes and illustrative examples are included either in italics within the subsections or listed in tables.

### ***Perceptions of education materials and intervention***

Parents generally reported that the materials were provided, but not culturally sensitive, and that intervention strategies lacked information and cultural adaptations. Other than the two major themes, six separate themes are also identified and listed in Table 2, with three providing detailed perceptions of education materials ("Schools have no capability", "I don't know about this very much" and "It is good enough") and three of intervention strategies ("There is no solution to problems", "Problematic but not in a cultural way" and "It is good enough").

**Table 2.** Perceptions and expectation: themes identified from interviews.

Subsection	Themes	Parents' comments
Perceptions of education materials	Schools have no capability	<p>"Because he is at an American public school, and it acts according to American public education and laws ... I do not think they can get familiar with our Chinese culture and traditions."</p> <p>"Because the teachers themselves have completely no understanding of Chinese Americans, including our culture and customs. They don't know anything ... how can they teach?"</p> <p>"So, I think ... there seemed to be no way to expect the school to, to educate things in relation to family culture. I could only say that I can teach her about our family at home, and the school probably ... knows nothing about us."</p> <p>"I think the professionals know nothing about us ... they cannot understand us, Chinese culture, and tradition. Therefore, they can't teach him."</p>
	I don't know about this very much	"It's been six years ... I only know three to four things ... they did not let us know how to use things ... they are all new to me ... I don't know if they considered culture."
	It is good enough	<p>"I am satisfied ... I think those things are good enough for him. He cannot accept more."</p> <p>"The materials don't really matter ... I think they are ok now. She needs to have more connections ... with the world."</p> <p>"I can't tell anything that I don't feel dissatisfied ... He has Chinese lessons online ... with his former classmates, so the education here is enough."</p> <p>"It's good in general ... he cannot catch up with the current ones."</p>
Perceptions of intervention strategies	There is no solution to problems	<p>"There are a lot of differences in our values and beliefs ... I ended up disputing for about three months ... they insisted on some very dogmatic things ... it's not working."</p> <p>"At last, there were no solutions ... There was no way to handle this problem ... they still have no idea now."</p> <p>"Some teachers will treat this child as a machine for training ... we can do nothing because we are not experts."</p>
	Problematic but not in a cultural way	<p>"I think he needs to figure out the language first ... when he is able to speak English fluently, he will understand ... it is not a big deal."</p> <p>"He is catching up now ... he is better at English teaching ... The ways they teach him is not different, but he can learn it more effectively ... it is more related to his language ability ... not the way they taught."</p>
	It is good enough	<p>"We came here just to give my son better treatment, which he did receive ... so we are satisfied about all of them."</p> <p>"I personally believe in science, what they did before in Hospital 1 (in China) was not effective to her (the autistic child). She was painful ... it's great here in the U.S."</p> <p>"It's effective ... very effective than before ... I believe."</p>
Expectations of culturally sensitive education	Create cultural identity	<p>"You need to first identify them. Then, you may use resources from different aspects, like videos and books ... some outside activities, such as Chinatown, Chinese red color, our festivals ... to teach them."</p> <p>"To have some cultural (-related) things is always good to her."</p>
	Understand cultural background	<p>"Of course, I hope they can first learn about Chinese traditional culture."</p> <p>"At least the school need to have an Asian, a Chinese American teacher ... they can help with us much better in cultural stuff. Now, there is no single teacher with Chinese background, even teaching assistant."</p>
	Adapt materials and strategies culturally	<p>"I don't feel any discrimination or discomfort, but it would be better if there are Chinese materials."</p> <p>"The primary problem now is about the language ... the readings need to be in both languages ... so he understands better and learns quickly."</p>

(continued)

**Table 2.** Continued.

Subsection	Themes	Parents' comments
	Culturally sensitive education is not of priority	<p>They need to adapt the methods to the way my son can understand, not always have my son to adapt for them.”</p> <p>“I don't emphasise my child has to have a Chinese background here.”</p> <p>“We don't think cultural ... sensitive ... education matters ... it would probably influence his schoolwork. He could be confused.”</p> <p>“He can be like his peers ... like all the other children in his class.”</p> <p>“I don't really care about this area, you suddenly mentioned this ... I don't know.”</p> <p>“The education materials do not matter. It's her connection to others that makes me feel very worried.”</p> <p>“We do as the Romans here in Rome.”</p>

*Education materials: provided but not culturally sensitive.* All parents could recall at least one example of materials provided by the educational institutions or individual educators to their children. However, most of them agreed that there were no special materials related to Chinese American culture or their family beliefs and tradition provided specifically for their autistic children from the public and institutional education:

I did not feel their school would provide special services for her because the child is from certain country or has certain background. I think it seems to be the same for every child. (1, mother)

Actually, I think they did not do anything special because you are Asian basically ... they treat you the same in general. (4, mother)

I think there is no emphasis on the cultural aspect, about our family's belief, or cultural tradition. (7, father)

Parents also reported unpleasant experiences happened because materials were inappropriate due to the differences in cultural values between Chinese American and American culture, which caused problems for their families. One mother described her daughter's experiences in teeth-cleaning:

I think this is related to language and culture differences in understanding of some things.... Name 1 (autistic child) used to have some black teeth, because she did not want to brush her teeth. She did not like to open her mouth very much.... Her therapist saw it ... and encouraged her to go to the dentist ... she kept telling Name 1 that it's going to be good ... it won't hurt ... show her pictures of dentist like that ... She wanted to go then, so we took her to clean teeth ... the result was that she did not get washed successfully, crying and screaming all the way back home ... we stopped working with the therapist then

... I think there might be some cultural reasons, and also probably some language reasons. Like teeth-cleaning, we Chinese people think this is not a very pleasant thing and we seldom go to dentist, but the therapist and the doctor here thinks teeth are important ... and good (for cleaning). (5, mother)

one talked about a particular material, the stress ball:

My son once brought the stress ball home. A black and round one that can be squeezed ... but his father, my husband didn't know what this is at first, and the school never gave us any information about what this is or how to use it ... he was very unhappy. Their place, in Place 1, ... see this (changing shapes of black round balls) as disrespectful to ancestors. It's not good ... and ... he was very unhappy. (4, mother)

Only one parent recalled that the school once introduced Chinese New Year Festival to children and taught a song in Chinese. Two parents described that they intentionally hired educators with a Chinese American background to provide their children with cultural education, using Chinese online courses.

*Intervention strategies: lack of information and cultural adaptations.* Although all parents described that their children had special education interventions, they were mostly unaware of the specific details of the intervention, especially after their children grew up and finished home-therapy. Many of them believed that autistic children needed more assistance in language, fine, and gross motor development afterschool than what had already been provided by the institution, but they were unable to name specific strategies other than speech therapy, Applied Behavior Analysis (ABA), or occupational therapy.

However, there were still complaints from parents about the inappropriate strategies provided by the educators and

institutions, mostly due to the cultural differences and language diversity. Two parents described that Chinese lunch-time habits have led to their conflicting ideas with the educator and impacted their children's learning.

She was once in a class, and, while she was in class, it was time for lunch. There was no way for her to do both, so ... I asked the teacher if she could take a break and finish her lunch and then do the exercise ... or have lunch and do the exercise together. Then the teacher felt as if I didn't arrange the time well, which influenced his teaching. I would feel a little bit uncomfortable because we care about lunch more than the white people do. That's our most important meal, not the dinner ... She (the autistic child) was used to eat well at lunchtime ... their schedule is for white children, not for us and ... the teacher refused to change ... she was hungry and wouldn't concentrate. (1, mother)

For example, my child was often considered as yelling at school.... They wrote in the ... home note saying he was yelling and screaming ... he had problem behaviors. But this is not his fault, he carried this from our family.... We can't say this is incorrect.... In Chinese families, you have to be loudly when speaking to people ... especially elderly. This shows your politeness ... and we Chinese ... parents used loud voices to educate him. But at school, they think this child is rude and ungracious.... I heard a teacher talking to him like this.... "You don't

have to yell. This is not right. Speak quietly." He was taught against his culture.... I feel ... he was discriminated because of this ... because of our culture habits ... and he seldom talked at school then. (6, mother)

Despite the dissatisfaction with education intervention processes, the two parents did not mention any solutions they implemented to solve the problems.

### Experiences and attitudes

The experiences of autistic children getting diagnosed varied depending on their characteristics and family backgrounds. With large variations across individuals, although no themes could be summarised, some important points were raised by parents. Parents also had different attitudes to children's autism diagnosis and characteristics. Three themes are identified and described in Table 3 ("A derogatory term", "A chronic disease", "This is what he is").

**Parents' experiences.** Most parents described the improvement in their children's education environment after immigration. Two parents reported that their experiences in China were unpleasant and even traumatic:

He has some traumatic experiences back then.... He has been locked up in small dark rooms ... in kindergarten ... he was treated in this way every time he misbehaved....

**Table 3.** Parents' attitudes: themes identified from interviews<sup>a</sup>

Themes	Feelings and reactions	Parents' attitudes
A derogatory term	<p>"The feeling? I even have the desire to die ... my strongest emotional breakdown lasted for six months."</p> <p>"My wife almost breakdown at the time, like going crazy ... I was so worried that she would be insane ... we were all desperate."</p> <p>"I think my husband is self-blamed ... he thinks he made the child like this."</p> <p>"We feel terrible ... why do I have to get (have a child like) this ... but it is like this ... we can only accept it."</p>	<p>"I think in China, this is a derogatory term."</p> <p>"This is shameful to both me and his father."</p> <p>"There are all kinds of discrimination, all kinds of humiliation related to this."</p>
A chronic disease	<p>"I wish my child can be typical, but she is sick ... so this is the fact ... we need to accept it."</p>	<p>"It is like a chronic disease ... you will have to raise her carefully, for very, very long time."</p>
This is what he is	<p>"We don't really care about the diagnosis, but he needs it so he can get the services he needs in school."</p> <p>"My husband often says: "Don't pin any stickers on the child" ... she is still very young."</p> <p>"I didn't expect that she was indeed a child with special needs ... but we take what we get ... she is still our child."</p> <p>"It takes time ... he needs to learn a lot ... to grow like typically-developed children."</p> <p>"You can't tell from the outside. It's inside him ... so no need to react."</p>	<p>"I told him: 'This is you. It is one of your attributes.'"</p>

<sup>a</sup>Feelings and attitudes summarised here are those of our study participants and do not reflect the beliefs of the authors. If these feelings or attitudes cause any distress for readers, they are encouraged to seek support from a mental health professional.



So when he was touched, he would have an emotional outburst ... that means his traumatic experience is very, very strong. (6, mother)

He was taken out of the corridor or in the aisle as a punishment. (7, father)

In contrast, the social environment in the United States was described by parents as friendly to their autistic children, especially in comparison with what they experienced in China. Parents agreed that there was no targeted discrimination towards them by the whole education system after they immigrated to the United States

I don't think she (the BCBA at school) was discriminating us ... it was not because of race. (1, mother)

Part of ... unpleasant (experience) is related to our cultural differences.... I can't say it is race. (4, mother)

However, although parents reported having better environment for their autistic children in the United States compared with in China, they experienced other challenges after immigration in adapting to the United States, primarily language barriers and lack of access to special education services:

For me, my problem has a lot to do with ... language and communication with the school. (2, mother)

We struggled for more than a year, to finally find him the ABA services. (4, mother)

Non-autistic people actually don't, don't know how they could seek for help.... If Chinese Americans have special need kids, then if they did not know some connections, they actually had very few services. (5, mother)

I think, most of the time ... it is related to differences in ... understanding of things.... We could hardly find help. (8, mother)

Parents believed less family members have participated in the child-rearing progress after immigration, but the whole nuclear families were involved in the child-rearing process of autistic children:

My husband has to go to work during the day ... after he is back at night ... my husband will play with her and read to her. (1, mother)

He (the husband) shows my daughter some learning videos during weekends. (5, mother)

When talking about the hardship experienced after immigration, parents lowered the volume of their voices and slowed down in their speaking. Some cried or expressed negative emotions. For most Chinese American parents, their social environments became more positive towards their children's autism diagnosis and certain characteristics after immigration. At the same time, parents still needed to overcome new obstacles in language and culture while spending more time in child-rearing and seeking for new education services in this foreign land.

**Parents' attitudes.** Parents reported that they had different attitudes towards explicit autistic characteristics (see Table 3). Most of them cared more about characteristics with obvious and salient phenotype, especially those that affected children's daily lives, like children's language delays and behaviour problems:

They provided him ... with the social group.... He is still screaming on the playground ... in front of so many people ... that's shameful.... (4, mother)

It's mainly because the child has behavior problems ... that he needs ... one-on-one intervention ... he has a lot of language and behavior problems. (5, mother)

You must be able to communicate.... If you are not able to speak ... how ... can you have others understand you ... it's going to be hard for him ... he needs to speak.... (6, mother)

His tapping ... makes him different.... We are more worried about this. (9, mother)

However, all parents tended to use the word "this" instead of "autism" when they are referring to their children's diagnosis. Long pauses lasting from 10 to 25 s also happened when three parents were asked about their feelings surrounding their child's diagnosis. One parent even cried when talking about the pain she experienced after the diagnosis.

Parents have also noted that people in the environment, especially those in China, had impacted how they reacted to their child's diagnosis, and whether they disclosed their child's diagnosis to their families and their families' responses. Some of them chose to not disclose the diagnosis to people outside their nuclear family (see Table 1). Some also reported that the attitudes of their immediate and extended family members did not matter to their understanding of autistic children's diagnosis and education:

It's just their attitudes.... It's not going to impact us. (2, mother)

I think we were determined enough.... I don't think their ideas really matter to us. (3, mother)

I don't think they [the attitudes of aunts] are important to my understanding. (10, mother)

However, five parents admitted that growing up in Chinese culture, they were very sensitive to their reputation and afraid to lose face. Therefore, they were hesitant to disclose the diagnosis to people outside the family and two of them tried to hide their children's autistic characteristics. This is also one of the major reasons that many of them chose to move to the United States. They have realised the potential negative influences of those stigma and were therefore more satisfied with the education environment without those impacts.

### *Expectations for education*

Parents' expectations for their autistic children's education could be summarised into three domains with one theme under each domain: short-term ("focus on academic performances"), long-term ("independent in life"), and culturally sensitive education ("diverse depending on children's autistic characteristics and birthplace"). Specifically, to explain the variations in the expectations of culturally sensitive education, four subthemes are extracted and summarised in Table 2 ("Create cultural identity", "Understand cultural background", "Adapt materials and strategies culturally" and "Culturally sensitive education is not of priority").

*Short term: focus on academic performances.* Depending on their children's degree of developmental delay and display of autistic characteristics, parents focused on different areas in academic development. For children with language delays, parents expected children to at least be able to speak one language and communicate with no barriers to others. For those without language delays, parents provided children with bilingual education in English and Chinese.

*Long term: independent in life.* Five parents identified having their children be independent as a lifelong goal:

I am trying to think if ... the child can live independently, such as eating by himself, doing his hygiene, taking a shower alone, and being able to have the ability to live independently. (3, mother)

He should be able to live by himself when me and his father were gone, live independently. (6, mother)

Independence, that's the priority ... we think it is the most important thing to teach him. (7, father)

If it is really impossible for her to recover ... let her learn to be self-reliant, to take care of her own life ... personal hygiene ... cook her own meal. (8, mother)

The requirements for such independence, as proposed by parents, required the training and learning in various areas, such as in cognitive, physical, and social development.

*Culturally sensitive education: diverse depending on children's autistic characteristics and birthplace.* Eight parents responded to this topic. Five parents desperately wanted their children to receive education that was adapted to their Chinese cultural background. They reported a lack of education materials they could use. These parents also suggested some steps for public educational institutions to follow (see Table 2).

Nevertheless, an opposite idea from three parents believed that culturally sensitive education was not their major concern in their children's education process. Instead, they worried that providing culturally sensitive materials would prevent their children from assimilating into the U.S. culture. These parents had autistic children who were, according to their parents, either delayed in language development or engaged in severe behaviour problems. Finally, there are also parents also believed that it was not the school's job to provide culturally sensitive education materials to children, rather, both family and community education should take the responsibility:

We as parents had to teach our children because the school have no ability to help us. (1, mother)

I think if the school could not do enough, then the community needs to consider and help ... to educate our children. (7, father)

Of course, we will consider our own special tradition, like celebrating our New Year at home.... He should be able to learn at our home. (8, mother)

In contrast to other parents, these parents have been in the United States for more than 8 years. Their autistic children were also born in the United States and most of them were well developed in language and cognition.

### *Parents' suggestions*

Parents have provided suggestions both for their peer support group and the entire special education system in the United States. Two themes were found in suggestions for their own group ("self-advocate", "cooperation and mutual assistance"), and three for the education system ("take more initiatives in communication", "provide language assistance", "create services network").

*Parent peer group: self-advocate, cooperation, and mutual assistance.* Three parents mentioned the important role played by Chinese American cultural groups. Two of them believed that all Chinese American parents needed to speak out and have their voices heard. Other than raising the volume of their voices, one parent also emphasised the importance of cooperation and mutual assistance within the group of Chinese American parents with autistic children:

At this point, we ourselves have a help group for Chinese American parents with special need children specifically. As you probably know, it is a mutual-help group.... We share what we should do within our group ... having an organisation to tell us what to do is very important. (6, mother)

In general, parents believed that one parent's suggestions and expectations would be hard to realise, instead, they needed to unite as a group to self-advocate and make their voices heard.

*U.S. education system: take more initiative in communication and provide language assistance.* Parents shared complaints about and suggestions for the U.S. education system. The suggestions mainly targeted the content of special education services as well as how these services were distributed to families. For the content of the services, Chinese American parents suggested the education institutions have more communication with them and provide more services as well as language assistance if necessary:

I think it's just the communication with my son's therapists ... I have an accent ... it would be better to have a translator. (1, mother)

We were very worried and wanted to find special education teachers who could speak Chinese, no matter for ABA, or social group, but we could not find any more. (4, mother)

I feel there is a big disconnect between the two. (10, mother)

*U.S. education system: create services network.* Most parents complained that more services could be provided by the public schools, but none were offered unless parents requested multiple times and even threatened to start lawsuits. At the same time, parents were able to understand the lack of services in the education system and they raised two suggestions for improving the special education system: to create service networks and to disseminate information broadly in different formats:

Sometimes we are also afraid that our own deficiencies in abilities would result in delays in some interventions for

[the child's name] ... if we can have more information from more people ... to proceed on this track ... might be better. (7, father)

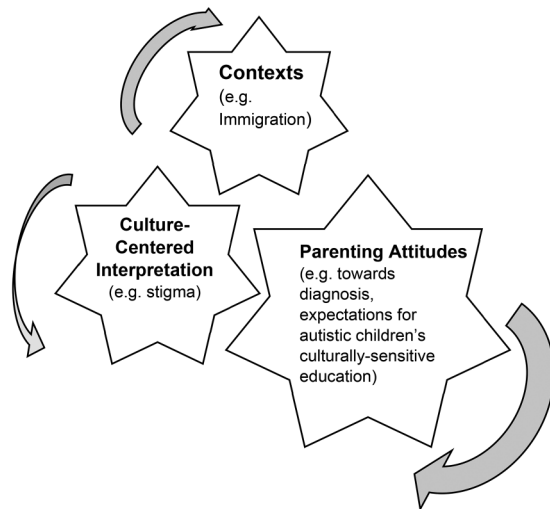
For public school ... it may be difficult for every school to have all these ... services. In State 1, for example, there are special education teachers from various cultural backgrounds in its public education system ... these services can be used to develop the network.... Using the Internet, teachers with a variety of languages and cultures ... would better serve us ... everyone can find a suitable teacher. (8, mother)

In general, Chinese American parents have provided suggestions to lower the pressure of the special education system and expected the education system to take more initiatives when providing services and information for them.

## Discussion

The current study intended to learn about the experiences and needs of Chinese American parents with autistic children in their autistic children's education process. After an inductive and interpretive analysis of the responses of parents, the results showed that most parents were satisfied with the education materials and intervention strategies provided for their autistic children in the United States. However, they varied in their expectations of whether the materials and intervention need to be adapted culturally for their children depending on children's autistic characteristics and their experiences pre- and post-immigration. Parents also indicated their diversity both in their perceptions of diagnosis and children's education after immigration and provided suggestions for educators and institutions. It is therefore important to ask Chinese American families' attitudes, beliefs, and experiences before educating their autistic children.

Given the results and based on the integrated conceptual framework, Mistry's model was adapted, with cultural-related stigma and context remaining as primary concepts, and swapping out developmental domains for parenting attitudes (Mistry et al., 2016; Ozturk et al., 2014) (see Figure 2). Themes identified in parents' attitudes and experiences reflected the important role played by Chinese cultural-related stigma, which was consistent with the adapted model. The model also explains the interconnected relationship between the context Chinese American lived in and their parenting attitudes towards the diagnosis and autistic characteristics as well as their expectations of culturally sensitive education, based primarily on how parents understand cultural-related stigma.



**Figure 2.** Model for culture-centered interpretation between context and parenting attitudes.

### *Cultural-related stigma*

Although parents did not report that cultural-related stigma influence their attitudes towards children's diagnosis and autistic characteristics, their responses showed that most underestimated the impact of their previous cultural environment in China. The unspoken word "autism" could indicate their hidden acceptance of stigma and stereotypes in Chinese traditional culture. Therefore, it is important to understand the cultural ideologies shared by Chinese American parents to interpret the relationship between the context and parenting attitudes. Traditional Chinese Medicine considers autism as a disease with a higher level of "Yin" than "Yang", which means the imbalance of energy inside the human body (Tosi, 2015). This would result in a "lack of interest/enthusiasm in social engagement and differences in social communication" (Li & Kimble, 2015, p. 130). The traditional ideologies also prioritise the importance of keeping autistic children as "normal" as possible or hiding their autistic characteristics so it will not be shameful for the family (Li & Kimble, 2015; Tosi, 2015). The stigma might have influenced how Chinese American parents perceive their children's diagnosis and reach for education services, which could account for some of their pre-immigration experiences. The results also reflected that the stigmatised ideologies became less obvious and influential to parents with their acculturation into the U.S. culture.

### *Contexts*

The major context this study focused on is immigration, which affects both family and social contexts of Chinese American parents. Immigration provided Chinese American parents with a more independent family context but potential difficulties in cultural and language aspects,

as well as a more inclusive and less discriminatory social environment but with hardship in searching for special education services. The results showed that changes in family structures and facing cultural barriers could increase parenting stress for parents with autistic children, which was also found among parents from other immigrant groups (Luelmo, 2018; Meadan et al., 2010). Variations were also found within this population in their family environment and abilities to adjust to the changes in social context. Although the current study could not provide a comprehensive picture for all Chinese American families with autistic children, it emphasised the potential changes these parents could encounter in their social and family environments, which need to be recognised and supported by educators and policies. More thorough investigation among diverse Chinese American parents with different family structures is still needed.

### *Parenting attitudes*

Universally, Chinese American parents cared most about their autistic children's ability to be independent and integrate into society. Those who had children with severe delays in development or behaviour problems expected the educational institutions to prioritise solving these problems. The length of time since they immigrated to the United States and their education levels were related to their acculturation process, which influenced the levels to which their attitudes got influenced by the cultural-related stigma and their expectations of culturally sensitive education (Krishnan, 2019). Children's ages ranged from preschool to pre-adolescent, which made them remain plastic to cultural variations and had high potential in their development and education. Parents therefore focused more on their autistic children's education needs and those who had younger children remained more optimistic to their children's education. Responses representing such a broad age range has other implications for our findings. Cohort effects would not be detectable here and given how quickly the landscape of autism has changed in the United States and internationally in recent decades, that could result in very different experiences between our youngest and oldest child participations.

In terms of autistic characteristics, Chinese American parents seemed to pay closer attention to the ones that would influence children's academic achievements and adaptations to the social environment. These characteristics are usually obvious and can easily distinguish autistic children from neurotypical children in public (American Psychiatric Association, 2013). Although the reason they provided was to help their children better merge into peer groups and become independent, further studies are needed to understand the role played by cultural-related stigma on parents' choices and emphasis on certain autistic characteristics.

Culturally sensitive education, which might emphasise differences between their autistic children and others, was therefore not a priority for all parents in their value system about children's education. Even within this small participant pool, this finding seems to be impacted by the cognitive abilities of the child. Further investigation of what types of culturally sensitive education are desired and in what contexts could help inform programming.

### *Culture-centered interpretation of interconnection between contexts and parenting attitudes*

The study showed an interconnected relationship between the contexts and parenting attitudes of Chinese American parents with autistic children. We highlight the role of cultural-related stigma played in the social and family contexts in Chinese culture, which continue to exert influence(s) on Chinese American parents' attitudes after their children's autism diagnosis to various degrees. Their expectations and needs conflicted with previous social environment, leading to their immigration and changes in social contexts.

Furthermore, parents' expectation and needs in education are also influenced by the immigration context. With the improvement in social context towards diagnosis, parents' expectations of culturally sensitive education tended to be less strong so their autistic children could adapt to the new environment. Multilingual contexts can elicit more parenting stress in these families (Ijalba, 2016; Jegatheesan, 2011). The lack of support in the family environment as well as limited communication with institutions also prevented Chinese American parents from accessing adequate education services and learning about their children's education process. Their attitudes and requests towards children's education were based less on their children's current special education condition, indicating the need for more communication with immigrant parents in proper ways. More introduction about services and abilities of the U.S. education system could help Chinese American parents learn about their rights and build confidence to satisfy their needs, especially in seeking for culturally sensitive education.

Within the model, culture plays a critical role in explaining the relationship among Chinese American parents, the context they lived in, and their parenting attitudes (Mistry et al., 2016). The aspect of culture this study focuses on is the Chinese cultural-related stigmatised ideologies in understanding autism. Considering the interconnected relationship between the immigration contexts and parenting attitudes, the model helps explain not only the experiences and needs of Chinese American parents when they make sense of their social and family contexts as well as children's autism diagnosis, but also gives practical suggestions for educators and institutions when providing culturally sensitive education to their autistic children.

### *Suggestions for practice*

Although results are based on a limited sample size, the consistency of responses from parents does provide some guidance for practice, upon which future research could focus. Developed for institutions and professionals working with families and children, the organisation-directed suggestions included:

1. Prior to offering services and education, understand parents' ideas of their autistic children's education needs and experiences, including their immigration years, attitudes towards children's autistic characteristics and learning abilities.
2. Initiate conversations and present Chinese American parents with special education information that are useful to their children in both English and Chinese, usually easily accessed materials like pamphlets and posters.
3. Learn about Chinese cultural-related stigma to make detailed explanations and clarifications to Chinese American parents and their families.
4. Train educators and clinicians on major common differences between Chinese and U.S. traditions in school environment and adapt the education strategies, for example, modifying therapy and intervention based on Chinese American families' daily routines.
5. Provide multilingual and culturally adapted education materials if necessary to further enrich children's education and prepare them to adapt to the U.S. social environment in the future (Sanders & Molgaard, 2019).
6. Share special education services that are valuable to Chinese Americans across schools, districts and even states and encourage organisations and social groups to work more closely with both public systems and private clinicians.
7. Introduce the U.S. education system to Chinese American parents in ways that can help them understand their autistic children's needs and the support their family can receive.
8. Integrate cultural experiences and perceptions into every stage of Chinese American autistic children's service provision process to create a warm and inclusive environment.

### *Limitations and future research*

The current study has some limitations that need to be considered. Compared with the whole integrated conceptual framework (Mistry et al., 2016), the current model is limited in the contexts it covered and aspects of parenting that have been discussed. A larger context, including social stratification, as well as more parenting aspects, like parenting stress, can also be included in future

research to improve and refine the model. In such cases, more research methods like observations may be used.

The study results also echo other research among Chinese American parents in many aspects and shared certain sample limitations, such as the lack of representation of certain family groups (Sakai et al., 2019). Given the structure of many Chinese families, perspectives of other family members are important to include and that due to space, these are not discussed in this article (Felnhofer et al., 2020). Children American parents with adolescents were also not included in the sample, which limited the diversity of parents' perspectives. More importantly, because the study uses interviews to understand the idea of a group of Chinese American parents, parents who participated in the study were all willing to send children for education and intervention and most of them had relatively high levels of reading and writing abilities. Our recruitment criteria also required parents to engage in U.S. culture and had a reasonable understanding of autism to participate. There is a likelihood that those with low education levels or had more stigmatised ideas and beliefs of autism might not even be able to get interviewed. Limitations of many qualitative studies like small sample size and interviewer bias also existed in this study, which may compromise the reliability and applicability of the results. Therefore, to better understand how parents respond to stigma attached to autism, methods like anonymous questionnaires may be used to reach more population and other family members in future research.

In addition, to understand Chinese American parenting experiences, participants should not be limited to only parents and people within the family. In fact, as some other research among Chinese and Asians have realised, Chinese culture recommends humility in response to questions and tends to hide the negatives of the family to strangers (Choi & Wynne, 2000; Tosi, 2015). The results of the study can also be limited due to this cultural factor. One potential way for future studies to lower the impact of such factors is through broadening the study sample to include perspectives from individuals outside Chinese American families, like community members, social workers, or educators. Their ideas and understanding of Chinese American parents may be indirect, but together with the results of this study, we have a broader picture and deeper understanding of Chinese American parents' needs towards cultural sensitivity of their autistic children's education.

## Conclusion

The current study adapted a theoretical framework that can be used by educators and researchers to apply among Chinese American parents when understanding their needs and experiences in educating their autistic children. The impacts of cultural-related stigma need to be

highlighted in such process. This is also the first study that explored the variations in Chinese American parents' perceptions and expectations of children's education materials and intervention strategies related to cultural sensitivity. Based on their perceptions and suggestions, there is still a significant amount of work for education institutions and system to adapt and address the needs of Chinese American parents and their autistic children. It is also critical to prioritise cultural sensitivity and incorporate diverse perspectives from Chinese American community into educational practices and policies to foster an inclusive and supportive environment for their autistic children.

## Acknowledgements

The authors would like to thank Dr. Ellen Pinderhughes and the Autism Community Advisory Board for their feedback and commentary during the development of the article.

## Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


## Ethics approval

This research study was conducted online with the approval of the Institutional Review Board (IRB) of Tufts University. The IRB ethical approval was granted by the Tufts Behavioral & Educational Research Institutional Review Board (STUDY00000973) on October 22<sup>nd</sup>, 2020.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Internal Grant from the Eliot-Pearson Department of Child Study and Human Development at Tufts University.

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## Supplemental material

Supplemental material for this article is available online.

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