



Published in final edited form as:

J Dev Behav Pediatr. 2019 May ; 40(4): 257–265. doi:10.1097/DBP.0000000000000660.

Parent and Provider Perspectives on the Diagnosis and Management of Autism in a Chinese Immigrant Population

Christina Sakai, MD¹, Christina Mulé, PhD¹, Amy LeClair, PhD², Frances Chang, MEd¹, Samantha Sliwinski, MPH¹, Yoyo Yau, MA³, and Karen M Freund, MD, MPH²

¹Department of Pediatrics, Tufts Medical Center, Tufts University School of Medicine, Boston, MA

²Clinical and Translational Sciences Institute, Tufts University School of Medicine, Boston, MA

³Boston Chinatown Neighborhood Center, Boston, MA

Abstract

Objective: Minority families experience disparities in the diagnosis and management of autism spectrum disorder (hereafter “autism”). To date, the experiences of Chinese immigrant families in the United States have not been explored. Utilizing parent and provider perspectives, this research sought to identify barriers and facilitators to the diagnosis and management of autism among Chinese immigrant children.

Methods: We conducted semi-structured qualitative interviews with sixteen parents of Chinese children diagnosed with autism and sixteen providers who assist in the diagnosis and management of autism. Participant characteristics were analyzed utilizing descriptive statistics. Interviews were audio-recorded, transcribed, translated, and independently coded by two researchers until consensus was reached. Coded data were analyzed using a modified grounded theory approach.

Results: Parents and providers both identified cultural beliefs as an influence on the understanding and acceptance of autism as a diagnosis. There was a high degree of alignment in themes related to barriers to health care access and parent-provider communication. Recommendations to improve the system of care include: (1) supporting communication, (2) cultural sensitivity, and (3) care coordination programming.

Conclusions: Findings reinforce that diagnosis and treatment of autism should take into account culturally specific beliefs about child developmental norms, and address systems-, provider-, and family-level barriers.

Keywords

Autism spectrum disorder; Chinese Immigrants; Health services; Qualitative research

Early identification of autism spectrum disorder (hereafter “autism”) has been linked to earlier service initiation and improved outcomes.^{1–4} Despite the clear importance of early

Corresponding Author: Christina Sakai, MD, 800 Washington St #334 Boston, MA 02111, csakai@tuftsmedicalcenter.org, Phone: 617-636-5621, Fax: 617-636-5621.

Conflicts of interest: All authors confirm that there are no conflicts of interest, including financial, consultant, institutional and other relationships that may lead to bias or a conflict of interest.

detection, diagnosis, and treatment of autism, many children go undiagnosed for years after the onset of initial symptoms.⁵⁻⁷ This delay is particularly evident in minority children, who are less likely than their white counterparts to be identified with autism, even if they meet diagnostic criteria.⁸⁻¹⁰ In addition, children from racial and ethnic minority groups receive initial diagnoses much later than white children and present with more severe symptoms at the time of diagnosis.^{11,12} Children born to parents who are foreign-born or whose primary language is not English also have reduced odds of early diagnosis.¹³

Reasons for racial and ethnic disparities in autism diagnosis are poorly understood; however, research has suggested that cultural considerations influence acceptance of autism screening and timely evaluations.⁸ Cultural beliefs and values may determine parental attitudes toward child-rearing, perceptions of typical development, and mental health stigma.¹⁴⁻¹⁷ The ease with which parents can communicate and express their concern with healthcare providers, as well as the fluidity with which they can access the healthcare system also influence early autism diagnosis.¹⁸⁻²⁰ In addition, family socioeconomic status,²¹⁻²³ parental education,²³⁻²⁴ and level of acculturation¹³ have been shown to be associated with timeliness of autism diagnosis and access to services.

While some research on autism in minority populations does exist, there is little research focusing on autism in Asian Americans and a complete evidence gap regarding the diagnosis and management of autism in Chinese immigrant communities. Studies have indicated that factors associated with mental health service use in other immigrant populations (e.g., English proficiency) are not as strongly associated in Asian immigrants, suggesting that Asians may experience different cultural beliefs related to mental health concerns.^{25,26} This study sought to identify barriers and facilitators to the identification and management of autism among Chinese immigrant children and recommendations for improving the current system of care. We specifically sought out the perspectives of both parents and providers to obtain a better understanding of the inter-relationship of systems and socio-cultural factors influencing family's abilities to carry out service recommendations.

METHODS

Setting

This study was conducted at a large academic medical center in the Northeast region of the United States. This medical center is situated within one of the largest Chinatown's in the United States where the predominant languages spoken among Chinese immigrants are either Cantonese or Mandarin. All activities conducted as part of this research were approved by the Institutional Review Board, and all participants were provided with informed consent in their primary language.

Recruitment and Eligibility

Parents were recruited through a clinic-based sample of children, ages 2;0 to 15;11 years, diagnosed with autism spectrum disorder and whose primary language was listed as Chinese-Cantonese or Chinese-Mandarin. A list was generated using electronic records of all patients meeting above criteria including age, patient language, and diagnosis (ICD-9

Data Analysis

All interview transcripts were analyzed using a modified grounded theory framework in which intensive group discussion and consensus led to identification of *a priori* codes (derived from literature review) and emergent codes (derived from the data).^{28,17} These codes and code definitions were summarized in a codebook. Following group discussion, a preliminary set of code definitions was delineated with illustrative examples.

For the parent interviews, the two bilingual research assistants (FC and SY) independently coded four transcripts from parent interviews. The research assistants then met with one primary investigator, who is also fluent in Mandarin (CS), to review all codes. Analysis was conducted in Chinese with transcript and code labels maintained in Chinese; codes and quotations were later translated into English by one of the research assistants (FC) for reporting purposes. For provider interviews, one research assistant (SS) independently coded four interviews, and two primary investigators of the research team (CM and AL) each independently coded two of those four interviews. Each group met to compare coded interviews, revise codes based on consensus, and solidify definitions for the final codebook.

Utilizing the final codebook all interviews were independently coded by two individuals. For parent interviews, the two bilingual research assistants each coded all 16 interviews. For provider interviews, one research assistant (SS) coded all 16 interviews and the two primary investigators (CM and AL) each coded eight of the 16 interviews. To achieve coding agreement and fidelity, where discrepancies arose, the research team met to discuss differences in coding until a resolution was reached.²⁹ Once the team had reached agreement on all of the coded interviews, transcripts were imported into Dedoose 7.6.21, a web-based software program that helps facilitate the organization and analysis of qualitative data.

RESULTS

Sample

Sixteen parents were interviewed. Two were fathers; 14 were mothers. All but one indicated that a Chinese dialect, as opposed to English, was their dominant language. On average, parents reported having been in the United States for 13.9 years and most attained either a high school degree (63%) or a college/professional degree (25%). Two parents (13%) indicated that they spoke and understood English “very well or like a native” (Table 1). The mean age of children was 5.9 years at the time of parent interview. The mean age of first concern about child development was 21 months. All but one parent discussed their concerns with child’s doctor; the mean age at which they discussed concern was 23 months. The mean age of autism diagnosis was 2.7 years for this sample. All but one had received Early Intervention (EI) services. In addition, there was a high level of use for recommended therapies for autism, with applied behavioral analysis (ABA; 81%) and speech therapy (94%) being the most frequently utilized. Conversely, fewer children accessed physical therapy (19%), occupational therapy (44%) and social skills training (44%). The majority (81%) received special education via an individualized education plan (IEP). Conversely, only one parent indicated use of alternative health care (“acupuncture, chiropractic care, relaxation therapies, herbal supplements, and others”).

Sixteen providers were interviewed (10 in-person; 6 via telephone). Demographic characteristics, professional background information, and relevant experience of the providers are provided in Table 2. The majority of participants were female, Chinese, and spoke a Chinese dialect. A variety of professions are represented within the sample, including physicians, nurses and nurse practitioners, behavior analysts, community support personnel, school psychologists, and social workers. The majority of participants worked out of an academic medical center or hospital and had been working in their profession for at least six years. All of the providers interviewed reported that they had received professional training in working with children with autism and their families, and 88% of participants reported that they had received some form of cultural competency training.

Cultural Considerations

Parents and providers provided insight into ways in which Chinese culture and family systems shape the process of obtaining an autism diagnosis and accessing intervention services. Mutually identified themes included (1) incongruent beliefs of what defines autism, (2) denial that the child has an actual problem, (3) beliefs that environmental exposures are the cause of symptoms, (4) stigma, and (5) family structure.

Incongruent Beliefs – “She is very lively”.—Incongruent beliefs of what qualities define autism shaped parents ability to initially accept autism as a diagnosis. The term *huóp* (“lively”) was often used by parents as being in opposition to their beliefs of what autism is. One parent described: “Everyone thinks that autistic children are closed-off to one-self, who may not communicate with the outside world, but she is not. She is very open...she likes to sing and often laughs loudly. So I thought she may be the kind who is too lively.”

The concept of *huóp* as someone who is healthy, energetic, and happy may make acceptance of a health disability more challenging. Other terms parents used to describe their child, which seemed to them in opposition of autism, included *jìng* (calm) and *w nshùn* (gentle). Several parents described how, following diagnosis, they were better able to understand the different levels of autism: “I thought autism may be related to [being] completely closed-off in one’s own world; that kind of autism. However, after the diagnosis, I realized that there are some mild behaviors that can also count as autism.”

Denial – “He’ll grow up just fine”.—Some parents described not viewing their child’s challenges as permanent. Frequently this denial of the problem delayed diagnosis. Over half of providers (63%) indicated denial as a barrier to quality care: “If we think the child has special needs, it’s really hard for parents to digest all this information. Parents will tend to say, ‘Oh, they will grow out of it. It is not a problem’ and, ‘actually he or she is doing much better at home’” (provider; community support).

Even when there is acceptance of autism diagnosis, parents described that, in China, the symptoms of autism may be viewed as temporary and believe the child will outgrow it: “In China, they might think that their child is just like that. They probably won’t think that there is a problem. They might feel that one day things are going to be better. When he grows up, he will be fine.”

Environmental Exposure – “Go back to our country”.—Providers noted that parents who do notice developmental differences in their children might attribute them to environmental exposure, rather than a developmental disorder. This may be because of a lack an understanding of autism: “Since they haven’t heard about autism, they’re more likely to think that his language is delayed because his mother does everything for him or he has an older sibling, and are less likely to recognize atypicalities” (provider; physician).

Similarly, some parents described being surprised by the diagnosis because “nobody in our family has that.” A number of participants reported that reduced social and language opportunities in their environment here in the United States contributed to the child’s symptoms. The concept of *huíguó* (returning to China) was often viewed as a way to resolve a child’s current symptoms by changing their environment. This concept of *huíguó* may also reflect wanting the opinion of those within their own culture: “We want to take him back to China so that he can be part of school there and give it a try. And then we can also talk to the Chinese teacher and ask her to pay attention to him.”

Stigma – “We don’t talk about it”.—Stigma as a barrier to initial diagnosis and concern was noted by 81% of providers. Providers explained that mental illness continues to be stigmatized in Chinese culture: “So, how other people see this family is very important to them. So save face kind of thing. They don’t want the kid to be autistic, because it would mean losing face in the community that they would have such an abnormal kid” (provider; physician). Similarly, parent participants noted that if a child has “these kinds of problems,” “we don’t talk about it.” One parent commented that it may even be easier to talk to those that are not Chinese about their concerns: “So now I think that it is easier to talk to *wái guó rén* (non-Chinese). They are more open. I can talk about this and that problem. But with Chinese, even if it is my best friend, we cannot talk about this, how can I say it?”

Family Structure – “Grandma and grandpa are very powerful”.—Providers also noted differences in family structure and its impact on the diagnosis and management of autism. Chinese culture is recognized to be less individualistic and more focused on the collective well-being of the family. As such, there is often a dependency on multigenerational households for the practical care of the child, as well as decision-making: “Usually the grandma and grandpa are very powerful in the family. You cannot ignore them. Most people would say, ‘I’m the parent, so I can give medications to the children.’ The grandpa and grandma would have very bad reaction to [this]” (provider; nurse).

Healthcare Access

Once Chinese families acknowledge a problem and decide to seek help, they often face challenges navigating the US health care system and obtaining a diagnosis for their child (see Table 3 for a sample of illustrative quotes). Long waitlists, as well as language and communication barriers impact access and utilization of services and treatment recommendations.

Waitlists to see specialists who evaluate for autism are long, frequently impacting the time frame in which families can utilize EI services. Following diagnosis, access to recommended

therapies (i.e. ABA therapy) continue to be problematic, and a number of families go without these services.

Language differences impact parents' ability to navigate the system, and one provider noted that Chinese families "have more difficulty accessing systems than most immigrant families." Once services are accessed, language continues to be a barrier for Chinese families to engage in services. Parents indicated wanting to understand, in their own language, what a therapist is working on in order to carry over that knowledge to help their child. Providers similarly indicated that families "don't know what to expect when a provider comes into their home," and how best to support the child. Finally, parents and providers both commented on limited availability of up-to-date resources in Chinese language. This impacts their ability to understand autism and its treatment recommendations.

The majority of providers (63%) also mentioned challenges to providing care due to family socioeconomic status. This included insurance not covering recommended services, particular challenges for parents to schedule time off work, and challenges reaching families after office visits to communicate concerns because of parents' work schedules.

Communication and Trust

Patient (parent)-provider communication and trust were noted as important in the diagnosis and management of autism (see Table 3 for a sample of illustrative quotes). A majority of parent participants (75%) made specific comments about "trusting professionals": teachers, physicians, and therapists. Even when there existed doubt regarding the diagnosis of autism, parents reported acceptance of professional opinions and recommendations.

Parents and providers discussed the use of interpreters to facilitate communication and trust. Providers noted challenges having not only bilingual/bicultural interpreters, but also those trained in mental health and developmental disorders. Parents reported the benefit of having interpreters that could explain developmental assessments using their own language.

Even with the use of interpreters, however, parents and providers commented on the negative impact of language and cultural differences on communication. They noted that this barrier makes it difficult to express concerns, understand the diagnosis, and discuss treatment recommendations (e.g., medications).

Additionally, participants commented on factors influencing rapport and trust between parents and providers. Appointment times were perceived as short, due to the need for interpreter services, and thus having a negative influence on the ability of both parties to review information and communicate concerns. Providers noted that perceived acknowledgement of information did not necessarily equate to understanding. Facilitators to rapport building and trust included recognition of family/personal values and providers bringing up or following-up on concerns even when parent do not express them.

Recommendations

Respondents were asked what recommendations they had for improved care. Cited themes include: (1) strengthening community resources, (2) assuring high quality interpretation and translation resources, and (3) providing comprehensive care coordination that crosses different systems of care.

Participants noted the need for increased community-based resources, such as support groups, resource specialists, classes and activities for autistic children, and parent education and training: “It is a matter of having more activities for our children to be together, and for us, [the parents] to be together. We can share experiences, exchange advice on how to do things, and what is available” (parent).

In addition, the specific role of community supports (e.g., parent support groups) in reducing stigma and shame was noted by some: “They’re aware of some of the stigma and some of the cultural perspectives of autism...for parents that I’ve worked with, having other families that they know have children who may be diagnosed with autism is really helpful. It’s having a network of family support” (provider; community support).

Addressing language barriers through appropriate interpreter services and having up-to-date resources available in Chinese language were viewed as important to support families’ understanding and decision-making around autism services. In particular, one provider noted the need for “more materials translated in a culturally competent context, because a lot of literature translated is probably educational, but does not fit into the cultural context.”

Both provider and parent participants mentioned the need for comprehensive care coordination among the various professionals and systems involved in the care of children with autism, noting that language barriers made it even more difficult to coordinate care: “Care coordination. That’s what the role of the family support person would be. I think that’s a key piece – having that person who speaks their language, who can make those connections for them if they’re not able to make them, and maintain a long-standing relationship. I think [it] is key to improving care for families of Chinese backgrounds and of all different backgrounds” (provider; physician).

DISCUSSION

This is one of the first studies to explore the experiences of Chinese immigrants on autism diagnosis and management. The results highlight the common barriers that all families experience (waitlists, care coordination) and those that are unique to families with limited English proficiency (language and communication barriers). It also provides understanding of culture-specific beliefs that influence autism diagnosis and management.

Cultural differences are recognized to influence families’ treatment decisions for children with autism.³⁰ Specifically, culture influences interpretation of symptoms, beliefs about the cause and course of autism, and interactions with the healthcare system.³¹ In this study, several cultural themes emerged and are linked to Chinese health beliefs. Parents noted that as their understanding of autism increased, including the different presentations of the

disorder, they were more readily able to acknowledge it in their child. This emphasizes the need for increased awareness and understanding of autism in the Chinese immigrant community. Recommendations for achieving this include strengthening providers' ability to effectively communicate through use of interpreters and increased cultural sensitivity, and increasing materials which provide information regarding autism and developmental delay in other languages.

Cultural beliefs also influenced perceived etiologic cause and course of autism. The majority of providers cited denial as a barrier to quality care in Chinese immigrant families. Parents frequently viewed the diagnosis of autism as having a Western influence. They also indicated that lack of exposure to social and language opportunities in the environment resulted in symptoms, rather than the child having a disorder him/herself. Many perceived that the child might still grow out of it. Recommendations from provider respondents help us to better understand that Chinese families may be willing to take action to help their child, even though they might not fully accept the diagnosis. Providers might partner with families to work toward mutually agreeable treatments and shared goals for the child.³²

Finally, stigma was mentioned as a cultural barrier to accessing supports in the community and within the healthcare system. Problems are often not talked about, especially "these kind of problems" (i.e., mental health / neurodevelopmental problems). Mental health and neurodevelopmental problems are viewed as harming family harmony, and admitting to a diagnosis of autism brings shame to family.³³ The Chinese term *miàanzi* (saving face) reflects the idea of shame when discussing things that might bring further emotional harm to others. Parents, however, noted the benefits of being able to talk about their concerns with other parents and providers. Family support groups were cited by multiple parents as instrumental in recognizing symptoms of developmental problems, knowing what to do about them, and accessing beneficial services and supports. This suggests that once conversations can be started, Chinese families find a high level of support both within their own families and with other parents.

Interactions with the healthcare system were often made challenging by language and communication barriers, corresponding with recommendations for improvement centering around improving access to language/cultural supports and increasing care coordination. Parents are seeking information about autism and look to professionals to discuss this in an accessible way. This requires use of interpreters who facilitate language and cultural exchange, as well as those who have understanding and awareness of autism and other neurodevelopmental disorders. This may be further facilitated in clinical settings where there exists resources specific to Chinese families. In settings where fewer specific resources exist for Chinese families, healthcare providers may still empower families with translated written materials or verbal information related to the diagnosis and services.

Increasing engagement with school and Early Intervention systems may also create increased understanding and care coordination, which may help facilitate barriers to navigating the healthcare system. Patient navigation is recognized as patient centered approach which helps decrease disparities in diagnosis, treatment, and support.³⁴ The

availability of cultural brokers who can help these families navigate the system, from initial concern to diagnosis and management, was noted to be beneficial in study findings.

Study results highlight the experiences of a broad range of professionals as well as parents. The diversity of backgrounds of study participants allowed us to capture themes that may otherwise have been missed if there was a more narrow focus. Providers, who have increased awareness of the healthcare and educational system, are better able to recognize the interconnectedness of these systems and thereby report on gaps that are present. While providers from different professional backgrounds were recruited, sampling methods (use of snowball technique) may have resulted in more ready saturation of themes during analyses. Parents provided us with more of their cultural views and direct experiences.

Our study population consisted of families with children who generally received timely autism diagnosis and services. Due to sampling methods, parents were already actively engaged in subspecialty clinics and family support groups and yet still identified significant barriers. As such, the experiences of those who are less engaged in the health care system may not be well captured in study results. In addition, parent participants had been in the United States on average of 14 years and were generally well educated, with the majority having completed high school or above. Their views may not be reflective of less-educated, less-aculturated, or single parent families.

Timely diagnosis and successful management of children with autism requires the navigation of complex systems with an emphasis on collaborative efforts between highly trained professionals and families.³⁵ For Chinese immigrant children with autism, this requires engaging families in their understanding of autism and establishing shared treatment goals. Recommendations to improve the system of care include: (1) supporting communication, (2) assuring cultural sensitivity, and (3) increasing care coordination programming.

Acknowledgments

Funding disclosure: *The project described was supported by the Deborah Monroe Noonan Memorial Research Fund and received assistance from the Child Health Working Group, part of the Addressing Disparities in Asian Populations through Translational Research (ADAPT) program at Tufts Clinical and Translational Science Institute (CTSI), supported by National Center for Advancing Translational Sciences, National Institutes of Health, Award Number UL1TR002544. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.*

REFERENCES

1. Zaigenbaum L, Bauman ML, Stone WL, et al. Early identification of autism spectrum disorder: Recommendations for practice and research. *Pediatrics*. 2015;136(S1):10–40. [PubMed: 26055846]
2. Dawson G, Rogers S, Munson J, et al. Randomized controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*. 2010;125(1):e17–e23. [PubMed: 19948568]
3. Remington B, Hastings RP, Kovshoff H, et al. Early intensive behavioral intervention: outcomes for children with autism and their parents after two years. *Am J Ment Retard*. 2007;112(6):418–438. [PubMed: 17963434]
4. Rotholz DA, Kinsman AM, Lacy KK, et al. Improving early identification and intervention for children at risk for autism spectrum disorder. *Pediatrics*. 2017;139(2) pii e20161061. [PubMed: 28082407]

5. Zablotsky B, Colpe LJ, Pringle BA, et al. Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *Am J Intellect Dev Disabil.* 2017;122(1):49–61. [PubMed: 28095057]
6. Sheldrick RC, Maye MP, Carter AS. Age at first identification of autism spectrum disorder: An analysis of two US surveys. *J Am Acad Child Adolesc Psychiatry.* 2017;56(4):313–320. [PubMed: 28335875]
7. Zuckerman KE, Lindly OJ, Chavez AE. Timeliness of autism spectrum disorder diagnosis and use of services among U.S. elementary school-aged children. *Psychiatr Serv* 2017;68(1):33–40. [PubMed: 27476809]
8. Zuckerman KE, Mattox K, Donelan K, et al. Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics.* 2013;132(3):445–453. [PubMed: 23958770]
9. Jarguin VG, Wiggins LD, Schieve LA, et al. Racial disparities in community identification of autism spectrum disorders; Metropolitan Atlanta, 2000–2006. *J Dev Behav Pediatr.* 2011;32(3):179–187. [PubMed: 21293294]
10. Pedersen A, Pettygrove S, Meaney FJ, et al. Prevalence of autism spectrum disorders in Hispanic and non-Hispanic white children. *Pediatrics.* 2012;129(3):e629–635. [PubMed: 22351889]
11. Mandell DS, Listerud J, Levy SE, et al. Race differences in the age at diagnosis among Medicaid-eligible children with autism. *J Am Acad Child Adolesc Psychiatry.* 2002;41(12):1447–1453. [PubMed: 12447031]
12. Mandell DS, Wiggins LD, Carpenter LA, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health.* 2009;99:493–498. [PubMed: 19106426]
13. Schieve LA, Boulet SL, Blumberg SJ, et al. Association between parental nativity and autism spectrum disorder among US-born non-Hispanic white and Hispanic children, 2007 National Survey of Children’s Health. *Disabil Health J.* 2012;5(1):18–25. [PubMed: 22226294]
14. Sotgiu I, Galati D, Manzano M, et al. Parental attitudes, attachment styles, social networks, and psychological processes in autism spectrum disorders: a cross-cultural perspective. *J Genet Psychol.* 2011;172(4):353–75. [PubMed: 22256682]
15. Zuckerman KE, Sinche B, Mejia A, et al. Latino parents’ perspectives of barriers to autism diagnosis. *Acad Pediatr.* 2014; 14(30): 301–308. [PubMed: 24767783]
16. Hock R, Ahmedani BK. Parent perceptions of autism severity: exploring the social ecological context. *Disabil Health J.* 2012 10;5(4):298–304. [PubMed: 23021742]
17. Bornstein MH, Cote LR. “Who is sitting across from me?” Immigrant mothers’ knowledge of parenting and children’s development. *Pediatrics.* 2004;114(5):e557–64. [PubMed: 15520089]
18. Montes G, Halterman JS, Magyar CI. Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics.* 2009;124 Suppl 4: S407–13. [PubMed: 19948606]
19. Kara B, Mukaddes NM, Altinkaya I, et al. Using the Modified Checklist for Autism in Toddlers in a well-child clinic in Turkey: Adapting the screening method based on culture and setting. *Autism.* 2014;18(3): 331–338. [PubMed: 23175752]
20. Zuckerman KE, Lindly OJ, Sinche BK. Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *J Pediatr.* 2015;166(6):1431–1439. [PubMed: 25888348]
21. Durkin MS, Maenner MJ, Meaney FJ, et al. Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS ONE.* 2010;5(7):e11551. [PubMed: 20634960]
22. Liptak GS, Benzoni LB, Mruzek DW, et al. Disparities in diagnosis and utilization of health services for children with autism: Data from the National Survey of Children’s Health. *J Dev Behav Pediatr.* 2008;29(3):152–160. [PubMed: 18349708]
23. Fountain C, King MD, Bearman PS. Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. *J Epidemiol Community Health.* 2011;65(6):503–510. [PubMed: 20974836]
24. Thomas KC, Ellis AR, McLaurin C, et al. Access to care for autism-related services. *J Autism Dev Disord.* 2007;37(1):1902–1912.
25. Bacerra TA, vonEhrenstein OS, Heck JE. Autism spectrum disorder and race, ethnicity, and nativity: a population-based study. *Pediatrics.* 2014;134(1):e63–e71 [PubMed: 24958588]

26. Kim G, Aguado Loi CX, Chiriboga DA, et al. Limited English proficiency as a barrier to mental health service use: A study of Latino and Asian immigrants with psychiatric disorders. *J Psychiatr Res.* 2011;45(1):104–110. [PubMed: 20537658]
27. Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey. 2011 Survey of Pathways to Diagnosis and Services. 4 2012 Available from URL: <http://www.cdc.gov/nchs/slait/spds.htm>.
28. Mays N, Pope C. Assessing quality in qualitative research. *BMJ.* 2000;320(7226):50–52. [PubMed: 10617534]
29. Willms DG, Best AJ, Taylor DW, et al. A systematic approach for using qualitative methods in primary prevention research. *Medical Anthropology Quarterly.* 1992;4(4):391–409.
30. Mandel DS, Novak M. The role of culture in families' treatment decisions for children with autism spectrum disorders. *MRDD Research Reviews.* 2005;11:110–115.
31. Carlsson E, Miniscalco C, Kadesjo B, et al. Negotiating knowledge: parents' experience of neuropsychiatric diagnostic process for children with autism. *Int J Lang Commun Disord.* 2016;51(3):328–338. [PubMed: 26833425]
32. Ravindran N, Myers BJ. Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *J Child Fam Stud.* 2012;21(2):311–319.
33. Hsiao FH, Klimidis S, Minas H, et al. Cultural attributions of mental health suffering in Chinese societies: the views of Chinese patients with mental illness and their caregivers. *J Clin Nurs.* 2006;15(8):998–1006. [PubMed: 16879544]
34. Rodday AM, Parsons SK, Snyder F, et al. Impact of patient navigation in eliminating economic disparities in cancer care. *Cancer.* 2015;121(22):4025–4034. [PubMed: 26348120]
35. Cuvo AJ, Vallelunga LR. A transactional systems model of autism services. *Behav Anal.* 2007;30(2):161–180. [PubMed: 22478495]

Table 1.

Child and Family Demographics (N=16)

Characteristic	
Child Characteristics	
	Mean ± SD
Age of child current	5.9 years ± 3
Age of first parental concern	21.2 months ± 5
Age first discussed with doctor	22.5 months ± 8
Age of autism diagnosis	2.7 years ± 1
Therapy (current or past)	
	n (%)
Early Intervention	15 (94%)
ABA (Behavioral) Therapy	13 (81%)
Speech Therapy	15 (94%)
Occupational Therapy	7 (44%)
Physical Therapy	3 (19%)
Social Skills	7 (44%)
Special Education Service, current	13 (81%)
Parent/ Family Demographics	
Marital Status, married	15 (94%)
Educational Attainment	
Less than high school completion	2 (13%)
High school / some college	10 (63%)
College / professional	4 (25%)
English proficiency-very good/like native	2 (13%)
Number of Years in United States	13.9 years ± 7

Table 2.

Provider Demographics (N=16)

Characteristic	Providers n (%)
Gender	
Male	3 (19%)
Female	13 (81%)
Race/Ethnicity	
Asian (Chinese)	12 (75%)
Non-Hispanic White	4 (25%)
Chinese-Speaking	
Yes	12 (75%)
No	4 (25%)
Profession	
Physician / Nurse Practitioner	7 (44%)
Nurse	2 (13%)
Community Support Personnel	4 (25%)
School Psychologist	1 (6%)
Social Worker	1 (6%)
Behavior Analyst	1 (6%)
Practice Setting	
Academic Medical Center	10 (63%)
Community Health Center	2 (13%)
Public School	1 (6%)
Other	3 (19%)
Work Experience in Years	
1-5 years	5 (31%)
6-10 years	4 (25%)
>10 years	7 (44%)
Cultural Competency Training	
Formal (course/workshop/conference)	11 (69%)
Informal (profession or heritage)	3 (19%)
None	2 (13%)
Autism Training	
Formal (course/workshop/conference)	11 (69%)
Informal (profession or experience)	5 (31%)

Table 3. Barriers and Facilitators to Care: Themes Identified From Individual Interviews and Illustrative Quotations

Themes	Parents' Comments	Providers' Comments
Access and Utilization		
Waitlists	<i>It takes too long to be seen. It takes over six months. It is so slow. If it could be earlier, I think he could have gotten more services in Early Intervention. And then we have to get ABA which has such a long wait list. You have to wait so, so long. Even now, I still have not found one.</i>	<i>And now we're looking at one year wait times and typically these children are referred to me at 18 months and they wait a year. Then they're two and a half by the time I can at least try to register them for service. Service takes about a month or two months to start, and then they're out of here in another four months. It seems like such a loss to me.</i>
Language - Challenges accessing and scheduling	<i>You don't know what to do or how to do it? You don't know who to talk to. The doctor referred me but did not give me an appointment. The system is too hard. I called and they told me I had to wait half a year because there are so many people. They told me I had to fill out a form in order to receive a first appointment. The form was all in English, and I did not know what to do.</i>	<i>My impression is that they have more difficulty accessing systems than most immigrant families. I don't know if that's because there are fewer interpreters available or the community is smaller, but I think that they tend to need more guidance accessing services and accessing the systems and also interfacing with the systems.</i>
Language - Challenges engaging in services	<i>I think if there was some volunteer next to you to help you understand what exactly is going on. What I mean is what exactly is ABA, and what will it do for your child. This will help you understand what the treatment is like...I think if Chinese speaking it would be much better. They would be able to explain it more clearly. Things are better here because I can speak Chinese. Everything is convenient for me, but I really want to have [Chinese-speaking] speech language therapy...I don't know how to speak English and when I go to the hospital for treatment, I don't understand. I don't know what to do.</i>	<i>Many of the services require interfacing with the system in English, and so it's very difficult for them to advocate and then the language barrier interferes with educating parents in how to work with their kids. So it's hard to get a therapist, and then it's twelve times as hard to get a therapist who can speak Cantonese. Even though now they have ABA services, they find challenges to communicate with the service providers because they don't speak the same language. They don't know what to expect when a provider comes into their home...It's kind of like a dance. They have to dance with the provider to find the fine line of support to support the child.</i>
Health literacy and language barrier	<i>When I go on the internet to look up things, very little is in Chinese. It is all English. So I need to use the dictionary. There is a lot of information all in English. Even in public places, all the information is in English. For new immigrants, I cannot understand this. They should translate everything to Chinese. I don't really understand autism. The doctor explained it in such professional language; I did not understand. I just understood that my child was diagnosed with autism. They gave me a lot of information about autism - what it is and what it means. They gave me a notebook to read at home. After I read it, I understood a lot more. But what if other families lack education or do not understand it? Or if they have not been in contact with children with special needs, what happens?</i>	<i>I think it really goes back to the information first- it has to be available in Chinese. Currently, really focus on language, because we realized the first difficulty, they have is the language barrier. As you know, there is not much information available in Chinese. Sometimes even if the information is available in Chinese, the quality of the translation is not great or culturally sensitive. It might have grammar error or it cannot relate back to their experience. Even though they got the information, it's not useful for them. That's why they call because they need someone who speaks their language to help them navigate the system or resources. I provide the family with information in their native language. The challenge is that you can't keep it updated. So, as time goes on from the date that the information was originally translated, it's less and less up-to-date, so I don't like giving it out.</i>
Communication-Trust		
Interpreter training	<i>That specialist also has a nurse helping him. The nurse is very helpful because if we don't understand what the activity is about, she will explain it to us. She will explain what is going on.</i>	<i>For immigrants, you need someone who is bilingual and bicultural to reach them. When you use the interpreter, sometimes it's not very effective. [Hospital] interpreters have no training in developmental disorders and it's a completely different kind of history than they're used to... You know, so there's a lot more layers there, particularly when you're talking about behavior and psychosocial things</i>
Impact of language on communication	<i>I took my child to the family doctor and told him about his behaviors and what my worries were. But I could not really express myself because of the language. I think the families could really use a lot of help. Language, I think language is an issue. You hope the doctor would give you more information [about autism] and explain it. But, even if the words are very clear, we might still not understand. That is because we have different backgrounds. It is so hard to understand what is going on.</i>	<i>I think the language barrier and cultural barrier is huge. For example, just like this case if mom could communicate with the other psychiatrists who prescribed the medication and say, "why you prescribe this medication? What's this for? When should I use it? If I don't think my child today has a big problem can I reduce the amount of medications?" I think because the family doesn't ask those questions, the provider will not know this is like the barrier and the family has lots of questions. They're just assuming the family agrees with what has been prescribed.</i>

Themes	Parents' Comments	Providers' Comments
Building rapport and trust	<p><i>I feel that the doctor sees too many of these kind of children. Every time we go is a 20 minute follow-up. And when I go, I bring so many evaluations and reports; I want to know how my child is doing. I don't know if that doctor is able to review everything.</i></p> <p><i>My son's doctor is very good. Even if I don't say anything, he already mentions it.</i></p> <p><i>It is easy to talk to my doctor. He understands my personal values.</i></p>	<p><i>I always feel like I have a good working relationship with the family when they're in the office with me and then when I see them in follow up I sometimes realize how little they were able to take from their interaction with me so that the teaching that I did didn't seem to have an impact on their understanding of their child. For example, they might not have accessed the services that I recommended or they may have accessed the services but they don't perceive the services to be helpful... And again, I guess I'm giving these answers based on the population that really doesn't speak English very well.</i></p>