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Authors

Stahmer, Aubyn C
Vejnoska, Sarah
Iadarola, Suzannah
et al.

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Caregiver Voices: Cross-Cultural Input on Improving Access to Autism Services

Aubyn C. Stahmer[1] · Sarah Vejnoska[1] · Suzannah Iadarola[2] · Diondra Straiton[3,4] · Francisco Rienosa Segovia[5] · Paul Luelmo[5,6] · Elizabeth H Morgan[1] · Hyon Soo Lee[5] · Asim Javed[2] · Briana Bronstein[3] · Samantha Hochheimer[2] · EunMi Cho[7] · Aritz Aranbarri[1,8] · David Mandell[3] · Elizabeth McGhee Hassrick[9] · Tristram Smith[2] · Connie Kasari[5]

Abstract

Decades of research have established that racial ethnic minority, low-income, and/or non-English speaking children with autism spectrum disorder (ASD) are diagnosed later than white children, and their families experience greater difficulty accessing services in the USA. Delayed access to timely diagnosis and early intervention may impact child outcomes and family quality of life. Despite their cognition of these disparities and their significant impact on the lives of those affected, explanations for the barriers experienced by underserved families are elusive, likely due to the complex interaction between structural and family factors. This study used qualitative methods to gather family and provider perspectives of perceived barriers and facilitators to obtaining an ASD diagnosis and accessing ASD-related services for underserved families. Themes from focus groups and interviews with families from three cultural groups (black, Hispanic/Latino, and Korean) and three primary languages (English, Korean, and Spanish) highlight specific barriers related to family, community, and systemic challenges as well as facilitators to accessing care for these populations. Family experiences are expanded upon with viewpoints from the providers who work with them. Recommendations are made for reducing disparities in the existing ASD service system including increasing professional, family, and community education; increasing culturally responsive care; improving provider-family partnerships; and addressing practical challenges to service access.

Keywords Autism spectrum disorder · Parent perspectives · Cross-cultural · Service access

Background

Autism spectrum disorder (ASD) is a developmental disorder characterized by deficits in social communication and restrictive or repetitive behaviors [1]. The Centers for Disease Control (CDC) estimates that 1 in 59 children in the United States (US) have ASD [2]. Long-term cognitive, social, and employment outcomes for this population are poor [3–6] and the annual cost of ASD-related services in the USA, currently estimated at $268 billion, is projected to rise to $461 billion by

✉ Aubyn C. Stahmer
astahmer@ucdavis.edu

1 Departments of Psychiatry, Psychology & Human Development, University of California, Davis MIND Institute, 2825 50th St, Sacramento, CA 95817, USA

2 Division of Developmental and Behavioral Pediatrics & Strong Center for Developmental Disabilities, University of Rochester Medical Center, 265 Crittenden Blvd., Rochester, NY 14642, USA

3 Perelman School of Medicine, Center for Mental Health Policy and Services Research, University of Pennsylvania, 3535 Market St., Rm. 3100, Philadelphia, PA 19104, USA

4 Department of Psychology, Michigan State University, 316 Physics, Rd., East Lansing, MI 48824, USA

5 Department of Psychiatry, University of California, Los Angeles Graduate School of Education & Information Studies & Center for Autism Research & Treatment, UCLA Semel Institute 68-268, Los Angeles, CA 90024, USA

6 Department of Special Education, San Diego State University, 5500 Campanile Dr., San Diego, CA 92182, USA

7 College of Education, California State University, Sacramento, 6000 J St., Sacramento, CA 95819, USA

8 Mental Health Department, Sant Juan de Deu Barcelona Children's Hospital, Itaka Building 1st floor, Passeig Sant Joan de Déu 2, 08950 Esplugues de Llobregat, Barcelona, Catalonia, Spain

9 A.J. Drexel Autism Institute, Drexel University, 3020 Market Street | Suite 560, Philadelphia, PA 19104, USA

2025 [7]. Access to timely diagnosis and early intervention is critical for children with ASD, as quality treatment can dramatically improve child outcomes [8, 9] and may reduce the cost of care over time [10]. Family quality of life also improves when disability-related services meet family needs [11].

Unfortunately, extensive disparities exist with regard to access to care, and quality of care, for children with ASD and their families. Decades of research demonstrates that children from racially and ethnically diverse groups, those with limited English proficiency, and families from low-income households are diagnosed much later than white children and children of higher socioeconomic status [12–17]. Children of color receive fewer evaluations overall [18], and are less likely to be identified as having ASD despite displaying similar symptom profiles [19, 20]. For example, although the Latino population represents the largest ethnic minority group in the USA [21] and is one of the fastest-growing groups of children diagnosed with ASD [22], they continue to be identified as having ASD 2.5 years later than white children [23]. Additionally, across cultures, children of foreign-born mothers tend to be referred for ASD evaluation later than non-foreign-born children [13]. Once diagnosed, children from under-represented groups are less likely to access ASD-related services [24] including sub-specialty care (e.g., gastroenterology, neurological testing [25]), and school-based interventions [26]. When accessing services, disparities persist, as evidenced by misdiagnosis of racial/ethnic minorities in healthcare and the ongoing segregation of children with disabilities—especially students of color and those with limited income—in schools [27, 28]. Explanations for these disparities have been slow to emerge, in part because they are likely complex and related to issues within the service system as well as family factors.

Structural factors in the service systems contribute to disparities in service access and quality. Providers often lack the resources, capacity, or mandate to equitably disseminate information to under-represented groups including the provision of appropriately translated information in the parents' language of origin [29]. Limited availability of screenings and related follow-up meetings in languages other than English likely contributes to later diagnosis. For instance, only 29% of primary care physicians offer developmental screening in Spanish, and even fewer (10%) offer ASD screening in Spanish [30]. Another group that experiences language barriers is Korean Americans, 76% of whom are born outside of the USA [31]. There are few Korean-speaking professionals in the service delivery system who can communicate with these families [32], making the completion of parent-reported developmental screeners especially challenging. These communication difficulties also affect English-only speaking providers who have consistently reported language barriers in addressing the needs of Asian-American families who do not speak English [33]. Even for minority families without language barriers, negative interactions with healthcare providers that have limited cultural awareness may perpetuate mistrust in the system [34, 35]. Indeed, black parents report feeling undervalued by service providers who do not understand their child and culture [36], and in turn they often perceive that medical professionals are biased against black families [37]. In combination, these systems-level factors create a difficult environment for the promotion of authentic engagement with families with marginalized identities in medical and educational settings.

Family factors such as cultural differences in the perception of child development and developmental disabilities may also reduce timely access to care. For example, Hispanic and Latino parents may expect language milestones to be achieved later than white parents [38, 39]. Compared to white families, black parents tend to report significantly fewer concerns about ASD, social interaction, and repetitive behavior even though race does not influence parent reports of non-ASD-related concerns such as disruptive behavior [40]. These differences in salience of developmental delay and ASD concerns may affect reporting to providers and in turn, timing of a diagnosis.

Because ASD is highly stigmatized in many cultures, it may be more challenging for families of color to accept their children's diagnosis, and consequently, this may delay efforts to seek social support and services [41]. Black parents report resistance to the ASD diagnosis due to social stigma around mental health concerns [37, 42, 43]. In Korean families, stigma may cause reluctance to seek or follow up on a developmental evaluation. Some Korean families view ASD as a hereditary disorder that threatens marriage prospects for relatives [44]; additionally, Korean parents are often blamed for their child's diagnosis of ASD [32]. Providers share concerns around cultural barriers for Asian-American families seeking an ASD diagnosis, such as differences in cultural norms regarding the disclosure of private information about one's family [33].

Disparities may also be due in part to a lack of knowledge regarding ASD symptoms and treatment and limited available information specific to children of color. For instance, being from a family of color or a low-income household has been associated with lower parental expectations of benefits from child therapy, lower caregiver engagement in services, and the belief that their child's condition is a mystery [45, 46]. Black parents report frustration regarding the dearth of evidence on the effectiveness of behavioral interventions for their children with ASD [37] Similarly, Korean immigrant families may enter the USA with limited knowledge about ASD interventions because little information on these interventions is available in Korea [32]. Additionally, black parents from low-income households are less likely to be aware of evidence-based ASD intervention options than black

families with middle-class incomes [47], suggesting that socioeconomic factors contribute to low awareness.

Regardless of race or ethnicity, families with lower household incomes use fewer available sources of information to learn about ASD (e.g., other parents of children with ASD, physicians, websites) than families with higher income [48], which likely contributes to reduced awareness of service options. Other explanations for limited service use may be more pragmatic. For instance, maintaining intensive treatment schedules can be challenging for families with lower incomes who also struggle to secure basic needs such as housing or food [49]. Providers also report difficulties engaging families with multiple life stressors (e.g., poverty, multiple children living in the household) and lower educational attainment [50].

Understanding how factors such as race, ethnicity, primary language, and income affect service access in ASD has gained traction in research, but most ASD studies identifying disparities in diagnostic and service access have used large datasets that show the scale of the disparity, but offer little insight into families' and providers' experiences of these disparities [12, 13, 15, 16, 18, 19, 25, 26, 51, 52]. The few studies that have used surveys and interviews have focused specifically on the experiences of single racial or ethnic groups [47], specific geographic regions [24, 53], or barriers to accessing parent-mediated ASD interventions only [48]. Fewer studies have examined families whose primary language is not English. Additionally, provider perspectives regarding concerns faced by traditionally underserved families, and challenges experienced helping families access care, have not been explored.

The present study gathers qualitative data on perceived barriers and facilitators to identifying developmental concerns, obtaining an ASD diagnosis, and accessing ASD-related services. The study directly compares experiences of low-resource families from three prominent cultural groups (black, Hispanic/Latino, and Korean) and three primary languages (English, Korean, and Spanish), as well as the providers who serve them. These specific groups were selected based on the populations of families in the participating sites, which span multiple states and settings (urban/rural). In this way, the present study provides a broad perspective of the complexity of service access disparities for children with ASD in the United States.

Methods

Focus groups and interviews were conducted as part of a larger multi-site study by the Autism Intervention Research Network on Behavioral Health (AIR-B Network), which includes the University of California, Los Angeles, the University of California, Davis, the University of Rochester, and the University of Pennsylvania. The goal of the AIR-B Network is to work with community partners to increase access to ASD services for families from traditionally underserved populations [54]. Our primary community partner at the lead site (UCLA) is Healthy African American Families (HAAF) and each site has partnered with local families, intervention agencies, funders, and providers who offer input to each phase of the project, including the current project. Focus groups and interviews were conducted in Los Angeles, CA (LA), Sacramento, CA (SAC), Rochester, NY (ROC), and Philadelphia, PA (PHI). Focus groups were chosen because they can elicit the overall opinions and attitudes of the participants [55].

Participants

Participants included 58 caregivers of children with ASD, and 55 ASD service providers and administrators. Focus groups for parents and providers were conducted separately. Nineteen focus groups were held across sites with six in LA, nine in SAC, one in ROC, and three in PHI. If participants wanted to contribute but could not attend a focus group, a structured interview was conducted by phone. Fifteen caregivers and three providers completed an interview, with two in LA, four in SAC, two in ROC, and ten in PHI.

Flyers were distributed in the community in treatment clinics, at parent meetings, via social media, and through other community settings. We recruited participants who had specific experience with the topic (ASD diagnostic and service delivery systems). Recruitment materials solicited general perspectives on caregivers' experiences accessing care and services. Community partners helped research staff organize and arrange focus groups in their areas of influence with special focus on recruitment of low-resource families and families of color. Korean-speaking and Spanish-speaking participants were recruited at the CA sites.

Caregivers Caregivers were either parents (50 mothers, 6 fathers) or legal guardians (2). Thirty-two spoke English; 12 (five in LA and six in SAC) participated in two Spanish language focus groups and three interviews, and 14 (six in LA and eight in SAC) participated in three Korean language focus groups. See Table 1 for caregiver characteristics. Caregivers were eligible if they had a child between the ages of 2 and 8 years who had been diagnosed with ASD within the last 2 years, and were Latino, black, or Korean. Efforts were made to over-enroll families with fewer resources as defined by receiving any government assistance such as Medicaid or participating in a supplemental food or nutrition program. Participants needed to speak English, Spanish, or Korean.

Table 1 Caregiver demographics

Site	Caregiver age in years (M, range)	Caregiver relationship to child	Caregiver race/ethnicity (N)	Annual income range	Child age in months (M, range)	Child age at dx (M, range)
Los Angeles (n = 20)	35.6 (23–49)	Mother: 17	Asian: 6	Under $30,000: 10	59.4	38.2 (13–60)
		Father: 3	Black/AFAM: 1	$30,000-49,999: 6	(35–104)	
		Guardian: 0	Hispanic/Latino: 13	$50,000-69,999: 4		
				Over $70,000: 0		
Sacramento (n = 27)	39.7 (25–73)	Mother: 23	Asian: 8	Under $30,000: 8	85.6	41.69 (20–92)
		Father: 3	Black/AFAM: 7	$30,000-49,999: 7	(32–237)	
		Guardian: 1	Hispanic/Latino: 12	$50,000-69,999: 5		
				Over $70,000: 6		
				Unknown: 1		
Rochester (n = 2)	40.5 (40–41)	Mother: 1	Asian: 0	Under $30,000: 0	55.5	24.0 (18–30)
		Father: 0	Black/AFAM: 2	$30,000-49,999:0	(48–63)	
		Guardian:1	Hispanic/Latino: 0	$50,000-69,999: 1		
				Over $70,000: 1		
Philadelphia (n = 9)	32.4 (25–42)	Mother: 9	Asian: 0	Under $30,000: 5	67.2	46.9 (18–96)
		Father: 0 Guardian: 0	Black/AFAM: 8 Hispanic/Latino: 1	$30,000-49,999: 2 $50,000-69,999: 2		
				Over $70,000: 0	(49–112)	
Total (N = 58)	37.1 (23–73)	Mother: 50	Asian: 14	Under $30,000: 23	66.9	37.7 (13–96)
		Father: 6	Black/AFAM: 18	$30,000-49,999:15	(32–237)	
		Guardian: 2	Hispanic/Latino: 26	$50,000-69,999:12		
				Over $70,000: 7		
				Unknown: 1		

All caregivers met eligibility criteria except the Korean American parents of children with ASD for the Northern California group (4 were not receiving assistance, 6 had children over the age of 8, 8 had children who were diagnosed more than 2 years prior). Korean-speaking participants were all first-generation immigrants

Providers The 55 providers included 11 administrators, 9 allied health providers (e.g., speech pathologist, occupational therapist), 6 educators, 5 mental health providers, 4 pediatricians, 12 service coordinators at agencies such as Part C or developmental services, 2 community liaisons, 2 parent advocates, 1 registered behavior technician/respite care provider, 1 postdoctoral psychology fellow, and 1 family resource center staff specialist. All providers spoke English. See Table 2. Providers were eligible if they worked with young children with ASD (under age 6) or if they referred families for diagnoses regularly, and if they worked with families of color, families who received government assistance, or families for whom Spanish or Korean was their primary language.

Data Collection Procedures

Focus groups were scheduled at times and locations convenient to the participants, and those who could not attend could participate in an interview. Food and beverages were provided. Childcare was provided for caregiver focus groups. Focus groups and interviews were led by a senior member of the research team and a community partner (parent or provider depending upon the group), and were audio recorded. Participants completed informed consent and a background questionnaire. The leaders (community member and researcher) welcomed participants to the meeting and provided a list of topics. To ensure input from all participants, the moderator asked different participants to respond to each question and to provide input throughout. All facilitators utilized a structured interview guide that included broad, overarching questions as well as follow-up probes. The guide served to provide consistency across sites. The discussion began with basic questions and then moved to more sensitive information regarding access to diagnosis and services (see Table 3 for the facilitator guide). Focus groups lasted up to 2 h and interviews no longer than 1 h. At the end of each group/interview, participants were thanked and given a gift card.

Data Analysis

English and Spanish focus group and interview audio recordings were transcribed by a professional transcription company. Korean language audiotapes were transcribed by a member of the research team fluent in Korean, followed by accuracy validation of transcripts by another Korean-speaking researcher.

Table 2 Provider demographics

Site	Provider age in years (M, range)	Provider gender (N)	Provider race/ethnicity (N)	Provider role/job (N)
Los Angeles (n = 17)	43.7 (25–67)	Female: 14	Asian: 1	Administrator: 7
		Male: 3	Black/AFAM: 9	Allied health provider: 1
			Hispanic/Latino: 4	Educator: 0
			White-Non Hispanic/Latino: 1	Mental health provider: 0
				Pediatrician: 0
			Mixed: 1	Service coordinator: 6
			Unknown: 1	Other: 3
Sacramento (n = 20)	41.3 (24–63)	Female: 20	Asian: 1	Administrator: 2
		Male: 0	Black/AFAM: 0	Allied health provider: 2
			Hispanic/Latino: 4 White-Non Hispanic/Latino: 15 Mixed: 0	Educator: 5 mental health Provider: 4 pediatrician: 1
				Service coordinator: 6
				Other: 0
Rochester (n = 5)	48.0 (34–64)	Female: 2	Asian: 0	Administrator: 0
		Male: 3	Black/AFAM: 0	Allied health provider: 0
			Hispanic/Latino: 0	Educator: 0
			White-Non Hispanic/Latino: 5	Mental health provider: 0
				Pediatrician: 3
			Mixed: 0	Service coordinator: 0
				Other:1
				Unknown:1
Philadelphia (n = 13)	42.8 (26–74)	Female: 12	Asian: 1	Administrator: 2
			Black/AFAM: 2	Allied health provider: 6
		Male: 1	Hispanic/Latino: 0	Educator: 1
			White-Non Hispanic/Latino: 10 Mixed: 0	Mental health provider: 2
				Pediatrician: 0
				Service coordinator: 0
				Other: 2
Total (N = 55)	43.0 (24–74)	Female: 48	Asian: 3 Black/AFAM: 11	Administrator: 11
		Male: 7	Hispanic/Latino: 9	Allied health provider: 9
			White-Non Hispanic/Latino: 30 Mixed: 1	Educator: 6 mental health provider: 5
				Pediatrician: 4
			Unknown: 1	Service coordinator: 12
				Other: 7
				Unknown: 1

Transcripts were uploaded into Dedoose: 7.5.9 [56], a qualitative data analysis program that facilitated data management.

Codebook Development Guided by the study's research questions, a senior member of the research team

Table 3 Focus group questions

Probes for	
Parents	**Providers**
First concerns and first step questions	
Who first noticed the problem and what did they notice?	Who usually first notices the problem?
What and who was helpful in finally getting a diagnosis?	What and who is helpful in getting an evaluation?
What got in the way of getting a diagnosis?	What gets in the way of getting an evaluation?
What would have helped you in getting this diagnosis sooner?	What would help families in getting this evaluation sooner?
Getting into services questions	
Was your child getting any help before the diagnosis?	
Think back to the time after your child was diagnosed with ASD. How did you go about getting services at that time?	Think back to one particular time after you referred a child to evaluation and he/she was diagnosed with autism. How did you follow-up on getting the services that were recommended in the evaluation?
What and who was helpful in getting these services?	What and who was helpful in getting these services?
What got in the way of getting these services?	What got in the way of getting these services?
What would have helped you get these services sooner?	What would have helped the child get these services sooner?
Suggestions for mind the gap intervention	
If you could have had any additional help or information in getting your child first evaluated and / or first into services, what would that be? Who do you want to get this information from?	If you could have had any additional help or information in getting the child first evaluated and/or first into services, what would that be?
	•Home-visit/in person?
	•Phone support?
	•On-line/phone based?
	Do you have a recommendation for the best timing for this intervention?

conducted a broad, open coding of the transcripts and identified a preliminary list of categories. Bilingual and bicultural research assistants verified the relevance of categories to the Spanish and Korean language transcripts. The list of categories was revised through multiple consensus discussions among coders across sites, resulting in a total of eight categories (see Table 4), which were used to develop a codebook.

Inter-rater Reliability Prior to applying the codebook to the transcripts, raters were required to achieve inter-rater reliability across all codes on two transcripts, as determined by kappa $\geq$ .60 [57, 58]. Two people independently coded each transcript and then 20% were also coded by a rater at a different site to ensure consistency. Any discrepancies were discussed and reconciled.

Coding and Thematic Analysis Members of the publication team served as independent coders. The coding team included individuals with expertise in qualitative analysis, as well as raters who received specific training in the coding procedures. Coders used line-by-line coding to assign categories to phrases, sentences or paragraphs; multiple categories could be assigned simultaneously to accurately capture the overall sentiments of the passage. Once all eight original categories had been applied to the transcripts, the team used axial coding to identify subcategories and explore how these related to the original, broader categories. Information from the category applications and identification of the subcategories guided the development of the final themes, which was also accomplished via group discussion and consensus across sites. For Korean and Spanish language transcripts, translation took place after coding was complete. At the axial coding stage, coders were blind to the cultural groups and backgrounds of the participants, as they were grouped by subcategories rather than by cultural group. The exception was for Spanish and Korean-speaking groups, as coding was completed in the original language, which is recommended to preserve cultural relevance of the interviews [59].

Once coded, transcripts were first sorted by provider or caregiver, and caregiver groups were further sorted by (a) language of the focus group or interview (English,

Table 4 Codes and definitions

Theme/code	Expanded code	Evidence/comments on:	
Process	Includes evalution process, referral process, services process; case management code	•The process of screening, getting a refferel, and other copies related to diagnosis and evaluation. •Process of obtaining services at school or community.	•ASD case management •Process to securing service in the past or currently. •Description of communicatio bettween providers/parents regarding services.
Helpers	Service helpers, evalution helpers, support network advocacy	• Person considered helpful. •Positive example of provider or parental accomplishments of getting services or evalution.	•Funding mechanisms •Accomodation •Social network/cultural brokers
Recommendations	Intervation ideas from parents and providers about sevices desired and technology	•Services programs that the parent or provider thinks would *benefit*.	•Ways to use technology with the family
Cultural differences	Cutural and linguistic diversity	•Different in culture, or aspects of culture. Includes race, SES, religion, generation, rural, and language barries from the provider or parent.	
Barriers	Includes all service barries, evaluation delay/problem, misdiagnoso, parent/provider conflict, financial.	•Anything that prevents or delays the evaluation, dianosis or services •Intial misdiagnosis,mislabel,or misdiagnosis at any stage/environment. •Issues that cause tension in the relationship betwen parents and proders.	•Famil accomodation such as needing to quit job to care for cild •Issues concerning transportation, finances, linited availability of service providers,denial/delay of services, waitlist, and other factors that limit service consumption;includes change/loss of services.
Knowledge	Includes education needed,parent /provider knowledge	•Knowledge or information parents or providers need,or that they do not process •The knowledge a parent or provider processes; seeking knowledge or info gathering.	•Confusing aspects of the process. •The use of technology by the family to gain knowledge
Parental concerns/-feelings	Includes mention of parental concern or feeling about child and process.	•Issues oe behaviors parents worry about in the community, at home or school •Parents 'feeling about getting te ASD dignosis,disability in general; stigma of disability; emotion, denial/acceptance.	•Instances were parent places a value (feeling or emotion) on a service, person, agency, or experience. •Service the parent wish they had specifically foe themselves.
Beginning stages	Mention of early signs and age of diagnosis.	Child behavior that indicate a potential issue or concern, people who first notice the problem and age of diagnosis.	• Any early sign, red flag, or parental concermn before te child gets the diagnosis

Spanish, or Korean) and (b) race/ethnicity of the focus group or interviewee (Hispanic/Latino, Black, or Korean). English and Spanish-speaking Hispanic/Latino groups were reviewed separately due to potential differences in acculturation.

Results

Results examine the similarities and differences across groups of parents and providers for the primary themes that emerged regarding barriers to service access and facilitators of service access. Themes typically related to family, community, and organizational factors that contributed to service access. Due to the commonalities among provider and family themes, we emphasize the voice of the participating families and summarize provider findings, highlighting any differences. Brief supporting quotes are provided in the text, while lengthier quotes are indicated by superscript letters associated with Table 5.

Barriers to Diagnosis and Service Provision

Almost all caregivers and providers noted significant barriers to diagnostic and treatment service access. There was considerable overlap in the barriers identified across racial and ethnic groups. For example, challenges to obtaining an ASD diagnosis were ubiquitous experiences across caregiver groups. Across groups, families identified limited access to high-quality providers as a barrier and indicated they often felt "stuck" with their providers. However, the reasons for these

Table 5 Supporting quotes from families

	Topic area	Groups mentioning	Representative quote
	Barriers		
	Limited provider ASD awareness and knowledge delays service access		
a	Wait and see approach	All	So, when he was two, I was always track everything he did, write it down, and tell the doctors. And, unfortunately, yes, they would say, 'Oh, well, he's only two. That's a typical two-year-old. they are going through the terrible two stages. That's just them.'
b	Normalizing challenging behavior/speech delay	All	To this day, we are up to his sixth pediatrician because I had a really hard time getting a diagnosis for him. Doctors were telling me that it was normal for a boy to behave the way that he was behaving. Now, it's I know that's not.
c	Concerns dismissed	BL, SS	I feel like in my situation that because of the color of my skin or because of maybe the way I decide to use my words or my tone or in my pitch or I use my hands a lot that I have been judged and treated poorly…throughout the whole entire process. So I think a barrier for me would be race.
d	Blame parent	BL, SS	[My son] was still biting, still having all these meltdowns that felt different than I had seen with other kids. And the pediatrician told me, 'I think what you really need is a nanny.'
e	Concerns dismissed	BL, SS	A mother reported, 'And then it was just shrugged off all the time as being a young parent. I am like, I am not that young…when I had him I was 25.'
f	Concerns dismissed	BL, SS	I would go every time he had his check up and talk to him about it. They were like, you are a young mom… just new to this and everything that you see is gonna alarm you.
g	Lack of provider knowledge of ASD	W, KS	Every time we come here I feel like oh great [the pediatrician] is going to call me out on something else. Something else she's going to – you know? And then finally at that 3-year visit she said, 'I do not know what he has. I do not know what he has.'
h	Lack of provider knowledge of ASD	W, KS	That was one thing I feel like the pediatrician failed me on was when she kept saying there was something wrong, there's something wrong, there's something wrong. I do not know why she did not tell me about a development pediatrician. I do not know why – I feel like again because J is so smart she was also like every appointment sort of a little bit like she did not know what to do with him either. Fine. Well then that's the very child that you should've referred out.
	Therapy is burdensome for working parents		
i	Limited support/child care	All	Right now I am a single mom with three kids. And I cannot come or go anywhere if nobody is providing any services. So I am still juggling because I do not know who to choose for care for my special kid because I cannot call anyone to help.
j	Job challenges	All	I had to switch off my jobs very quickly because you know after some time I feel that they want me to go out of the workplace. They do not want moms who have young kids. They do not understand that. They will make adjustments to others but they do not feel sympathy of any kind for a working mom.
	Language barriers limiting access to information and services		
k	Need to learn English	KS, HS	Like me, I have to go to classes every day for four hours every day to have that communication with the therapy because everybody is in English. Maybe it's now a person, one, two, you have – school is the same, but I am okay because I here living and I have to get the language.
l	Child services in multiple languages	KS, HS	I think that's another thing as well is there's a conflict of psychologists because our son was in speech therapy and the first psychologist said – because he's bilingual said only speak to him in English. The second psychologist he saw at the same building said it's better for him to be bilingual from the beginning. So we do not know. At the end she works and I work, and he spends most of his time with his Grandma, and she only speaks Spanish. So he speaks Spanish to her and he understands Spanish. But then to us he'll speak to us in English. So it's very confusing, I guess, for him.
m	Lack of bilingual providers	KS, HS	We still have not gotten confirmation because we went to a third party psychologist but our son is bilingual and the psychologist performed the test in just English. So we have been trying to get a bilingual to help just like [Part C Agency] said they were not going to help us because he wasn't qualified to get help. So we are still in the middle of that struggle where we are not sure what's going to happen.
n	Language barriers leading to avoiding checkups	KS	We could have gotten the diagnosis earlier because [our son] had some complications at birth […] the pediatrician told us to come in every six months […] for six months he asked us to come but we did not. We went exactly once and then never again […] I do not even know English so I wasn't in a condition to go there by myself. I could not go. If we had gone in

Table 5 (continued)

	Topic area	Groups mentioning	Representative quote
			every six months as we were told, I think we could have gotten the diagnosis and services faster for our son.
o	Blaming bilingual exposure	KS	The doctor asked us if our child can say things like, 'here, mommy' while playing with toys. So we said, 'our child cannot speak very well.' We were using both Korean and English. So because we use two languages, we thought that's why he was a late talker. Our daughter was like that too. She was a late talker.
p	Language barriers limited professional access	KS	There are a lot of people who try to take advantage of us [Korean parents]. I had an experience before and again this time… We want to find Korean professionals because we cannot speak English. If we need to find a doctor, for example a psychiatrist, we would get referrals from our friends, and finally get connected to a Korean doctor. But it all comes down to this. 'I will see your child so give me $500 per hour.' Or 'for an hour, give me this much.' Stuff like this needs to stop… but we still go to them because we have no other choice.
q	Language barriers limiting advocacy	KS	Even if both mom and dad make the effort together to find services, since our English is not perfect, we cannot get any information in the American society. The only thing we get is the school telling us to 'do this' or 'do that' and all of a sudden they announce, 'we are moving [your child] to a special class… That's the best for the child.' 'Yes, okay,' we would just say that… I do not have a choice. 'Okay, we'll [have him] go.'
r	Language barriers limiting advocacy	KS	If I could speak English well, I could have pushed but I could not. Actually I am pretty good at arguing in Korean, but when it's in English I cannot…You have to know the language in order to fight well [laughs] in order to get services.
Community factors act as barriers to diagnostic and service delays			
s	Limited services in rural community	All	But if there were more meetings available, the front door meetings for OPWDD [i.e., state-funded] services, with a variety of times, whether it's like maybe evenings for parents to attend. I know they have different locations, but some of these are like really far from me, that are coming up…
t	Long waitlists	All	I have been waiting for [the diagnostic evaluation] for two and a half years and they just called me last week. And they are like, 'Okay, we have someone available for you.'
u	Long waitlists	All	That's a wait, you know, the wait to see the developmental doctor. And time goes by, and the child – your child is already – maybe they have met some of their milestones, or have not met milestones, but they have to wait so long to be seen, and to be identified, that that time would be helpful.
v	Family dismissive	All (BL example)	A lot of people still were kind of skeptical, but my grandmother, she is open to it now…People are so stuck in their ways that they do not like to think outside the box sometimes that maybe this could be this or it could be that.
w	Concerns trivialized by family	All (H example)	And it was always something in the back of my mind. But I never wanted to confront it. My parents would tell me, 'Oh, you did not talk that well.' So I thought okay, maybe that's something too. Maybe she's shy, maybe this. But still it kept coming back.
x	Friends and family dismissive	All	So my problem is you know like nobody believes in the family or friends. When I told one of my very, very close friends that my child got diagnosed with autism they said, 'I do not believe it.'
y	Stigma limits sharing of diagnosis	All (W example)	…but there is stigma in our family and friends too. So we thought that it might be challenging; we were not sure how to share the diagnosis and if and when to because of that.
z	Poor parenting as cause	SS, BL	People were so quick to say, 'Ain't nothing wrong. They just bad. They need a butt whooping' and stuff like that.
aa	Poor parenting as cause	SS, BL	'You are not giving enough time to your child. That's why they are struggling.' It's like, 'You need to spend more time with the child instead of going to work. You should take off and spend time, more compassionate.' So they said that it's not – They do not believe in this diagnosis. So I kind of stopped telling about the diagnosis to anybody because then if nobody believes the blame is coming on me.
bb	Isolation	HS, KS, BL (H Example)	Also, in my case in the beginning I did not have support from anybody and it kind of shut me down from even wanting to get help from my daughter.
cc	Isolation	H, KS, BL (BL Example)	As far as my community I do not really reach out to my community. I feel like I went through most of the process very alone and I am okay. I do not want people because I just received a phone call, like, 'You know we are here for you,' from the doctor's office but that was just now, you know what I mean? But throughout the getting everything set up I did everything

Table 5 (continued)

	Topic area	Groups mentioning	Representative quote
			alone. I did not really have anybody to talk to or reach out to or help me, you know what I mean, personally so it was really hard, you know what I mean?
dd	Cultural concerns	BL	So, just educating myself and kind of having an open mind, not being – because I think a lot of people are embarrassed and I think a lot of black people in different communities are embarrassed.
ee	Cultural concerns	BL	I am coming from a culture and a community that does not – that wants to deny. I am coming from – of which I consider myself to be somewhat educated. So to me a little bit of open-mindedness is there.
	Systemic barriers contribute to diagnostic and service delays		
ff	Limited information	All	The resources are very limited. It makes it difficult because you have to—it's a little bit easier going through a college course than trying to get information and help on the support, the services.
gg	Limited help	All	Well I almost just started breaking down crying right now because I did not get that toolkit and I was turned away from [center] right when I walked in five years ago. And I did not turn back around and say, 'Wait a minute. Is there –?' I did nothing because I did not know that's what I should have done.
hh	Confusing/conflicting information	All	She [the pediatrician] said, 'Oh, well, the last time you were here, I told you he has autism.' I said, 'Yeah, but I did not know. You did not tell me that. You said you think he has.' I work in a law office. They are very precise, very particular. You have to choose your words wisely. You are speaking to someone who does not know apples from oranges about any of these things. You are not being very empathetic…She just wasn't clear at all.
ii	Fighting for services	All	…People only give you kind of what you allow them to. Nowadays, you have to fight for these services for these children, you know?
jj	Conflict among systems	All	Like I have gone to a place and I am like yeah why am I here? Someone told me to come here. Oh I do not know why they told me to come here. What do you offer? Nothing.
kk	Conflict among systems	All	So everybody sort of on the surface agrees that he needs someone unless they are the ones paying for it. So when they are the ones paying for it then all of a sudden he's fine. When they are not the ones paying for oh yeah, yeah he needs some help. And you know when you sit back at these meetings it sounds ridiculous the inconsistencies that come out of people's mouths. And then parents are left to navigate that whole field.
ll	Fighting for services	All	I am currently going to court with social security because I took his diagnosis to social security because they do not want to consider him disabled anymore.
	Facilitators of diagnosis and service provision		
	Caregiver proactive participation facilitates service access		
mm	Persistence	KS, SS (SS example)	…si no hubiese insistido y me hubiese guiado por lo que decía la gente de alrededor pues no hubiese conseguido un diagnostico tan temprano. (…if I had not insisted and would have been guided by what the people around me said, I would not have gotten a diagnosis [for my child] so early.)
nn	Self-advocacy	KS, SS (SS example)	…cuando fue mucha mi frustración y mi desesperación, me fui al distrito y pedí hablar con alguien del departamento de recursos especiales. Y entonces salió alguien... y ella me dio más consejos… (when my frustration and despair was too much, I went to the district and asked to speak to someone from the special resources department. And then someone came out... and she gave me more advice…)
oo	Self-advocacy	KS, SS (KS example)	In my case, I wanted my child to get extra help, so I asked his teachers. 'His language is delayed, so please talk to him more. Since my English pronunciation is bad, please read books to him at school.' And the teachers would continuously talk and read to him. Instead of spending hundreds of dollars on extra services as some parents do, I was able to get that help from school teachers.
pp	Using the internet to get information	KS, SS (SS example)	[El] responder a los recursos del internet, de la computadora, en casa, en mi propio tiempo, a la hora que yo podía, como le digo, pasaba madrugadas buscando información. (Responding to the resources of the internet, of the computer, in my home, in my own time, at the time I could, as I say, spent dawns looking for information.)
	Family members provide important supports		
qq	Practical support from family	All	My mother, my daughter's grandmother, had printed off a list of – a checklist of autism and it suggested that I talk to her pediatrician.
	Provider advocacy and coordination makes a difference		

Table 5 (continued)

	Topic area	Groups mentioning	Representative quote
rr	Key provider partnerships	All	She [the Head Start teacher] told me you should go here. I told her. Yeah, you know what, I have been telling them, but I already took him to the doctor. She was like no. She took me a form and she said, 'I am going to bring you a form and we are going to do it. You just write down everything and then I will come and pick it up and then we will score it. That will let you know for sure.' That's how we started.
ss	Key provider partnerships	All (SS example)	…fue muy buena, muy útil su ayuda, de esta persona que trabaja en el distrito [escolar]… después de que hablé con ella e hice la carta, fue que empezó a avanzar, despacio, pero empezó a avanzar las cosas para (Name). (…it was good, her help was very useful, of this person who works at the [school] district… after talking to her and writing the letter, it was that it started to move forward, slowly, but things started to move forward for [my child].)
tt	Key provider partnerships	All (KS Example)	I got a lot of help from the school. When my child started talking, they even let him switch classes four times in a single year. At first, they moved him to a class with kids who could listen to him and have conversations with him. And then, they moved him to a class with other kids with disabilities who could talk, so they could have conversations and socialize together.
uu	Interpreters	KS, SS (KS Example)	The second interpreter I brought to the school had majored in counseling, so she knew how to say things in a certain way to get the school to give us more services. She paid attention to details. She also noticed that my child has had seizures. Unless I speak perfect English, I am always going to need an interpreter. Depending on how much an interpreter knows about the child and special education, the range of services families get can vary a lot.
vv	Providers interest and outreach	SS, H, BL (SS Example)	…le dije [a la trabajadora de la guardería] que el niño se tapaba los oídos y que yo tenía preocupación. Y ella fue quien me dijo, 'Si tú tienes preocupación… pide ayuda, ve al centro regional' y ella fue la que me dijo aquí que viniera. Y aquí me lo diagnosticaron con autismo. (I told [the daycare employee] that the child covered his ears and that I was concerned. And she was the one that told me, 'if you have concerns… ask for help, go to the regional center (developmental services agency)' and she was the one that told me to come here. And it was here that my child was diagnosed.)
ww	Provider relationships	All (BL example)	When I saw their willingness to tell me certain things then I just put my guard down…And that's when I was okay I let everything go, humbled myself. Then I could be open. I was ready to be taught. And so they showed me things. They opened up a whole new world for me.
	Other parents of children with asd provide critical support		
xx	Peers as counselors or mentors	All	So, after he got the diagnosis, I just shut down. I did not say anything, I did not tell anybody… I just – I could not do it. So, one of the moms calls me…She called me at work and I just started bawling and I told her that this is what happened.
yy	Peers as mentor	BL	So if you do not know how to read or there's a certain skill that you do not know how to do – because we are in this together you need to speak up or you need to take somebody to the side and you need to get it. It's not important about who knows what. we are all in this together. we are trying to see a better future for our kids. So check your ego at the door and then let us do this.
zz	Peers as advisors	SS	…cuando fui a un party de mi amiga, ellos, como ya tienen niños con autismo… me dijeron que por lo menos la llevara [a la niña] a chequear porque no era normal. (…when I went to my friend's party, since they already have children with autism… they told me to at least take [the child] to get checked because it was not normal.)
aaa	Peer support reduces isolation	A	[She] gave me another family who was autism, an Indonesian family…yes and I find – yeah it's finding hope because we are not alone.
	Communities provide unique supports		
bbb	Practical support from community	All	I do not feel like I can leave him at a daycare and be okay so yes it affected my job greatly and if I did not have the supervisor that I had that's willing to work with me I would probably be unemployed right now, you know what I mean?
	Recommendations		
ccc	Knowledge of ASD	All (SS example)	…nosotros los hispanos tenemos muy poco conocimiento acerca de los… acerca de… los síntomas del autismo y de las… de los síntomas de cualquier enfermedad del comportamiento. (…we Hispanics have very little knowledge about the… about…the symptoms of autism and the… of the symptoms of any behavioral illness.)
ddd	Too much information at once	All	And then a lot of times I would get packets handed to me. And then you look like, 'Oh my gosh I have to read through all this?'

Table 5 (continued)

	Topic area	Groups mentioning	Representative quote
eee	Cultural matching	All	But I think that if we are focusing on minorities, women, women of color or whatever – whatever the – there are so many groups of different minorities. I think that [cultural matching] helps because they could understand but [as a professional] she might also be compelled to understand as well. You know so it should not matter but I think it makes the people feel a little more comfortable.
fff	Need for guidance	All	If you were, like, assigned a person that says, 'I can help you with each step, if you have a question call me.' There were plenty of times I had questions and I am just, like, I do not know who to talk to.
ggg	Peer support	All (BL example)	It's a lot different hearing [information] from somebody who is just like you, than hearing it from a practitioner.

All, all groups mentioned; *BL*, Black; *H*, Hispanic; *A*, Asian; *W*, White; *SS*, Spanish speaking; *KS*, Korean speaking

barriers differed among groups and were described as being associated with race and ethnicity or language barriers.

Limited Provider ASD Awareness and Knowledge Delays Service Access

Several of the concerns raised by families around service access related to provider characteristics, such as poor understanding of ASD. Many families experienced initial misdiagnosis although reasons for this varied across groups. For example, speech and global developmental delays were more commonly reported by Korean and Hispanic/Latino caregivers, whereas black caregivers uniquely reported ADHD and other externalizing disorders as the first diagnosis they received. Many caregivers, and some providers, thought that delays in diagnosis were exacerbated by provider minimization of parental concerns. Caregivers who expressed concern about their child's development or behavior were often told to "wait and see."[a] Concerns about behavioral outbursts or speech delays often were normalized as "boys being boys."[b]

We are up to his sixth pediatrician because I had a really hard time getting a diagnosis for him. Doctors were telling me that it was normal for a boy to behave the way that he was behaving. Now, it's I know that it's not.

Although all caregivers expressed frustrations that providers dismissed their concerns, black and Spanish-speaking caregivers often described this as related to their race or culture.[c] For instance, one black mother described how a medical provider blamed her parenting and refused to refer her for a diagnostic evaluation, which she perceived as being due to her race.

I feel like in my situation that because of the color of my skin or because of maybe the way I decide to use my words or my tone or in my pitch or I use my hands a lot

that I've been judged and treated poorly throughout the whole entire process. So I think a barrier for me would be race.

Among black and Spanish-speaking caregivers, mothers felt they were repeatedly invalidated when expressing worries.[d] Several mothers described how their concerns were attributed to their youth and inexperience, and how they were subsequently dismissed.[e, f] These dismissals delayed referral for a diagnostic evaluation.

And then it was just shrugged off all the time as being a young parent. I'm like, I'm not that young…when I had him I was 25.

Korean-speaking caregivers felt their pediatricians were confused about ASD [g, h] and reported frustration that oversights due to a lack of understanding of the diagnosis and dismissals of parental concerns delayed their child receiving appropriate referrals.

소아과 선생님은 가서 물어봐도 전혀 모르세요. '얘가 전혀 웃지도 않고, 눈도 안마주치고, 아이가 3개월, 6개월 되어도 눈 앞에서 어떤 물건을 들고 이렇게 가도 얘가 안 따라온다' 그랬더니 선생님이 '애들은 다 그래요' 라고 했어요. [다른 에이전시에 연결해주는 것도] 전혀 없었어요. 그래서 제가 직접 알아봐서 에이전시에 연락을 해서 스케줄을 잡았더니… 소아과에서 거꾸로 연락이 왔어요. 그 때 소아과 선생님이 저한테 뭐라고 그랬냐면, '내 허락도 없이 그 에이전시에 왜 연락했냐, 내가 괜찮다고 했는데, 왜 먼저 엄마가 뭐 안다고 연락했어요?' 라는 거에요. 대박이죠? (I asked the pediatrician but he was completely clueless. I told him, 'My child doesn't smile or make eye contact, and even at 3 or 6 months he didn't visually follow objects held in front of him.' And he said, 'That's normal.' He didn't even make any referrals. I had to call a different agency to schedule an appointment. When he

found out, the pediatrician called me and said, 'Why did you call them? I told you your kid was okay. What does a mom know?' It's ridiculous, isn't it?)

Providers noted differing perceptions among service providers about specific intervention programs (i.e., applied behavior analysis; ABA) as a potential barrier. Some providers would advocate for more ABA-based services, while others held strong opinions against ABA that might limit referrals and education for families about these services. Providers thought that these differences in theoretical background and understanding of ASD treatment by providers often led to confusion for families.

Therapy Is Burdensome for Working Parents

Access to childcare was raised by many caregivers as "the biggest problem," posing a barrier to accessing family services such as support groups, and to working, especially for single mothers.[i] Some caregivers reported giving up jobs to manage their children's services, including attending appointments (e.g., "I had to stop working so therapy could come in") or needing to frequently pick up their children.[j] Other caregivers felt pressure to stay home with their children: "So anything that I wanted to do as far as working, that killed everything…That's my baby. It's my responsibility to make sure that they are right." Another caregiver echoed, "I quit my job and I started taking more care of him myself." Across families, leaving work was not a preference, but was perceived as a necessary sacrifice to provide optimal services and supports to their children.

Language Barriers Limit Access to Information and Services

Language barriers to service access were reported by providers, Hispanic/Latino caregivers (both English and Spanish-speaking groups), and Korean-speaking caregivers. For instance, some caregivers noted that information was not always provided in Spanish. Caregivers described the need to learn English to communicate with their child's therapist [k] as well as provider confusion around which language their child should speak.[l] Caregivers and providers both described how a lack of bilingual providers slowed down diagnosis and access to services.[m] Korean-speaking participants, all first-generation immigrants, reported that language barriers and scarcity of Korean-speaking professionals undermined service quality and provider selection.[n] They thought that the diagnosis was delayed, at least in part, due to caregivers and providers attributing child language delays to limited exposure to English.[o] They felt especially vulnerable to being taken advantage of by some Korean doctors (e.g., overcharged), but reluctantly continued to see them for ease of communication.[p] These

caregivers also reported that they could not advocate for their children due to language barriers, even when they felt that services were inappropriate.[q, r]

제 영어가 좀 잘 되고 하면, 더 푸쉬하고 좀 할텐데 그걸 못 했고. 제가 사실 한국말도 잘 하고 잘 따지기도 해요. 그런데 이제 영어가 거기 들어가면 못 하잖아요… 왜냐하면 싸움을 잘하려면 언어를 알아야 하거든 [laughs]. 서비스를 잘 받으려면. (If I could speak English well, I could have pushed but I couldn't. Actually I'm pretty good at arguing in Korean, but when it's in English I can't…You have to know the language in order to fight well [laughs] in order to get services.)

Providers Perceive Family Challenges as Lack of Engagement

One family factor raised by providers was the inverse of the concern families had about providers. Much like caregivers thought that providers minimized concerns, providers described difficulty engaging caregivers in pursuing services perhaps due to discounting provider recommendations. For example, some providers noted that caregivers would not make necessary calls to access services. Also, providers identified the tendency of caregivers to undervalue services as a barrier to service access. Providers reported that they often needed to give additional explanation about the importance of services over multiple visits for these families, and emphasize the potential benefit to the child across the lifespan, in order to engage families in services at all. Both providers and Spanish-speaking caregivers indicated a lack of caregiver knowledge regarding child development as contributing to a delayed diagnosis and engagement with the system.

Community Factors Act as Barriers to Diagnostic and Service Delays Community factors, such as location and rurality, reportedly contributed to diagnostic and service delays according to caregivers and providers. Although these barriers are commonly reported in broader populations of parents of children with ASD, participants highlighted how location (i.e., rurality and logistical barriers) and cultural factors (e.g., stigma, cultural belief system) exacerbate more general barriers to place under-represented families at further risk.

Transportation and Distance Limits Access to Skilled Providers Distance to large cities reduced both access to, and quality of services often leaving families struggling to find adequate supports: "There are programs, but I don't feel we should have to go to (close by city) or out of our immediate [area] in order to get the help for our kids. That's not fair." Another caregiver indicated that living in a rural county made it difficult for her to engage with the organization that coordinates state-funded services.[s] A caregiver from Philadelphia summarized: "In order to get them helpful services, you have

to be willing to travel," highlighting the intersection of location of services with transportation issues. In both urban and rural areas, long waitlists were a commonly reported barrier to timely diagnosis and intervention access across groups of parents and providers.[t, u]

Stigma Related to ASD Leads to Isolation and Delayed Acceptance Across groups, caregivers reported adverse responses from family members and people in their community related to their child's development or recent diagnosis. They described the process of finding out about their child's disability as a "trauma" and used words such as "shocking" and "painful." Providers reported similar concerns about stigma related to ASD as limiting service access due to concerns about identifying their child as having a disability. Caregivers reported that family and community members did not necessarily believe that their child had a disability, dismissing or doubting caregivers' concerns, which led to reluctance to share the diagnosis.[v, w, x, y] Spanish-speaking and black caregivers reported a community tendency to attribute behavioral symptoms of ASD to a need for discipline and "boys being boys," rather than a developmental concern. They were, in particular, often blamed for poor parenting.[z, aa]

> So my problem is you know like nobody believes in the family or friends. When I told one of my very, very close friends that my child got diagnosed with autism they said, 'I don't believe it.'

Parents also described increased feelings of isolation and this concern was echoed by providers. Specifically, Hispanic/Latino, Korean-speaking, and black caregivers reported feelings of loneliness and limited support.[bb, cc] Notably, black and Hispanic/Latino caregivers described shame and stigma associated with disability as manifesting in their communities in ways such as being told that their child's behavior was related to parenting style. They described the importance of countering this view by educating themselves and remaining open-minded.[dd, ee] Korean-speaking caregivers had significant concerns regarding stigma as well, due to the negative view of disability in Korean culture. They mentioned specific behavior that resulted from stigma such as keeping their child's ASD diagnosis secret from the child's grandparents, and family members dismissing parents' concerns.

> 저희 시댁은 미국사람들이고 그러다 보니까… 그 때 저희가 진단을 받고나서 진짜 너무 depressed 해가지고 시댁 어른들한테만 오픈하고 다른 사람들한테는 공개를 안했어요… 근데 이제 친정쪽으로는 어린 아이에 대해서 그런 말을 한다고 친정엄마는 되게 싫어해요. (My in-laws are [white] Americans, We were so depressed after we got the diagnosis, so we opened up to my in-laws but

didn't tell anyone else… On my side of the family, my mother really hates that I say such things about a young child.)

Systemic Barriers Contribute to Diagnostic and Service Delays Systemic factors were endorsed by caregivers and providers across groups. Again, although participants shared concerns that have been raised in broader groups, at times, they identified how the intersection of *culture* (e.g., language) with those barriers creates additional obstacles. For instance, some participants expressed a fear of approaching services providers because of their immigration status. Hence, specific cultural issues of immigration added another layer of barriers to accessing a timely diagnosis and services.

Information About ASD Is Hard to Access Information gaps were particularly frustrating. Both providers and caregivers indicated that parents had insufficient awareness of available resources and services because information was not disseminated systematically. Providers indicated a lack of parent access to information about ASD delayed diagnosis and services for many children. Caregivers also reported that the lack of communication around ASD first signs and diagnosis impeded them from obtaining a timely diagnosis and appropriate services.[ff, gg]

> The resources are very limited. It makes it difficult because you have to—it's a little bit easier going through a college course than trying to get information and help on the support, the services.

The ASD System of Care Is Complex and Confusing The evaluation and service access processes confused caregivers. Many caregivers reported that they did not get the help they wanted navigating the system of developmental disability and special education services: "Nobody is following through on what's happening with your child." Spanish-speaking caregivers often discussed receiving conflicting information from different providers. There were also concerns that the requirements and expectations for obtaining services are not explained in a coherent or family-friendly way. A mother highlighted this concern in relation to the evaluation report: "Just handing it to somebody. That's a lot. This is like a college student, like here's your homework for the semester. And it's like what am I supposed to do with this?" In some cases, providers thought they were communicating relevant information, but caregivers did not perceive it as helpful.[hh]

Parents Perceive a Need to Strongly Advocate to Access Services Caregivers across groups and sites also recounted

"fighting" for services and supports. They described service agencies or officials as being unresponsive because they denied or did not deliver services.[ii] They also reported disagreements among payers, especially insurers, over who should provide or pay for services.[jj, kk] These difficulties often led to a "constant battle" for services, sometimes through the legal system.[ll]

> So everybody sort of on the surface agrees that he needs someone unless they're the ones paying for it. So when they're the ones paying for it then all of a sudden he's fine. When they're not the ones paying for it.. oh yeah, yeah he needs some help. And you know when you sit back at these meetings it sounds ridiculous the inconsistencies that come out of people's mouths. And then parents are left to navigate that whole field.

Facilitators of Diagnosis and Service Provision

We elicited specific information regarding provider and caregivers' perceptions of strategies that they found to be facilitators of engagement in the service system for children. While some strategies were specific to racial/ethnic groups, most strategies were cited by all groups as helpful for any family from a traditionally underserved background.

Caregiver Proactive Participation Facilitates Service Access Caregivers and providers in all groups discussed the need to be persistent in trying to obtain resources and services for their children. The Korean and Spanish-speaking groups brought up this theme most consistently. Caregivers' efforts consisted of persistently working to obtain desired services (e.g, through continued phone calls and requests)[mm] and engaging in self-advocacy.[nn] Many Korean-speaking parents could not voice their concerns at meetings due to language barriers, so they remained passive and reluctantly agreed to service or placement decisions that agencies and schools made for their children. Parents who reported more positive experiences with school tended to be more active.[oo]

> si no hubiese insistido y me hubiese guiado por lo que decía la gente de alrededor pues no hubiese conseguido un diagnostico tan temprano. (if I had not insisted and would have been guided by what the people around me said, I would not have gotten a diagnosis [for my child] so early.)

Black, Korean, and Spanish-speaking caregivers highlighted the importance of using the internet and technology to gather information about resources and to make better-informed decisions.[pp] Ten out of 14 mothers in the Korean-speaking groups explicitly mentioned using a discussion forum for Korean mothers in the US, called MissyUSA [60] to gather general information about ASD, which led to offline meetings among parents to exchange information and find social support.

Family Members Provide Important Supports While some caregivers indicate that stigmatization by family members could be a barrier to service access (see above), people in all groups noted that their family members, typically the caregivers' parents, were helpful in many areas of their lives. Common supports included babysitting, housing assistance, moral support and advice, and transportation. Participants shared the importance of having their family involved in the initial diagnostic process, including recognizing first signs and recommending an evaluation, as well as providing emotional and other logistical supports. In one illustrative example, a caregiver explained the support she received from a family member in pursuing an ASD diagnosis.[qq]

Provider Advocacy and Coordination Makes a Difference One key facilitator providers and caregivers across groups discussed was provider advocacy for children, with particular emphasis on the relationships caregivers built with providers. Caregivers explained how providers taking specific steps to assist the family was instrumental in facilitating access to services, referrals, and evaluations. Caregivers stressed the importance of collaboration with providers and appreciated when providers went "the extra mile."[rr] Providers also reported success when they had the time to advocate on behalf of families, especially those that did not have the resources to advocate for themselves. Notably, caregivers often referenced providers in early intervention centers, pre-schools, daycares, and elementary schools as particularly helpful when families were seeking an evaluation and in providing support throughout the child's education.[ss] Families reported that school providers were often the first to prompt parents to seek an evaluation. Sometimes, teachers offered information about districts and placement options.[tt] Other providers that also played a significant role in helping families obtain services included interpreters. Korean parents believed that service access was aided by interpreters' knowledge of the special education system.[uu]

> She [the Head Start teacher] told me you should go here. I told her. Yeah, you know what, I have been telling them, but I already took him to the doctor. She was like no. She took me a form and she said, "I am going to bring you a form and we are going to do it. You just write down everything and then I will come and pick it

up and then we will score it. That will let you know for sure. That's how we started.

Provider Partnerships Facilitate Caregiver Engagement Many parents talked about partnerships with providers that helped them access care. Strategies used to form partnerships varied among racial and ethnic groups. Specifically, black, Hispanic/Latino, and Korean caregivers described partnerships that were established through hands-on strategies (e.g., frequent communication, having trusted providers introduce the family to a new service system) and a focus on building trust. Providers also mentioned the importance of understanding the family culture (family-centered care) and the importance of having multilingual, multicultural providers.

All groups discussed how providers helped families access services. Black and Hispanic/Latino caregivers and providers cited strategies that addressed logistical concerns (e.g., meeting outside of normal working hours, having more community settings for diagnosis and services, receiving updates about the child's treatment in the child's backpack), as well as outreach from providers who showed genuine interest and excitement in the child's treatment.[vv]

Black, Hispanic/Latino, and Asian caregivers emphasized the importance of provider assistance and their relationships with providers. They found it especially helpful in accessing services when a person with knowledge of the system had a relationship with them, advocated on their behalf, and made information understandable.[ww] Similarly, a Korean-speaking mother shared that staff at a community-based organization educated her about different types of services before her initial appointment with a *Part C Agency*. She felt this equipped her with knowledge that helped her obtain services for her child.

Other Parents of Children with ASD Provide Critical Support Caregivers in all racial/ethnic categories and providers all viewed support from other families of children with ASD or other disabilities as critical. Subthemes included an "all in this together" approach and "feeling like you are not alone." Caregivers noted that networking with other families, attending support groups and informal meetings with other caregivers, calling other caregivers, and sharing knowledge and experiences were helpful throughout the beginning of their child's diagnostic process.

Although participants often viewed other caregivers as valuable helpers in the diagnostic process, the function of this peer support differed across cultural groups.[xx] Several subthemes related to peer parents emerged specific to black caregivers, including: a shared sense of community with other caregivers in which black caregivers were able to express their feelings without judgement, the value of mentoring and community-building opportunities, supporting other caregivers in specific areas of need (e.g., caregivers with lower literacy levels or less fluency in speaking formal-register English), value in being told concrete and practical advice, and favoring "straight talk."[yy] Hispanic/Latino families thought that having a community of parent peers gave them a sense of familial connection when their biological family was far away. Spanish-speaking caregivers found the information about rights and resources from parent groups helpful. They also noted the importance of having close friends alert them to potential child developmental problems.[zz] Providers also identified the use of cultural brokers (people who mediate between the culture of the individual and service delivery systems), as an important community resource for facilitating access to care [61].

So, after he got the diagnosis, I just shut down. I didn't say anything, I didn't tell anybody… I just – I couldn't do it. So, one of the moms calls me… She called me at work and I just started bawling and I told her that this is what happened.

Black caregivers identified parent networks as important and viewed their peers as a gateway to information despite barriers related to their socioeconomic status. Asian families thought that peer parents kept them from feeling alone, and explained that talking to other Asian families who shared common experiences provided them with a sense of relief.[aaa] All caregivers viewed relationships with other peers as particularly helpful in engaging them in accessing care, as these relationships provided caregivers with a sense of therapeutic relief through networking opportunities and conversations about shared experiences. Providers identified the use of family resource/empowerment centers as an important method of obtaining peer support and advocacy resources.

Communities Provide Unique Supports Caregivers from various racial and ethnic groups also identified key people within their community as actively helping them access services for their child. Across participants, friends, colleagues, and health care professionals provided supports such as moral support, flexibility with work responsibilities, and recommendation for evaluation services for the child. For example, one mother shared her concerns about leaving her son at a daycare facility and praised her supervisor for allowing flexibility in her work schedule to help her during the process.[bbb]

Discussion

Race, ethnicity, and income-based disparities for children with ASD and their families are part of longstanding systemic barriers to effectively engage and support traditionally under-resourced groups. While our and other studies find family-

level and systemic contributors to disparities for children with ASD, historically it has been difficult to explore these themes because (1) most studies have relied only on quantitative data, which does not fully represent the richness of family experience to be represented; and (2) studies have only examined experiences of one cultural group at a time, whereas explicating systemic and institutional discrimination requires investigation across groups. This study addressed these gaps through the use of qualitative methodology and comparisons among multiple groups from different racial, economic, language, and ethnic backgrounds. To our knowledge, this is the first study to examine barriers and facilitators to service access across a range of traditionally underserved groups from different cultural backgrounds, and the professionals who provide them services. Overall, while caregivers and providers across groups consistently described similar barriers and supportive strategies, within these themes we also identified important issues specific to different cultural groups.

One consistent theme raised across groups is that promoting access to care to all families requires successful and authentic partnership between providers and families that includes providers advocating for the child's needs and providers supporting the family's access to care. The emphasis on partnership is unsurprising, as it parallels research on promoting parent engagement in other contexts, such as schools [62, 63]. However, our cross-cultural analysis revealed preferences for different types of partnerships based on caregiver needs and culture. For example, Hispanic/Latino and black caregivers stressed the need for relationship and trust-based partnership, which is consistent with literature in other areas of mental health [64, 65].

In most cases, having a mentor or professional who could help families navigate the system of care and identify relevant information about ASD increased timely access to care. Instances in which families of color expressed that they experienced strong provider advocacy and partnership often appeared due to providers engaging in cultural brokering strategies.

Across groups, ubiquitous challenges about obtaining timely diagnosis and services were reported. Common barriers included providers dismissing concerns, difficulty navigating a confusing system, and limited provider availability due either to location or waitlists. Within these common themes, cultural differences consistent with the literature [29, 32, 36, 38] emerged related to language barriers (Spanish and Korean-speaking families), discrimination based on perceived parental youth (black families), and lack of community understanding of child development (Spanish-speaking families).

Providers and parents often had different lenses through which they viewed similar challenges. This is not necessarily surprising, given that providers often have very different cultural backgrounds from parents, which may bias how they view interactions [66]. For example, consistent with previous literature, providers often reported challenges with "parent engagement" as well as tensions between parents and educators as barriers to accessing care, feeling that families may not understand how services can help their child [45, 63]. On the other hand, parents talked about the systemic barriers that contributed to limited engagement, including cultural differences in perceptions of child development, stigma around disabilities, issues of work, scheduling, provider availability, limited calls back from providers, and frustration with the complex system as barriers to care. Especially concerning is confirmation from families that accessing service for their children often resulted in loss of work hours or employment [67]. Some of these points have also been raised in previous studies [17] and highlight that focusing solely on family factors may not lead to reduced disparities.

Recommendations

Findings from this diverse group of stakeholders in three states can help guide improvements to the service system to reduce disparities. Our recommendations are based on the themes extracted from the family and provider focus groups across the four sites, including responses to a question specifically asking for their recommendations. These recommendations are inspired by the findings from the current paper, but they also integrate current research on access to care for traditionally underserved families. Where relevant, we specifically integrate cultural considerations and strategies to reduce disparities based on race and ethnicity.

Enhance provider education around salient issues, including ASD diagnosis, intervention options, and providing culturally responsive care and increase diversity in the professional workforce.[ccc]

1. Providers should engage in an iterative process of self-assessment and reflection regarding their own biases that may influence accurate identification of neurodevelopmental concerns. Concerns raised about over-identification of behavioral or externalizing disorders in black children and dismissing concerns of language delay in children from non-English speaking households pervade the literature [20, 68]. Participation in general training on cultural responsiveness is a good first step, but providers should specifically examine potential diagnostic biases on an individual basis, through discussion with other clinicians, and in training and supervision [69, 70].

2. To reduce minimizing parent concerns and maximize respect for parents, educate providers on how to authentically communicate and engage with families. This includes specific training in culturally humble and responsive practices. Unaddressed cultural differences can negatively affect client

engagement and adherence [34]. Understanding cultural influences such as stigma around developmental disabilities in the community, family understanding of child development, and family knowledge of ASD red flags may help providers support families who may not recognize early signs of ASD or developmental delays. Expanding this knowledge will also give providers context for parental concerns for their child, engaging providers and parents in more productive conversations around potential diagnostic identification. Building positive parent-provider relationships is critical to providing family-centered care in ASD [71] and it can influence important treatment decisions, such as use of alternative treatments [72]. When possible, providers should receive training that specifically emphasizes cultural humility, parent communication, and relationship-building with caregivers. Although formal trainings can be cost-prohibitive, there are myriad online resources that address effective cross-cultural communication [34].

3. Ensure that written information provided in diagnostic and progress reports (including recommendations and resources lists) are clear and written in lay language.ddd Effective verbal and written communication is associated with better adherence and outcomes [73]. Providers should give personalized information regarding what is most pertinent for the child and family in that moment. Providers can make written information accessible by talking about key points with the parent during the visit, assessing for understanding (e.g., asking the parent to say what they think the important points and next steps are), and encouraging parents to ask questions or express concerns. These strategies have been successful in improving outcomes in a variety of populations, including those from low-income households and those with low literacy skills [74, 75].

4. Increase the diversity of the professional workforce. Cultural and linguistic similarities between caregivers and providers can enhance their relationship and help families feel more comfortable and understood.eee Enhancing organizational diversity requires systemic change and time, but it can increase trust between families and medical and educational systems [76]. Workforce diversity can be improved through specific recruitment of racially, ethnically, and linguistically diverse individuals. In addition, promoting a positive organizational culture around diversity and inclusion may help recruit and retain professionals from diverse backgrounds. For example, although the number of Latino students nationwide has increased from 17% to 24% between 2001 and 2011, 85% of K-12 public school teachers are white [77]. It is increasingly essential to have a professional workforce that is culturally competent to teach a diverse student body and work with parents from diverse backgrounds.

Disseminate more comprehensive, culturally-appropriate, and accessible information to communities about child development, ASD, intervention options, and the service system to reduce stigma and increase parent empowerment.

1. Medical, educational, and community providers should provide clear direction to families about how to engage with the service system. Service recommendations should be accompanied by *specifics* about how to access those services (e.g., steps to completing paperwork, direct phone numbers, specific agency names). Individualized guidance about enrolling and engaging with service systems may be especially important for racial/ethnic minorities.fff

2. Develop community-specific resources that have been reviewed by professionals to facilitate dissemination of evidence-based information about ASD and related interventions. Post-diagnosis, many parents report that they did not receive enough information about ASD [78], which may inhibit their understanding of the diagnosis. Similar gaps were evident with regard to understanding treatment options. Resources explaining ASD diagnosis and services should be in places where parents are likely to go (e.g., agencies, parent groups, online) to supplement what is shared in the diagnostic visit. Materials written using accessible language, and available in the family's native language, can help guide families to reputable information. Materials should also represent diverse families by including pictures of individuals of varied races, ethnicities, genders, and ages.

3. Promote awareness and disseminate information about ASD in varied and culturally mindful ways. Different communities may need to receive information in different ways or they may trust information from certain sources over others. For example, information given via web or app-based technology may facilitate access for some cultures (e.g., Asian families) and for families living in rural communities. Alternatively, other groups may benefit more from information from "everyday" sources such as television and radio, particularly local stations that have relationships with the community. Provide informational resources on relevant topics (e.g., milestones, developmental screening, local parent groups) in areas that are important to the community, such as faith organizations, public markets, barber shops, libraries, and recreation centers. The presence of ASD-related resources in trusted spaces may serve to lift up the conversation about ASD to extend community-wide and it may also reduce the stigmatization of developmental disorders that leads to delay in diagnosis and care [23, 79]. Additionally, it is important to translate materials into multiple languages while also considering the beliefs and attitudes of the culture [80].

4. Offer parents opportunities to develop advocacy skills, especially among immigrant families and families who do not speak English as a first language. Families often feel overwhelmed, lost, or dismissed by the service system, which can interfere with their ability to effectively advocate for their child. Parents should have access to educational trainings specifically on advocacy skills that are offered through local systems (e.g., schools, community agencies, parent groups). This is particularly important for families who are trying to navigate the system in their non-native language, which can result in feelings of "alienated advocacy" [81]. For these families, education sessions should include strategies to request interpretation services and local resources that provide these supports.

Strategically plan for parent-provider and parent-to-parent partnerships that include service navigation.

1. Build infrastructure for providers to assist caregivers with system navigation. Service navigation is a clear need for families of children with ASD [82]. Patient/family navigator programs involve professionals dedicated to assisting families in understanding the complexities of accessing care and providing families with social-emotional support. These programs have improved care access for underserved families across multiple conditions and systems [83–85]. Navigation services have been effective specifically for parents of children with ASD, and they may be especially helpful for underserved families when they are culturally adapted and mediated through others with similar experiences (e.g., "promotoras," or other families of children with ASD) [86]. In addition to helping families process a diagnosis and access services, navigators should provide "check-ins" as needed, following recommendations and referrals to allow for more supportive guidance to help families fully engage with the service delivery system.

2. Establish a warm hand-off between services agencies and between providers. Families will likely move from provider to provider as their children age and develop. Systems that are designed with the capacity to facilitate a coordinated transition through a referral process, wherein the referring provider introduces the patient to a new provider, may be particularly effective in engaging and retaining patients [87], especially for black and Hispanic/Latino caregivers [88]. Warm handoffs can be resource-intensive, and when it is impractical, alternative supports may include making personal referrals, vetting the new provider, and giving the family a follow-up call to assess their satisfaction with the new provider.

3. Connect families with other caregivers of children with ASD for support and guidance. Access to peers who have similar experiences may help parents adjust in the initial stages of diagnosis, and ongoing relationships with other families can provide parents with informational support (e.g., local providers, treatment options).ggg Some families may benefit from being linked with culturally and language matched peers to address issues related to stigma and to promote advocacy skills [89]. Caregivers should receive resources related to parent support groups, online parent groups (e.g., Facebook pages), and other community-based groups where they are likely to connect with other parents.

Consider and address practical barriers to service access.

Logistical barriers, such as transportation, child care, and job commitments prevent many families from engaging with available service systems [24]. Schools and agencies that develop infrastructure to address these barriers will be better-equipped to engage and retain diverse individuals with ASD in their services.

1. Provide opportunities to engage in services remotely. To address transportation barriers and lack of participation due to conflicting work or childcare obligations, consider distance learning opportunities such as telehealth (for medical or behavioral visits or parent training), teleconsultation (e.g., for school or center-based programs), and teleconferencing (e.g., remote participation in conferences and meetings for parents who cannot leave work for extended periods). Telehealth models have successfully engaged parents of children with ASD [90] and have been associated with improved outcomes [91].

2. Develop supports for parents with multiple children. Increase access to care on evenings and weekends and provide childcare for appointments and meetings that parents attend (e.g., healthcare and mental health appointments, support groups, IEP or parent-teacher meetings).

Addressing individual, family, and systemic barriers to ASD service access requires dedicated resources, implementation of explicit strategies and policies, and incorporation of the principles of cultural and linguistic competence. Although effecting systemic change requires significant time and commitment, changing the climate of our service system is necessary to ensure that all families and individuals receive equitable services and can fully participate in available community supports. Striving for this goal supports a model of true inclusion for individuals with ASD and their families.

Compliance with Ethical Standards

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