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Latino Parents' Perspectives of Barriers to Autism Diagnosis

Katharine E. Zuckerman, MD, MPH^{1,2}, Brianna Sinche, MPH¹, Angie Mejia, MA, CAS^{1,3},
Martiza Cobian, BA^{1,4}, Thomas Becker, MD, PhD⁵, and Christina Nicolaidis, MD, MPH^{6,7}

¹Child and Adolescent Health Measurement Initiative, Oregon Health & Science University, Portland, OR

²Division of General Pediatrics, Oregon Health & Science University, Portland, OR

³Department of Sociology, Syracuse University, Syracuse, NY

⁴Department of Psychology, Pacific University, Hillsboro, OR

⁵Department of Public Health and Preventive Medicine, Oregon Health & Science University, Portland, OR

⁶Department of Internal Medicine and Geriatrics, Oregon Health & Science University, Portland, OR

⁷School of Social Work, Portland State University, Portland, OR

Abstract

Background—Latino children are diagnosed with Autism Spectrum Disorders (ASDs) at older ages and at the point of more severe symptoms.

Objective—To qualitatively describe community, family, and health care system barriers to ASD diagnosis in Latino children.

Methods—Five focus groups and four qualitative interviews were conducted with 33 parents of Latino children previously diagnosed with an ASD. Participants described Latino community perceptions of autism and barriers they experienced during the diagnostic process. Sessions were audio recorded and transcribed. Transcripts were coded by two researchers, and data were analyzed using thematic analysis.

Results—Parents reported low levels of ASD information and high levels of mental health and disability stigma in the Latino community. Parents had poor access to care due to poverty, limited English proficiency, and lack of empowerment to take advantage of services. Providers sometimes dismissed parents' concerns. The ASD diagnostic process itself was slow, inconvenient,

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Address correspondence to: Katharine E. Zuckerman, MD MPH, Oregon Health & Science University, 707 SW Gaines Rd., Mail Code CDRC-P, Portland, OR 97239; zuckerma@ohsu.edu; tel: 503-494-1930; fax: 503-494-2475.

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confusing, and uncomfortable for the child. These factors led many parents to normalize their child's early behaviors, deny that a problem existed, and lose trust in the medical system.

Conclusions—Additional educational outreach to Latino families, de-stigmatization of ASD, streamlining the ASD diagnostic process, and providing additional support to Latino parents of at-risk children may decrease delays in ASD diagnosis among Latino children.

Keywords

Autism Spectrum Disorder; Delayed Diagnosis; Hispanic Americans; Health services accessibility; Qualitative Research

Introduction

Recent estimates suggest that Autism Spectrum Disorders (ASDs) affect more than 1% of U.S. children over age 3, and rates ASD diagnosis may be increasing.¹ ASDs can be reliably diagnosed,² and early diagnosis is associated with improved long-term developmental and family outcomes.³ However, many children meeting ASD diagnostic criteria are never diagnosed⁴ or are diagnosed years after onset of symptoms.^{4,5} Delayed diagnosis is a particular problem among Latino children:^{6,7} Latino children receive a diagnosis of an ASD 2.5 years later than white non-Latino children.⁸ Latino children are also less likely to carry an ASD diagnosis; however, when diagnosed, they are more likely to have severe symptoms than white non-Latino children.^{4,9,10}

Reasons for ethnic variation in ASD diagnosis are poorly understood. Some investigators posit that Latino children manifest different patterns of symptoms than other children, which may make ASD more difficult to identify for parents or providers.¹¹ Providers may also be less comfortable identifying the early signs of ASD in Latino children.¹² Given known ethnic disparities in health care access and quality generally,¹³ as well as ASD services in particular,^{14,15} delayed diagnoses may reflect disproportionately poor service quality in Latinos. Diagnostic delays may also reflect family and community factors, such as parent beliefs about ASD and developmental delay, awareness of ASDs, health literacy and acculturation, and logistical issues such as difficulties with transportation and child care.¹⁶⁻¹⁸ To our knowledge, no prior studies have focused on ASD diagnostic delays from the Latino family perspective.

Therefore, the goals of this study were to assess barriers to ASD diagnosis in the Latino community. We used a qualitative research design based on focus groups and individual interviews with parents of Latino children previously diagnosed with ASD; this research strategy is useful for gaining a deeper understanding and for generating hypotheses in areas where knowledge is limited.¹⁹ In our investigation, we sought to understand the community and social context in which Latino parents lived and sought care for their children. In addition, we elicited specific barriers that families experienced seeking ASD care.

Methods

Recruitment and Eligibility

We recruited parents of Latino children with ASD to participate in a focus group or semi-structured interview. Eligible parents spoke English or Spanish and had a child age 2–10 diagnosed with ASD. Participants were recruited from a university autism clinic research registry, a county developmental disabilities service, and a community advocacy organization for Latino children with disabilities. We used purposive sampling²⁰ to include parents in urban and rural areas, and parents with English or Spanish primary language. Participants were initially approached via mail and telephone; interested individuals were invited to participate in a focus group in their geographical area and preferred language. We made special efforts to accommodate parents facing barriers to attendance by reimbursing for public transportation, and providing food and child care. Participants who were still unable attend a group due to timing conflicts, geographical distance, child care problems, or severity of their child's ASD, were offered an individual interview via telephone or in person. Recruitment continued until we reached thematic saturation. The Oregon Health & Science University Institutional Review Board approved the protocol.

Procedures

Focus groups were conducted by a bilingual Latina facilitator and a bilingual research assistant. Groups were conducted in English or Spanish, took place at community settings in Oregon, and lasted approximately ninety minutes. Individual interviews were conducted by a bilingual research assistant at a time and place convenient for the parent.

Verbal informed consent was obtained prior to interviews or focus groups. Interviews and focus groups followed the same interview guide (Appendix Table 1) which was informed by literature on delayed diagnosis for other developmental and behavioral disorders.²¹ The guide had three domains: community perceptions and knowledge of ASD, barriers experienced before and during the ASD diagnostic process, and suggested ways to overcome barriers. The facilitator asked probing and clarifying questions or asked participants to elaborate on emerging themes. After the focus group or interview, parents completed a survey assessing child and parent demographic characteristics (Table 1).

Data Analysis

Focus groups and interviews were audio-recorded and transcribed verbatim in their original language. Data were analyzed using thematic analysis, an inductive approach at the semantic level that uses an essentialist paradigm (i.e. we theorized participants' motivations and meanings based on what they said, rather than from existing literature, theoretical constructs, or the socio-cultural context that enabled their accounts).²² The PI, two bilingual/bicultural research assistants, and two Latina parents of children with an ASD read selected transcripts, discussed their general impressions, and identified preliminary themes. Based on the results of these discussions, we developed preliminary codes. The research assistants then independently coded each transcript in its original language, using QSR NVivo 10 (Victoria, Australia). The PI reviewed all codes and independently coded selected transcripts. Both research assistants met with the PI after coding each transcript to resolve any coding

disagreements by consensus. The code list was updated when new ideas emerged. After initial analysis, the team met to review coding and to generate themes and subthemes. We particularly considered themes that were frequently endorsed, that were less frequently endorsed but were emphatically endorsed by some participants, and that may be unique to Latinos (as opposed to all parents seeking an ASD diagnosis). Codes were reviewed a final time to assess variations within each theme, differences in views among participants, and differences between interviews and focus group results. Final themes were reviewed by one Latina parent of a child with ASD to assess for face validity. Spanish quotations selected for this manuscript were translated by a bilingual team member with training in medical translation; translated passages are marked with an asterix.

Results

Sample

66 families were invited to participate; of those, 36 were reachable by mail or phone. 24/36 families (33 parents) eventually participated in 5 focus groups (ranging from 2–12 parents) and 4 individual interviews. All but one participant identified as Latino (one participant's partner was a Mexican-origin man; she considered her son Latino). Most participants were Spanish-speaking, Mexican-born women with less than high school education. Median age at ASD diagnosis was 2.8 years, with an older age of diagnosis in children whose parents attended Spanish focus groups (Table 1).

Themes

We identified themes describing barriers to ASD diagnosis and organized these themes into three categories: *Latino community knowledge and perceptions of ASD*, *parent and family factors*, and *health care system factors*. From these factors, additional *adverse consequences* resulted. Figure 1 shows the relationship of themes to each other and to ASD diagnostic delays.

Latino Community Knowledge and Perceptions of ASD

Lack of parent and community information about ASD: Nearly all parents felt there was little knowledge about ASD in the Latino community, and that lack of knowledge impeded early ASD identification. Many said that they knew little or nothing about ASD prior to their child's diagnosis. One mother commented:

“I didn't know anything. The day that they told me [that my child had autism] I didn't know what it was.”*

Some parents were still unsure what it was. In every focus group and interview, parents cited “lack of knowledge” or “ignorance” about ASD as a problem in their community. Parents pointed to lack of attention to ASD in the Latino media relative to mainstream media as one important cause of low information availability.

Parents also felt that their community knew little about ASD because conditions like autism “do not exist” in many Mexican communities. Children in Mexico might behave differently, or have a disability, but these children would not be labeled with a medical condition:

“Well sometimes Latino people do not understand, because in reality in Mexico we don’t have a diagnosis of autism. No one knows about it. It’s like, here you come to understand so many things that over there, we didn’t know what they had or didn’t know the name of it.” *

As a result, sometimes a child’s ASD would go unexplained or poorly understood.

Mental health and disability stigma prevented parents from seeking care. Parents thought many in the Latino community perceived disabilities, and particularly mental health problems, as embarrassing or shameful, and that this might be a reason that families did not discuss developmental concerns with community members, health care providers, or even each other.

“...but all of us know that in Mexico they call them idiots. ... I remember when I was a young girl I saw one, an autistic person. I asked, ‘What is that?’, and they told me, ‘That’s an idiot.’...”*

“...so there [Mexico], parents ignore their children if they have some disability. If they are born with a deformed ear they say ‘this child isn’t worth anything’ or if they go to a party and they have a child in a wheelchair, all the children go out [to play] and leave the child in the wheelchair behind. Or if the mother goes outside the house to talk with someone selling something, she closes the door so no one can see him.”*

Parents felt that in many Mexican communities, a family of a child with ASD would hide a child that acted differently. Community members might think that the child was improperly disciplined (especially, in need of spankings). They might also think that the child was crazy, had an intellectual disability, or had Down syndrome. As a result, when parents observed their child’s behavior, they felt uncomfortable sharing their concerns or even admitting they had a concern.

Machismo, or a traditional view of Latino male gender roles,²³ was perceived by mothers as particular problem for their male partners. Mothers felt fathers saw having a “weak” or “disabled” boy as a poor reflection on them as a man:

“There are still too many men still that are way too macho, and their kids can’t be, this is my son’s dad’s issue.... He doesn’t get it or he’s too macho to understand, to have a child that sick and that’s a big deal. How’s he gonna have a sick kid when he’s this big tough guy?”

“I mean, one of the questions he wanted me to ask at the evaluation is, is he gonna be able to have a normal life and have children and get married? And I said they’re not gonna be able to tell us that.... And he’s like, if that’s the case, I need to know so that we can have another child.”

As a result, fathers might discredit mothers’ concerns, be uncooperative with the diagnostic process, or take a passive role in their child’s care. Notably, no fathers stated specifically that *machismo* affected their interaction with their child, or how they perceived their ASD diagnosis; however, they stated that ASD changed how they envisioned their son’s ability to

perform “normality” in a culture influenced by traditional gender norms and expectations. For instance, one father described how he had hoped to show off his boy at rodeos, which now seemed hard to imagine given the boy’s autistic behaviors.

Parent and Family Factors—*Limited English Proficiency (LEP)* made every step of the diagnostic process more difficult – Parents in every focus group and 2/4 interviews cited LEP a significant barrier. Even parents in English focus groups and interviews pointed to LEP as a barrier for other parents who spoke English less well. Language issues made scheduling appointments and arranging transportation particularly difficult. Poor interpreter access or quality also made it difficult for parents to express their concerns and navigate the diagnostic process.

Poor awareness of available services and lack of empowerment to take advantage of services: This theme was more prevalent in the English focus groups and interviews. English-speaking mothers felt that less-acculturated Latina mothers did not realize their child was entitled to services, or did not feel comfortable “speaking up” or “being strong with people” to get the needed services:

Parent 1: “They didn’t speak up. Either because they didn’t have the voice or they just, I don’t know.

Parent 2: “Or they’re intimidated.... A lot of these parents are also immigrants. That I think is a big one. But just the fact that, I don’t know, I think it has a lot to do with the fact of not speaking up.”

Poverty and its associated problems made seeking care more difficult. Although few parents directly said they lacked money to pay for diagnostic appointments (probably because most children in the study were publicly insured), several said cost of appointments might affect other families. However, poverty indirectly affected families’ access to care: for instance, restrictive insurance coverage or lack of money for transportation or child care made appointments harder to schedule. Some parents worked multiple poorly-paying jobs, in temporary or seasonal work, with no flexibility to take days off to take their child to appointments. Also, because of poverty, some parents may “push aside” their developmental concerns because of more pressing economic needs.

Health Care System Factors

Primary care provider dismissed parents’ concerns: Experiences with primary care providers were mixed. Some parents felt their provider helped them obtain an ASD diagnosis quickly; others felt their concerns were ignored. Some parents switched health care providers several times before finding one who took their concerns seriously. Parents felt that providers’ dismissive behaviors and/or lack of inquiry into parents’ concerns delayed diagnosis. One parent recounted such dismissive behavior:

“I brought him to the doctor, telling her that I was worried because my son didn’t speak, I mentioned the four words [that he used to say] and since then, he doesn’t talk at all and it’s like he is mute... So the doctor examined him, saw that he ran and all that, but she never said anything to me about autism. She said: ‘Don’t

worry. Let's wait until he is 3 years old. There are some children that start to talk at 3 years. Sometimes not all children speak early, others [speak] late. Don't worry..."*

Few parents thought that these behaviors were due to bias or racism; however, some English speakers felt that providers underestimated their level of education or understanding, and many Spanish speakers felt that language barriers prevented them from expressing their concerns optimally with providers.

The diagnostic process was complex and slow: Getting an ASD diagnosis often entailed visits with multiple medical and school personnel. There were often long waits to get care. Because many providers were involved, and did not communicate well, the process felt slow and disjointed.

"The most difficult part was the fact that I was sent to so many different specialists. And the specialist will only look at one piece of a puzzle; they just don't put everything together. And that's what I found mostly, is that the time between seeing different people was a long time. So that made it really, really difficult to be able to get any kind of answers and any kind of help for [child]."

The complexity of the process was particularly challenging for less acculturated families. Many small delays added up to larger delays for parents seeking diagnosis and treatment for their child.

Getting an ASD diagnosis was inconvenient: For the most part, children could not be diagnosed with an ASD in their community. Getting a diagnosis for many families meant arranging child care for other children, taking time off from work, and often having to rely on medical transportation or public transit to take them long distances.

Getting an ASD diagnosis was uncomfortable for the child: Given that many children with ASD have challenges with sensory issues, changes in their routine, and interacting with strangers, ASD diagnostic evaluations were often unpleasant for the child. This was particularly the case for families who had to come for multiple visits. These factors may have made parents reluctant to follow up after an initial experience, especially if that experience was a negative one.

Consequences

ASD concerns were normalized, leading to inaction: Because parents had little information about ASD, community members were uncomfortable discussing it, and because providers sometimes dismissed parent concerns, parents heard many normalizing messages about their child's problem.

Interviewer: "Okay. And when you told your husband, 'Something is going on with the child.' What did he say?"

Parent: "That I was the one who was crazy. That the child didn't have anything."*

As a result, parents doubted their concerns or delayed taking action on them.

Parents felt confused and conflicted about ASD: As many parents noted, even doctors are confused about ASD, which has no clear cause or cure. However, when parents had little information and doctors and community members suggested parents' concerns were invalid, their confusion was compounded. Parents were not sure what ASD meant, or what they should do, even after receiving an ASD diagnosis. This was particularly the case for children with diagnoses of pervasive developmental disorder, not otherwise specified (PDD-NOS); parents were unsure whether the child really had ASD or not. Parents often left their diagnostic appointments unsure exactly what their child had, or what to do next.

Parents initially denied that their child had ASD: Receiving an ASD diagnosis was stressful for many families, and many needed time to emotionally adapt, which may have delayed care-seeking.

“It took like four months to understand autism and find help. I had to look in the mirror and say, “what am I doing? What am I going to do? Where? Who do I have to go talk with?” I didn't want to talk with my family or my husband about it. My husband also couldn't get over it. It took a long time, but eventually he accepted it, and we moved ahead...”*

Several parents also speculated that other Latino parents purposefully avoided seeking out an ASD diagnosis because it would be too depressing to accept that the child had a serious problem.

Parent trust in the health care system eroded: Most parents trusted providers throughout the diagnostic process; this was particularly the case in Spanish focus groups. However, as the process stretched out over time, parents became frustrated. Some began to doubt whether providers were acting in their child's best interest. One parent suggested that perhaps providers were deliberately making services difficult to access for Latinos in order to save money. Another felt that her ASD diagnostic visit was mainly for conducting autism research rather than for diagnosing her child. Because providers' diagnoses and recommendations seemed less trustworthy, some parents may have put off acting on these recommendations.

Discussion

In this study, we found that Latino parents faced many difficulties in the ASD diagnostic process. In the community, families found little information about ASD. They felt their developmental concerns were normalized, and that community members overtly or subtly discouraged them from sharing information about their child's ASD. Parents had difficulty accessing care due to poverty, limited English proficiency, and lack of awareness of, or advocacy for, disability services for their child. When they did access care, they were sometimes inappropriately reassured by providers and participated in a diagnostic process that was often confusing, time-consuming, inconvenient, and unpleasant for their child. Parents had to struggle with or circumvent normal processes to get the care their child needed.

Although little else is specifically known about barriers to ASD diagnosis in Latinos, our study is consistent with recent research suggesting high levels of overall unmet service need in Latino families of children with ASD.²⁴ It additionally aligns with literature showing minority families have less access to information about mental health diagnoses^{25,26} and experience high rates of mental health stigma in their communities.²⁷ Substantial evidence also suggests that minority families receive less anticipatory guidance or family-centered care,^{28,29} and experience frequent obstacles when seeking health care,^{30,31} which our study also found. Our finding that Latino parents are reassured by providers about their developmental concerns, and are confused about access to developmental care, is consistent with other recent qualitative studies of minority families.³² However, our investigation provides greater depth of inquiry into the cultural basis for some of these disparities. In particular, our findings about the relationship of machismo with care-seeking, as well as the degree of denial and normalization that Latino parents experience, could be important targets for future community-based interventions seeking to reduce ASD diagnostic disparities.

This study has important limitations. First, data were collected retrospectively, and may be subject to recall bias, or may not reflect current health care barriers. This analysis was also based on the experiences of families who were ultimately successful in accessing ASD diagnoses, and many received a diagnosis relatively early compared to other samples of Latinos.^{7,8} Some families of children meeting ASD diagnostic criteria are never diagnosed;⁵ these families may experience the most significant barriers to care. Likewise, participants were contacted through service and support providers, and thus may have better service access than the average Latino family of a child with ASD.

We did not conduct any research with parents of non-Latino race/ethnicity. However, some barriers we found, such as LEP, are likely more specific to Latinos. Others, such as machismo, could be similar in other cultures, but may be framed differently by Latinos.²³ Additional barriers, such as the slow diagnostic process, may not have an ethnic association. Further research is needed to understand which of these barriers represent ethnic differences or disparities. An additional limitation is that the sample consisted of Mexican-origin Latino families. Considering that health outcomes in Latinos vary substantially according to national origin,³⁰ Latino families of other national origins may have different experiences than the parents we studied. Likewise, given state-level differences in coverage of ASD services, experiences may vary for Latino parents living outside of Oregon. Some barriers to ASD care may have been difficult to detect, particularly in focus groups. For instance, undocumented parents may have delayed accessing care due to concerns about their own legal status, or due to experiences of racism, which may have been uncomfortable to raise in the focus group setting. Some findings were primarily parents' generalizations about family and community members' views rather than personal experiences and should be interpreted with caution. Finally, as with most qualitative research, our sample size was relatively small; however, our sampling strategy may allow transferability to other similar groups of parents.

The study's findings have significant clinical and policy implications. Perhaps the most important message for providers to understand is that many Latino parents operate in an environment poor in ASD information, high in messages that their child's behavior is

normal, and high in feelings of embarrassment and shame about disability and mental health issues. If a Latino parent discloses a concern about ASD, providers should address this concern with seriousness and sensitivity, since it may have taken a great deal of effort for the parent to raise it. In addition, parents may not know even basic information about ASD and may not be able to effectively navigate the ASD diagnostic process without significant assistance from providers or other community members.

Table 2 shows other action steps suggested by the study's primary findings. In particular, the findings highlight the importance of ASD screening in primary care, so that early concerns can be promptly detected.³ The purpose of screening should be explained to parents so they feel comfortable participating. Additionally, Spanish-language and non-print-based patient materials about ASD should be made available to improve parent understanding. Building the bilingual and Latino provider workforce would also improve information dissemination and community ASD perceptions.³³ Finally, Latino community outreach may reduce some of the barriers we found. For instance, the Centers for Disease Control's campaign, "Learn the Signs. Act Early" which has free Spanish language materials, would help Latino families understand more about the early signs of ASD;³⁴ Partnering with community-based agencies such as WIC to raise ASD awareness or screen for ASD may allow for earlier identification in Latinos.³⁵ These are just a few of many possible interventions our project's results might inform.

All children with ASD deserve access to timely, accurate diagnosis and prompt initiation of effective treatment. We hope the research presented here will help health care providers and stakeholders make care more accessible for Latino children at risk for ASD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

ASD	Autism Spectrum Disorder
LEP	Limited English Proficiency
PI	Principal Investigator

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What's New

Latino parents of children with autism spectrum disorder (ASD) report low information about ASD, mental health and disability stigma, lack of empowerment, dismissive provider behaviors, and a slow and confusing diagnostic process as barriers to ASD diagnosis.

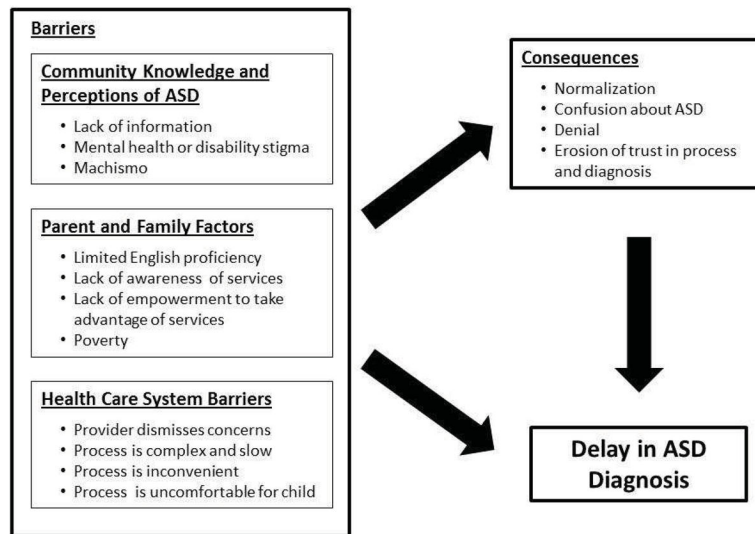


Figure 1.
Relationship of themes to each other and to ASD diagnostic delays

Table 1

Focus Group and Interview Participant Demographics (n = 32)

Characteristic	Median or Percentage (range or n)	
	Spanish focus groups and interviews (n = 25) ^a	English focus groups and interviews (n = 7)
Parent Gender		
Female	68% (17)	100% (7)
Male	32% (8)	0% (0)
Parent Age	36 years (32 – 44)	28 years (23 – 37)
Years of education	8 years (1 – 17) ^d	12 years (12 – 16)
Number of Children	2 children (0 – 4)	3 children (1 – 8)
Age of child with autism	7 years (3.3 – 10.7) ^d	4.6 years (3.5 – 10)
Age of child at diagnosis	3.1 years (2.4 – 4.9) ^{d,e}	2.6 years (1.8 – 3.3) ^{d,e}
Parent Nativity		
Mexico	96% (22) ^d	29% (2)
United States	4% (1) ^d	71% (5)
Years in United States ^b	14 years (7 – 25)	28 years (28 – 33)
Acculturation ^c	Less acculturated (1.68)	More acculturated (4.18)
Ethnicity		
Non-Hispanic	0% (0)	14% (1)
Hispanic	100% (25)	86% (6)
Race		
Other	44% (11)	14% (1)
White	16% (4)	86% (6)
No Response	40% (10)	0% (0)

^a One parent in a Spanish language group did not complete the demographic survey^b Assessed only in parents who have not lived in US entire life^c Measured using the Short Acculturation Scale for Hispanics; scale range 1–5; lower score indicates less acculturation^d Proportion or median calculation based only on participants who had information available^e Information obtained via medical chart review; all other data obtained from parent survey

Table 2

Recommendations based on study findings

Study finding	Recommendations	Sample Quotations
Lack of parent and community information about ASD	<ul style="list-style-type: none"> Providers should not assume that Latino parents have heard of ASD or know its symptoms.* Primary Care Providers could make more information about ASD available at routine visits, or during ASD screening. Non-print material may be particularly helpful for families with low literacy.* Health care professionals could conduct educational outreach to Latino communities; campaigns should stress the importance of early diagnosis.* 	
Latino Community Knowledge and Perceptions of ASD Mental health and disability stigma	<ul style="list-style-type: none"> Providers should more actively and sensitively elicit parent developmental concerns.* Formal developmental and ASD screening (in English and Spanish) should be implemented at routine visits and any time a parent has a concern.* Providers should explain the purpose of developmental screening to parents so that they feel comfortable participating. Trusted community members could assist as information brokers. Information provided to families should emphasize that ASD and developmental delay are biological conditions and not the result of poor parenting or the child being "crazy." Provide bilingual parent and family counseling for families of recently diagnosed children.* 	<p>"Maybe like for places where a lot of the Latino community comes together, possibly churches, have somebody come in that's knowledgeable about it and present it to them like, 'if you have concerns, then come to us so we can refer you'."</p> <p>"I think with every well child check, they should have a checklist of autism symptoms... just to get people thinking or talking about it ... I think it just needs to be brought up every chance that you can especially at school, and with doctors."</p>
Machismo	<ul style="list-style-type: none"> Clinicians should encourage father participation in clinical encounters. Agencies should develop family-to-family support programs for fathers. 	
Parent and family factors Limited English Proficiency	<ul style="list-style-type: none"> High-quality interpreters should be made available for all clinical encounters.* Clinics should hire more bilingual/bicultural staff and providers.* 	<p>"Just making sure that you do have those Spanish-speaking people available to anybody ... If you see a child's M-CHAT test come out negative, and it's a Hispanic family, they should throw somebody in there, and say, 'Okay, we had these red flags' ... Throwing somebody in there with the language right away."</p>

Study finding	Recommendations	Sample Quotations
	<ul style="list-style-type: none"> Clinical programs should aggressively recruit and train bilingual providers. 	
<p>Poor awareness of available services, and lack of empowerment to take advantage of them.</p>	<ul style="list-style-type: none"> All parents should be advised of their child's disability rights. Newly diagnosed or at-risk families should receive enhanced case management. Newly diagnosed or at-risk families could be paired with mentor families. 	<p>"The most important thing is that the whole world be informed about autism, that they find out, that they know that children with autism have the same rights as everyone."***</p>
<p>Poverty</p>	<ul style="list-style-type: none"> Providers should advise families that Early Intervention and Early Childhood Special Education incur no cost to families. Information should be made available to families about other free or low-cost community resources. Families who may be eligible for Supplemental Security Income (SSI) should be advised of the program and encouraged to enroll. 	
<p>Primary Care provider dismisses parent concerns</p>	<ul style="list-style-type: none"> Providers should respond to any parental expressions of developmental concern, since these concerns may be very difficult for parents to raise.* Providers should be trained in early identification of ASD and in normal language development among bilingual children.* 	
<p>Health Care System Factors</p> <p>Diagnostic process is complex and slow</p>	<ul style="list-style-type: none"> Efforts should be made to increase the number of providers trained to diagnose ASD, including training non-specialist providers. At-risk children should be referred immediately to autism specialists.* 	<p>"Doctors should listen to parents, because sometimes I think that they don't [listen]".** "They need to learn to identify the characteristics, and don't wait until [the child] displays all of them. At the slightest suspicion, refer them."***</p>
<p>Diagnostic process is inconvenient</p>	<ul style="list-style-type: none"> Offer outreach ASD clinics in rural communities. Offer evening and weekend diagnostic visits. Cooperate with school systems to obtain diagnosis in educational setting. 	
<p>Diagnostic process is uncomfortable for child</p>	<ul style="list-style-type: none"> Offer "clinic tour" prior to visit. Break visits up into several shorter visits for families without work or transportation issues.* 	

* Quality improvement idea directly suggested by study participants

** Quotation translated from Spanish