

10-2014

## Conceptualization of Autism in the Latino Community and its Relationship with Early Diagnosis

Katharine E. Zuckerman  
*Oregon Health & Science University*

Brianna Sinche  
*Oregon Health & Science University*

Martiza Cobian  
*Oregon Health & Science University*


Marlene Cervantes  
*Oregon Health & Science University*

Angie Mejia  
*Oregon Health & Science University*

*See next page for additional authors*

**Let us know how access to this document benefits you.**

Follow this and additional works at: [http://pdxscholar.library.pdx.edu/socwork\\_fac](http://pdxscholar.library.pdx.edu/socwork_fac)

 Part of the [Community Health and Preventive Medicine Commons](#), and the [Social Work Commons](#)

---

### Citation Details

Zuckerman, Katharine E.; Sinche, Brianna; Cobian, Martiza; Cervantes, Marlene; Mejia, Angie; Becker, Thomas; and Nicolaidis, Christina, "Conceptualization of Autism in the Latino Community and its Relationship with Early Diagnosis" (2014). *Social Work Faculty Publications and Presentations*. 129.

[http://pdxscholar.library.pdx.edu/socwork\\_fac/129](http://pdxscholar.library.pdx.edu/socwork_fac/129)

This Post-Print is brought to you for free and open access. It has been accepted for inclusion in Social Work Faculty Publications and Presentations by an authorized administrator of PDXScholar. For more information, please contact [pdxscholar@pdx.edu](mailto:pdxscholar@pdx.edu).

---

**Authors**

Katharine E. Zuckerman, Brianna Sinche, Martiza Cobian, Marlene Cervantes, Angie Mejia, Thomas Becker, and Christina Nicolaidis

Published in final edited form as:

*J Dev Behav Pediatr.* 2014 October ; 35(8): 522–532. doi:10.1097/DBP.0000000000000091.

## Conceptualization of Autism in the Latino Community and its Relationship with Early Diagnosis

Katharine E. Zuckerman, MD, MPH<sup>1,2</sup>, Brianna Sinche, MPH<sup>1</sup>, Martiza Cobian, BA<sup>1,3</sup>, Marlene Cervantes, BS<sup>1</sup>, Angie Mejia, MA, CAS<sup>1,4</sup>, Thomas Becker, MD, PhD<sup>5</sup>, and Christina Nicolaidis, MD, MPH<sup>6,7</sup>

<sup>1</sup>Child and Adolescent Health Measurement Initiative, Oregon Health & Science University, Portland, OR

<sup>2</sup>Division of General Pediatrics, Oregon Health & Science University, Portland, OR

<sup>3</sup>Department of Psychology, Pacific University, Hillsboro, OR

<sup>4</sup>Department of Sociology, Syracuse University, Syracuse, NY

<sup>5</sup>Department of Public Health and Preventive Medicine, Oregon Health & Science University, Portland, OR

<sup>6</sup>Department of Internal Medicine and Geriatrics, Oregon Health & Science University, Portland, OR

<sup>7</sup>School of Social Work, Portland State University, Portland, OR

### Abstract

**Objective**—Early identification of autism spectrum disorders (ASD) has been linked to improved long-term developmental outcomes. However, Latino children are diagnosed later than white non-Latino children. We aimed to qualitatively assess the understanding and conceptualization of ASD in the Latino community in order to understand potential community barriers to early diagnosis.

**Method**—We conducted 5 focus groups and 4 qualitative interviews with 30 parents of typically-developing Latino children in Oregon. Participants were asked structured questions concerning video vignettes that follow a Latina mother from the time she begins to worry about her 3-year-old son's behaviors to the time he receives an ASD diagnosis. Focus groups and interviews were audio-recorded, transcribed and independently coded. Coded data were analyzed using thematic analysis.

**Results**—Many Latino families in the study had not heard of ASD or had little information about it. Families sometimes assumed ASD red flags were normal or could be attributed to family dysfunction. Families also had concerns about provider communication and access to language services. Having a child with a developmental delay was associated with embarrassment,

---

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.

**Conflicts of Interest and Source Funding:** The authors have no conflicts of interest to disclose. The authors have no financial relationships relevant to this article to disclose.

rejection, and family burden, making it difficult for parents to raise developmental concerns with providers.

**Conclusion**—Pediatric providers should not assume that Latino parents have heard of ASD or know its symptoms. Providers should be aware that parents may be reluctant to mention concerns due to cultural factors. The health care system needs to improve resources for Latino parents with limited English proficiency. Policies should encourage the use of developmental screening in primary care.

## Keywords

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

---

## Introduction

Autism Spectrum Disorders (ASDs) affect up to 1 in 68 U.S. children over the age of three,<sup>1</sup> and early ASD identification has been linked to improved long-term developmental and family coping outcomes.<sup>2</sup> However, racial/ethnic disparities in ASD diagnosis continue to be problematic.<sup>1,3,4</sup> Latino children are diagnosed with an ASD 2.5 years later than white non-Latino children,<sup>5</sup> and are more often missed in diagnosis despite meeting ASD diagnostic criteria.<sup>6,7</sup> Latino children are also more likely to have severe ASD symptoms at time of diagnosis than are white non-Latino children.<sup>3</sup>

Reasons for ethnic disparities in ASD diagnosis are poorly understood. Latino/white ASD disparities may partly reflect cultural factors, although studies specific to ASD are lacking.<sup>8</sup> However, studies have shown cultural differences in Latinos' views of parenting and disability generally. For instance, compared to other parents, Latino parents have distinct views of when children reach certain developmental milestones, such as recognizing parents and smiling,<sup>9</sup> which may be important in early ASD identification. Studies also show that Latino parents differ from other parents in views of normative parenting behaviors, such as how strictly rules should be enforced,<sup>10</sup> but may have similar expectations for disabled versus non-disabled children, such as being respectful and responsible.<sup>11</sup> From a medical perspective, Latino parents may be less likely to consider behavioral and emotional problems as having a mental health basis and more likely to attribute them to “emotional” or “personality” factors,<sup>12</sup> which could also affect whether parents seek medical attention for their child's condition.

Additional factors may also affect early diagnosis of ASD in Latinos. Research is conflicting regarding whether Latino children differ in clinical manifestations of ASD symptoms, with some studies showing differences in performance on standardized ASD measures,<sup>13</sup> and other studies showing little difference.<sup>14</sup> Differences in ASD presentation, if present, may make ASD more difficult for providers to identify. Providers may also lack confidence in identifying ASD in Latino children due to language or cultural differences,<sup>15</sup> even when children meet all case criteria. Finally, access to primary care and specialty care, awareness of ASDs, acculturation, health literacy, and logistical issues such as transportation and child care may play major roles in early access to diagnoses.<sup>16-18</sup>

Current research has investigated barriers to ASD identification in Latinos from the perspective of health care providers<sup>15</sup> as well as parents of affected children.<sup>8,17,19</sup> However, parents of typically-developing children may also offer important insights into family and community factors affecting ASD diagnostic delay. Usually, a parent is not aware that his/her child has ASD until the child is at least 2-3 years old. Most parents of children with ASD do not have particular knowledge about the condition before their child's diagnosis. However, asking parents of children with ASD to reflect back on family and community barriers to their child's diagnosis is difficult, since that time may be quite distant. Additionally, parents' recollections of that time may be altered by subsequent experiences. In contrast, parents of typically-developing children may be in a good position to comment on community knowledge and views of ASD and mental health in general.

Therefore, in this study, we approached parents of typically-developing Latino children, to better understand community ASD knowledge and views, and how these views may affect care-seeking for children at risk for ASD. To facilitate a deeper understanding and to generate hypotheses in areas where knowledge is limited, we used a qualitative research design based on focus groups and individual interviews. Participating parents watched video vignettes portraying a mother's concerns about her child's development and the process of receiving an ASD diagnosis. We used parent responses to the videos to inform discussion about ASD early signs, ASD characteristics, and community attitudes toward ASD and other mental health conditions.

## Methods

### Recruitment and Eligibility

Latino parents of typically-developing children were recruited to participate in a focus group or semi-structured interview. Eligible parents self-identified as Latino, spoke English and/or Spanish, and had children between age 2- 10 years with no major developmental or behavioral problems, defined as negative response to the developmental/behavioral items on the Children with Special Health Care Needs Screener.<sup>20</sup> Parents were recruited from three pediatric clinics serving significant numbers of Latinos in Northwestern Oregon. At two clinics, parents were accrued via a random sample from the electronic medical record; at one clinic, parent contact information was solicited by clinical staff when attending an urgent or routine visit. From these sources, families were purposefully selected in order to have adequate representation by both language and geographical area.

Selected participants were initially contacted by mail and/or telephone, screened for child developmental problems, and asked to participate in a focus group about "child development." Parents who were interested in participating but unable to attend a focus group due to timing conflicts, distance from site, or transportation issues, were invited to participate in a semi-structured in-person interview. Recruitment continued until thematic saturation was achieved. Oregon Health & Science University's Institutional Review Board approved the study.

## Procedures

Focus groups were led by a bilingual Latina facilitator and a bilingual research assistant. Four groups took place in primary care settings, and one took place in a community setting. Child care was provided on site; families were reimbursed for public transportation and received a grocery store gift card for participation. Focus groups lasted 90 minutes and included 5-9 parents each. Individual interviews were conducted in person, lasted one hour, and were facilitated by a bilingual research assistant at a convenient time and place.

Focus group and interview content was based on reactions to four video vignettes, performed by the same actresses in either English or Spanish (Figure 1). The videos, which were developed in consultation with a developmental pediatrician treating children with ASD, two parents of children with ASD, and two health care disparities researchers, depict several conversations between a fictional Latina mother (“Maria”) and her Latina friend, regarding Maria’s 3-year-old son, “Josue.” The videos span the time from Maria’s first concerns about Josue’s behavior to the time he receives an ASD diagnosis. Josue has symptoms meeting all main DSM-IV criteria for ASD, although details were deliberately kept vague to leave room for discussion. Parents were asked to take the role of Maria’s friend and give her advice. Vignettes were designed specifically to elicit community knowledge about ASD, awareness of resources, and community mental health stigma. Summaries of the video vignettes are shown in Table 1. All interview and focus group participants viewed the same vignettes.

After each video vignette, facilitators used a semi-structured interview guide to pose questions regarding the videos, such as how parents would react to the situation or how they would advise Maria (Table 1). After responding to all four vignettes, participants were asked additional questions about barriers to mental health care in the Latino community and strategies to help Latino families during the ASD diagnostic process. Although the interview guide was the same for all groups, the facilitator asked additional questions to clarify or elaborate on emerging themes. In focus groups, the facilitator made special efforts to solicit opinions of all participants and not only those who were the most vocal. After each focus group/interview, participants completed a self-administered survey assessing socio-demographic and acculturation information (Table 2).

## Data Analysis

Focus groups and interviews were audio-recorded and transcribed verbatim in their original language. Data were managed using QSR NVivo 10 (Victoria, Australia) and analyzed using thematic analysis, an inductive approach in which themes were generated from data rather than existing literature, theoretical constructs, or investigators’ hypotheses.<sup>21</sup> The principal investigator (PI), two bilingual/bicultural research assistants and a Latina mother of typically-developing children read two randomly chosen transcripts (one interview and one focus group) to identify emerging themes. The themes were used to create a preliminary coding framework. Three bilingual research assistants then independently coded all transcripts using this framework. For focus group transcripts, the entire focus group was coded as one transcript, although each speaker’s contributions were clearly identified. After coding each transcript, the research assistants met with the PI to review findings pertaining

to that transcript, to discuss new ideas that emerged, and to modify the coding framework as needed. The PI also independently coded and reviewed selected transcripts to assess coding agreement and fidelity.

After coding was complete, the research team met to review and discuss the coding framework and to identify themes. Greater attention was deliberately given to factors that might constitute barriers to ASD care. The team considered both themes that were mentioned by multiple parents as well as themes that were mentioned by only a small number of parents but were stated emphatically. Codes were repeatedly reviewed in conjunction with the themes to ensure congruence. The team specifically examined how themes varied by focus group/interview; since transcripts were coded by speaker, the team assessed whether any individual's views were over-represented. The final list of themes was reviewed for face validity by a Latina parent of a typically-developing child and a Latina parent of a child with ASD. Spanish quotations selected for this manuscript were translated by a bilingual study team member with training in medical translation; original language is noted after each quotation.

## Results

### Sample

Ninety-four families were invited to participate; of these, 60 were reachable by mail or telephone. Thirty parents (21 families) ultimately participated in 5 focus groups (2 English, 3 Spanish) and 4 individual interviews (1 English, 3 Spanish). Most participants were Mexican-born women with less than a high school education and low acculturation (Table 2).

### Themes

In analyzing data, we identified and present themes describing barriers to ASD diagnosis spanning across vignettes. We organized these themes into four categories: *interpretation of early signs, information needs, mental health stigma, health care access and quality*.

#### Interpretation of Early Signs

**Symptoms represented a problem in family relations:** A majority of parents found the video depicting the child with ASD concerning; however, in all but one focus group and interview, parents' initial reaction to the video depicting signs of ASD was to attribute the child's symptoms to poor relationships among family members. Parents frequently suggested the child needed "more attention" or "more love" from his parents. For instance, one parent hypothesized that perhaps the child was acting out because his father was working too much and he lacked male role models. As shown here, a parent suggested that the child was having behavioral problems because family relationships were poor:

It has to do with the relationship [the parent] has with the child. How the home is. Because sometimes problems between the parents can have an influence ...  
Because if the parents are irritated and the child asks for something in that moment, they tell them to wait or they get even more mad. So, it is important that the parents are okay; if they are well, the children will be well... (Spanish Focus Group)

As a result, many parents initially perceived the child's troubles as a problem to be solved through improving family interactions. Parents later reflected that this relational approach to mental health problems might be common among Latinos, and might delay medical evaluations for ASD:

Participant: In Latino families, every problem with your child is different. You don't go to the doctor; you resolve it at home with your family, with your husband. [It's not] like "Okay, let's go to the doctor because he has a solution," you know? It's like, "Behave," you know? Things like that. It's not like doctors' stuff, you know? You don't go there that much. Only when you get sick.

Interviewer: *When you get physically sick?*

Participant: *Yeah. Not because your child is acting weird, you know?* (English Focus Group)

Although most parents ultimately did feel Maria (the mother) should take her child to the doctor, the reason was often so she could seek social support or family therapy resources, not a developmental evaluation per se.

**Behaviors may be in normal range:** Although information provided in the initial video was limited, the child's behavior pattern met DSM criteria for ASD and would almost certainly be considered abnormal by clinicians. However, parents seemed divided over whether the child's behavior was within the normal range, and often took a more flexible attitude toward early childhood development:

Because I have seen, with my children and nephews, that each one is different and that each one has their own personality. Because not all of them will [develop] according to what the pediatrician says. I'm more about observing them and not comparing them to anybody. (Spanish focus group)

Many parents thought that Josue was likely just displaying bad toddler behavior, and that he would likely "grow out of" his problems. Other parents thought perhaps this was normal behavior for a child that didn't have siblings. For that reason, some parents were doubtful of pediatrician expressions of concern and recommended giving him more "space" or time.

**Separation of language delay from behavioral problem:** Parents often focused on the child's lack of language, or his poor behavior and socialization with other children, but did not necessarily link these. One parent thought that perhaps several developmental problems were occurring simultaneously:

I think he has problems with his speech, and also I think that, well I don't know if there are 2 or 3 problems, but he has one speaking problem, and another, which is that he doesn't want to play with the kids, and he gets upset when they take the trains away, he always wants to play with [trains], and I think he could play with other toys. (Spanish interview)

Perhaps because ASD awareness was low (see below), the child's different problems did not often suggest a unifying diagnosis. Exceptions to this rule were focus groups in which a



parent had a personal contact with a child having ASD; these parents were unsurprisingly more capable of viewing all of the symptoms as part of one condition.

### **Information needs**

**Lack of knowledge about ASD:** Overall, knowledge about autism was quite low, and was lower in Spanish focus groups/interviews than English focus groups. In every Spanish focus group there was at least one parent who had never heard of autism, and 1/3 of Spanish interview subjects had never heard of it. In contrast, only one English focus-group participant acknowledged never having heard of autism. As one parent said:

I have no idea how to describe [autism] because... this is the first time I've heard of it. I haven't heard it anywhere. Perhaps I have heard it, but I haven't paid attention. The word doesn't sound familiar to me. (Spanish interview)

Of those who had heard of it, many had no idea what the word meant. Those who knew something about ASD often described it as a condition of being a “bad” or generally disruptive child, particularly in the focus group setting. Some parents were aware of social deficits associated with ASD, particularly that a child with ASD was “in his own world” and not very socially interactive. Parents in English focus groups and those with a community contact with a child with ASD had more knowledge about ASD symptoms. Few parents in any group had any information about ASD treatments.

Multiple parents subsequently speculated that lack of information about ASD was probably a particular problem in the Latino community. As one parent said,

I think that one thing is that we are lacking in information. In our culture... we have very little information about mental illness. In speaking about the Latino community, it's lack of information. (Spanish focus group)

**Lack of information about developmental resources:** There was almost no awareness of Early Intervention, Developmental Disabilities Services, or other specialized community resources for children with developmental delay. Parents cited doctors, teachers, and family or friends, as good sources of information for Maria. Other suggested community resources included the Women Infants and Children (WIC) Supplemental Nutrition Program, the Department of Human Services, which in Oregon oversees child protective services, and churches.

**Poor quality of information:** Parents felt information available to them about problems like ASD was of poor quality. One issue was a general lack of Spanish language material for parents. However, even when Spanish materials were available, their quality was often poor or the Spanish was incorrect. English materials could also be confusing because they contained medical jargon. Parents noted that print-based material also might be problematic for some families:

Let's say you're getting information about autism. You're giving terms, you're giving examples, things like that. If it's, this is a person with limited reading skills, this person is not gonna get it. He's not gonna get the message. And sometimes people is ashamed of saying “I don't understand this.” (English focus group)

## Health Care Access and Quality

**Access to adequate interpreters:** Many parents with Limited English Proficiency felt interpreting services are often inadequate because interpreters are unavailable, poorly trained, or only available by phone which seemed inappropriate for “these types of issues.”

**Access to developmental surveillance:** Some parents felt primary care providers were attentive to developmental questions and concerns, and some parents thought providers were not listening carefully. Regardless, parents valued providers' feedback on their developmental concerns and wanted providers to elicit concerns more actively, either via screening or more intensive surveillance. One parent suggested that if perhaps providers watched the child playing, they might directly observe ASD risk factors.

**Quality of doctor-patient relationship:** Parents recognized that having a child with a developmental delay could be stressful. They felt doctors do not always make parents feel safe, and as a result parents are not forthcoming about their concerns, or might say everything is fine when it is not.

I think the doctor needs to find a way to make Maria feel safe, comfortable, saying comforting words like “don't worry, everything will be okay.” So that she can feel like she can talk about it... (Spanish focus group)

Parents also felt it was important for doctors to spend adequate time with families and to give parents time to process information about child developmental delays.

## Community Mental Health Stigma

**Embarrassment, Shame, Rejection:** When asked to reflect upon why the parent in the video, or why Latino parents in general, might experience barriers to ASD identification, participants frequently pointed out that problems like ASD might feel somewhat embarrassing or shameful. They often perceived Mexican culture in particular as less accepting or inclusive of disability:

In Mexico, you often see that parents, instead of helping their child and teaching people about the problem that their child has, that he is a special child or that he has autism, they hide or cover them, so that people don't look at them, they don't take them outside to play at the park or do different activities, and for me, that is bad. (English focus group – spoken in Spanish)

In every focus group and in one of four interviews, parents speculated that having a child with a disability or delay might lead the child or his family to experience rejection. The child might be ignored by community members, laughed at, not paid adequate attention to, or bullied. As a result, parents might be hesitant to say anything to others about the problem.

I think they would have fear of rejection more than anything. They want to cover it up: “Oh, my son is not well, but, I don't want anyone to know. I will be ashamed.” (Spanish focus group)

**Denial:** Because the early ASD symptoms could be subtle, and because parents viewed the diagnosis as potentially stigmatizing, parents felt some people might delay even after they knew their child's behavior was atypical.

Because sometimes there are moms who don't want to realize that their children have this problem. I know a mom of a girl, and I said to her “she has a problem, you need to go [to the doctor],” and she said “no, no, she doesn't have anything.” It's like, she doesn't want to accept it. (Spanish Focus Group)

**Burden on the family:** Several parents speculated that having a child with a disability like ASD might place an unpleasant burden on family members. Even if family members were not directly involved in the child's care (for instance, even if family members were in Mexico), knowledge about the problem might cause anxiety (or “nervios”), especially for older relatives:

But sometimes I limit the things I say because my mom had diabetes, and my husband's mom suffers from nervios, and so sometimes I only tell them half of the story. (Spanish focus group)

Since information about ASD might cause stress to family members, participants speculated that parents like them might just want to keep it to themselves.

**Suggestions for improvement—**Table 3 displays parents' suggestions for improvement of early identification of ASD. Overall, parents felt that, given their low level of ASD awareness, more time and attention needed to be given to ASD in primary care. Parents recommended that providers regularly review early ASD signs with families, and that bilingual written or video material be available so to parents. They recommended written materials be accurately translated and at a low reading level. Accessible parenting classes that discuss child development, especially those that provide child care, were of great interest. Parents also recommended health care providers partner with teachers, other early education professionals, and community agencies to disseminate ASD-related information. Targeted radio or TV media campaigns that give simple, concrete information were suggested. Specifically, families felt campaigns should emphasize early signs of ASD, explain that ASD is a medical condition, and encourage parents to talk with a health care provider about their concerns. Parents also suggested that providers approach the topic of ASD risk sensitively, giving parents time to come to terms with the idea that their child might have ASD. They suggested that providers immediately offer social and psychological supports to families of newly diagnosed children.

## Discussion

In this study of Latino parents of typically developing children, we identified multiple family and community factors that could contribute to delayed ASD identification. In particular, many families in the study had not heard of ASD or had little information about it. Some families viewed ASD early signs as in the normal range or as due to problems in family relations. Parents had concerns about providers' abilities to communicate effectively, provide adequate language services, and spend enough time with families of at-risk children.

Additionally, families speculated that having a child with developmental delay was associated with stigma, embarrassment, rejection, and family burden, making it difficult for parents to raise concerns with providers or community members.

The finding that many parents had not even heard the word “autism” was particularly notable, especially considering that ASD is prevalent.<sup>22</sup> This finding is consistent with previous research; for instance, a recent study showed that primary care providers viewed Latino parents as having low information about ASD,<sup>15</sup> and a previous qualitative study of parents of children with ASD showed that many retrospectively said they knew little about ASD prior to their child's diagnosis.<sup>8</sup> Though population-based studies are needed, this study suggests that ASD knowledge gaps could be an important reason for ASD diagnostic disparities: if Latino and other minority families are less likely to have heard of ASD, they may also be less likely to approach a health care provider with ASD-specific concerns. This type of knowledge gap is likely not unique to ASD, as previous research has also shown that Latino families have lower awareness of other common pediatric mental health diagnoses, such as Attention Deficit Hyperactivity Disorder.<sup>23</sup>

The finding that families perceive primary care providers as providing little information about ASD as well as not proactively assessing for it, is also consistent with previous literature on lower health care quality experienced by Latino families. For instance, few primary care providers offer Spanish language developmental screening,<sup>15</sup> and Spanish primary language parents are less likely to be asked about their developmental concerns, even when their child is at risk for developmental delay.<sup>24</sup> The finding that parents report providers not listening to their concerns or providing needed information has been reported as a particular problem for Latino parents.<sup>25</sup> Several recent studies have also specifically noted that a variety of patient-centered quality outcomes are lower among Latinos and other minorities than white non-Latinos with ASD.<sup>26-28</sup> Themes describing normalization and denial of ASD symptoms are also consistent with recent qualitative work with parents of children with ASD,<sup>8</sup> as well as other studies showing normalization of other mental health problems in Latino and other minority communities.<sup>23,29</sup>

In addition to complementing previous work, this study adds new concepts to our understanding of how parents conceptualize the early signs of ASD. In particular, the idea that families initially view ASD as a problem with family interactions has not been previously reported for Latinos. If ASD signs are viewed as internal family issues and “not doctors' stuff” (in the words of one of our focus group participants), parents may not mention them to a health care provider. Furthermore, if parents mention developmental concerns in the context of problematic family interactions, providers may not think to assess the child's ASD risk. The fact that parents do not put together the different aspects of the ASD diagnosis could also be important information for providers and policymakers seeking to increase ASD awareness. For instance, the Center for Disease Control's campaign, “Learn the Signs. Act Early,”<sup>30</sup> which explicitly states early risk factors for ASD and has free Spanish resources, might help Latino parents put pieces together. Though our study suggests that some Latino parents may be surprised that ASD and screening and surveillance is part of routine pediatric care, the fact that so many parents requested additional resources

suggests that such programs would be acceptable to families if done in a culturally-sensitive way.

The study has limitations. Since the purpose of the study was to generate hypotheses about barriers to ASD care in the Latino community, we assessed the experiences of Latino parents only. This study does not explore whether barriers experienced were unique to Latinos in either type or degree. While some barriers (e.g. lack of interpreters and Spanish language materials) inherently are more common Latinos versus white non-Latinos, other barriers (such as parents' denial that a child has a problem) may not have a particular ethnic pattern. Additionally, some barriers may be present in other cultures experiencing difficulty with health care access. We hope to explore such issues further in future research by comparing Latinos to other ethnic groups. Regardless of the specificity of the findings, the barriers we found may make useful quality improvement targets, since improving health care disparities often raises the standard of care for all families.<sup>31</sup>

We recruited patients through primary care settings, and held most focus groups in primary care settings, which may have led parents to emphasize medical interventions more than they might have otherwise. To address this limitation, we specifically compared the interviews and focus group held in community settings versus clinical settings but did not find any thematic differences. Likewise, combining interview with focus group modalities might have altered results, since a focus group setting can create social desirability bias and might overly emphasize certain individuals' views. To assess this limitation, we specifically assessed all of the themes according to focus group versus interview mode, and noted a few differences, particularly in terms of discussion of mental health stigma and conceptualization of ASD symptoms.

We chose a video vignette format so that parents would have a concrete scenario to respond to. However, characteristics of the vignettes may have led parents to focus on particular issues and minimize others. For instance, the videos deliberately paid attention to the parent's concerns about disclosing ASD to family and community members, which may have led parents to voice more concerns about mental health stigma than they might have in another context. Likewise, videos did not focus strongly on logistical barriers to care which may be important access issues for the Latino community.<sup>16</sup> Perhaps as a result, these themes were not broadly represented in our focus groups.

We targeted families of typically developing children to understand the early thoughts and understanding of ASD among families of children who ultimately develop the condition. However, since ASD is poorly understood, families of children who ultimately develop the condition may differ systematically in concerns compared to families whose children never develop ASD. Since factors such as Spanish language, acculturation, and parent education were highly correlated among participants, it was difficult to disentangle language effects from other socio-cultural factors. Finally, the study consisted of mostly Mexican origin parents living in Oregon, which limits generalizability to Latinos of other national origins or in other U.S. regions. As with most qualitative research, our objective was to gain deeper understanding from a small sample of key informants; although generalizability may be limited, we do feel the results may be transferrable to other similar groups of parents.

Despite these limitations, the study has important implications for clinicians and policymakers. First, providers should not assume Latino parents have heard of ASD or know much about it. Providers may need to actively elicit ASD symptoms from Latino families, since they may not see these symptoms as a cohesive disorder, may conceive of them as a problem of psychosocial interactions, or may be embarrassed or ashamed to mention concerns. Study findings strongly support routine ASD screening as a way to identify at-risk children; however, screening will be more successful if providers explain why it is important. At a more fundamental level, providing adequate language services to families, both in terms of access to professional medical interpreters as well as high-quality parent information about child development, is critical to enhance provider-family communication.

The U.S. Latino population is increasing rapidly.<sup>32</sup> In some states, Latino children are the majority.<sup>33</sup> Providing adequate access to ASD care for this population is no longer an issue of concern only to specialists or to practitioners working in heavily Latino communities. Understanding and reducing barriers to this common developmental condition in a large portion of the U.S. child population is the concern of all pediatric health care providers. We hope this research represents a first step toward identifying evidence-based quality improvement opportunities in this area.

## Acknowledgments

The authors would like to acknowledge Leonor Garcia, Lori Ball, and Teresa Gomez, and Kelly Diaz for their helpful support and perspectives, Drs. Somnath Saha and Ellen Lipstein for help regarding qualitative techniques, and Dr. Christina Bethell for material support.

**Funding Source:** This project was funded by #1K23MH095828 from the National Institute of Mental Health (PI = Zuckerman).

## References

1. Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR Surveill Summ.* 2014; 63(Suppl 2):1–21.
2. Johnson CP, Myers SM. American Academy of Pediatrics Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. *Pediatrics.* 2007; 120(5): 1183–1215. [PubMed: 17967920]
3. Liptak GS, Benzoni LB, Mruzek DW, et al. Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's Health. *J Dev Behav Pediatr.* 2008; 29(3):152–160. [PubMed: 18349708]
4. Centers for Disease Control and Prevention (CDC). Mental health in the United States: Parental report of diagnosed autism in children aged 4-17 years--United States, 2003-2004. *MMWR Morb Mortal Wkly Rep.* 2006; 55(17):481–486. [PubMed: 16675944]
5. Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among Medicaid-eligible children with autism. *J Am Acad Child Adolesc Psychiatry.* 2002; 41(12):1447–1453. [PubMed: 12447031]
6. Mandell DS, Wiggins LD, Carpenter LA, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health.* 2009; 99(3):493–498. [PubMed: 19106426]
7. Mandell DS, Ittenbach RF, Levy SE, Pinto-Martin JA. Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *J Autism Dev Disord.* 2007; 37(9):1795–1802. [PubMed: 17160456]

8. Zuckerman KE, Sinche B, Mejia A, Cobian M, Becker T, Nicolaidis C. Latino parents' perspectives on barriers to autism diagnosis. *Acad Pediatr*. 2014; 14(3):301–308. [PubMed: 24767783]
9. Pachter LM, Dworkin PH. Maternal expectations about normal child development in 4 cultural groups. *Arch Pediatr Adolesc Med*. 1997; 151(11):1144–1150. [PubMed: 9369877]
10. Bornstein MH, Cote LR. “Who is sitting across from me?” immigrant mothers' knowledge of parenting and children's development. *Pediatrics*. 2004; 114(5):e557–64. [PubMed: 15520089]
11. Arcia E, Reyes-Blanes ME, Vazquez-Montilla E. Constructions and reconstructions: Latino parents' values for children. *Journal of Child and Family Studies*. 2000; 9(3):333, 333–350.
12. Yeh M, Hough RL, McCabe K, Lau A, Garland A. Parental beliefs about the causes of child problems: Exploring racial/ethnic patterns. *J Am Acad Child Adolesc Psychiatry*. 2004; 43(5): 605–612. [PubMed: 15100567]
13. Magaña S, Smith LE. The use of the Autism Diagnostic Interview-Revised with a Latino population of adolescents and adults with autism. *J Autism Dev Disord*. 2012
14. Chaidez V, Hansen RL, Hertz-Picciotto I. Autism spectrum disorders in Hispanics and non-Hispanics. *Autism*. 2012; 16(4):381–397. [PubMed: 22399446]
15. Zuckerman KE, Mattox K, Baghaee A, Batbayar O, Donelan K, Bethell C. Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics*. 2013; 132(3): 445–453. [PubMed: 23958770]
16. Zuckerman KE, Perrin JM, Hobrecker K, Donelan K. Barriers to specialty care and specialty referral completion in the community health center setting. *J Pediatr*. 2013; 162(2):409–14. e1. [PubMed: 22929162]
17. Magaña S, Lopez K, Aguinaga A, Morton H. Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellect Dev Disabil*. 2013; 51(3):141–153. [PubMed: 23834211]
18. Flores G. Committee On Pediatric Research. Technical report--racial and ethnic disparities in the health and health care of children. *Pediatrics*. 2010; 125(4):e979–e1020. [PubMed: 20351000]
19. Iland ED, Weiner I, Murawski WW. Obstacles faced by Latina mothers of children with autism. *Cal J of Health Promot*. 10(1):1–12.
20. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002; 2(1):38–48. [PubMed: 11888437]
21. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res in Psychol*. 2006; 3:77, 77–101.
22. Blumberg SJ, Bramlett MD, Kogan M, Schieve LA, Jones JR, Lu MC. Changes in parent-reported prevalence of autism spectrum disorder in school-aged U.S. children: 2007 to 2011-12. *Nat Health Stat Rep*. 2013; 65
23. Gerdes AC, Lawton KE, Haack LM, Schneider BW. Latino parental help seeking for childhood ADHD. *Adm Policy Ment Health*. 2013
24. Zuckerman KE, Boudreau AA, Lipstein EA, Kuhlthau KA, Perrin JM. Household language, parent developmental concerns, and child risk for developmental disorder. *Acad Pediatr*. 2009; 9(2):97–105. [PubMed: 19329100]
25. Guerrero AD, Chen J, Inkelas M, Rodriguez HP, Ortega AN. Racial and ethnic disparities in pediatric experiences of family-centered care. *Med Care*. 2010; 48(4):388–393. [PubMed: 20220533]
26. Magaña S, Parish SL, Rose RA, Timberlake M, Swaine JG. Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellect Dev Disabil*. 2012; 50(4):287–299. [PubMed: 22861130]
27. Montes G, Halterman JS. White-black disparities in family-centered care among children with autism in the United States: Evidence from the NS-CSHCN 2005-2006. *Acad Pediatr*. 2011; 11(4): 297–304. [PubMed: 21622042]
28. Parish S, Magana S, Rose R, Timberlake M, Swaine JG. Health care of Latino children with autism and other developmental disabilities: Quality of provider interaction mediates utilization. *Am J Intellect Dev Disabil*. 2012; 117(4):304–315. [PubMed: 22809076]

29. Bussing R, Zima BT, Gary FA, Garvan CW. Barriers to detection, help-seeking, and service use for children with ADHD symptoms. *J Behav Health Serv Res.* 2003; 30(2):176–189. [PubMed: 12710371]
30. Centers for Disease Control and Prevention (CDC). [Accessed June 4, 2014] Learn the signs. Act early. <http://www.cdc.gov/ncbddd/actearly/index.html>
31. Unequal treatment: Confronting racial and ethnic disparities in healthcare. Washington, D.C: National Academies Press; 2003.
32. United States Census Bureau. [Accessed June 3, 2013] The Hispanic population: 2010. <http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf>
33. National Council of La Raza. [Accessed June 3, 2014] Toward a more vibrant and youthful nation: Latino children in the 2010 census. [http://www.nclr.org/index.php/publications/toward\\_a\\_more\\_vibrant\\_and\\_youthful\\_nation\\_Latino\\_children\\_in\\_the\\_2010\\_census/](http://www.nclr.org/index.php/publications/toward_a_more_vibrant_and_youthful_nation_Latino_children_in_the_2010_census/)
34. Marín G, Sabogal F, VanOss Marín B, Otero-Sabogal F, Pérez-Stable EJ. Development of a short acculturation scale for Hispanics. *Hisp Journal of Behav Sci.* 1987; 9:183.





**Figure 1. Video Still**

**Table 1**

**Video Vignette Summary**

Vignette Summary	Sample Question Prompts
<b>Video 1</b>	
<p>Maria, the mother of three-year-old Josue, is concerned because Josue doesn't seem to talk well. He often repeats words that Maria says, but she is not sure he knows what they mean. The only word that he seems to know is "no." Josue's behavior is also sometimes very difficult – it seems like he is only interested in trains and screams and throws a fit when his toy trains are taken away. He isn't interested in playing with other children his age.</p>	<ul style="list-style-type: none"> <li>• What advice would you give Maria?</li> <li>• What do you think is going on with Josue?</li> <li>• Why do you think Josue is having this problem?</li> <li>• Who should Maria talk to about Josue's problem?</li> <li>• Are there any community resources you know of that would help Maria?</li> </ul>
<b>Video 2</b>	
<p>Maria takes Josue to the pediatrician and tells the doctor her concerns about Josue. The doctor examines Josue and has Maria fill out a checklist with questions about Josue's development. The doctor tells Maria that Josue might have autism.</p>	<ul style="list-style-type: none"> <li>• How would you describe autism?</li> <li>• In your opinion, what causes it?</li> <li>• Do you think that there are any treatments for autism? What treatments have you heard about? Do the treatments work?</li> <li>• How long do you think autism usually lasts for?</li> </ul>
<b>Video 3</b>	
<p>Maria's doctor tells her that she needs to schedule additional tests for Josue to find out if he really has autism. Maria hasn't told her husband or parents about the situation and is wondering how to break the news to them.</p>	<ul style="list-style-type: none"> <li>• What do you think Maria should tell her family?</li> <li>• How do you think she should tell them? Are there any pitfalls to avoid?</li> <li>• Why do you think she is concerned about telling them?</li> <li>• If you were in Maria's situation, what would you tell your family?</li> </ul>
<b>Video 4</b>	
<p>Maria does the additional tests and finds out that Josue has autism. Now, Maria is concerned because Josue is scheduled to start preschool next month. She doesn't know if she needs to tell Josue's teachers and the parents of the other children that Josue has autism.</p>	<ul style="list-style-type: none"> <li>• Do you think that Maria should tell the teacher that Josue has autism?</li> <li>• Do you think that Maria should tell the other parents that Josue has autism?</li> <li>• Why do you think some people would decide not to tell the other parents?</li> <li>• What should Maria tell other parents if they ask why Josue doesn't talk?</li> </ul>

**Table 2**  
**Focus Group and Interview Participant Demographics (n = 30)**

Median or Percentage (range or n)		
Characteristic	Spanish focus groups and interviews (n = 16)	English focus groups and interviews (n = 14) <sup>c</sup>
Parent Gender		
Female	75% (12)	79% (11)
Male	25% (4)	21% (3)
Parent Age	35 years (24-57)	30 years (22-51)
Years of education	9 years (0-12)	12 years (10-17)
Number of Children	3 children (1-5)	3 children (1-5)
Age of Children	8 years (0.2-34)	7 years (1-26)
Parent Nativity		
Mexico	100% (16)	64% (9)
United States	0% (0)	36% (5)
Years in United States <sup>a</sup>	14 years (6-26)	20 years (12-33) <sup>d</sup>
Acculturation <sup>b</sup>	Less acculturation (1.75)	Less acculturation (2.93)
Ethnicity		
Non-Hispanic	0% (0)	0% (0)
Hispanic	100% (16)	100% (14)
Race		
Other	56% (9)	43% (6)
White	25% (4)	14% (2)
American Indian	0% (0)	7% (1)
No Response	10% (3)	36% (5)

<sup>a</sup> Assessed only in parents who have not lived in US entire life

<sup>b</sup> Measured using the Short Acculturation Scale for Hispanics<sup>34</sup>; scale range 1-5; lower score indicates less acculturation

<sup>c</sup> One participant was not a parent but was the child's primary caregiver.

<sup>d</sup> Proportion or median calculation based only on participants who answered the question.

**Table 3**  
**Parent suggestions for improving early identification of ASD**

Domain	Suggestions	Sample quotation(s)
Interpretation of Early Signs of ASD	<ul style="list-style-type: none"> <li>• Doctors should regularly review the early signs of autism with parents.</li> <li>• Early signs of ASD could be incorporated into prenatal advice.</li> <li>• Doctors should screen for autism at routine visits.</li> <li>• Doctors should explain the purpose of screening and screening results to parents.</li> <li>• Media campaigns should target early signs and symptoms of ASD.</li> <li>• Information could also be disseminated through the early education system, or through community nutrition and social support agencies.</li> </ul>	<p>I think it would be a good idea to have like commercials on television about the symptoms of autism, for instance.* I think... [information] should be given to the parents and not wait until the parents ask for it.</p>
Information needs about ASD	<ul style="list-style-type: none"> <li>• Information about ASD should be incorporated into parenting classes.</li> <li>• Parenting classes should be accessible to low-income families and provide child care.</li> <li>• Written information should be at a low reading level and professionally translated into Spanish.</li> <li>• Information should be available in video format for parents with lower literacy level.</li> <li>• Parents should be directed to reliable internet sources of information.</li> </ul>	<p>If a Latino dad comes to his child's visit, I think the doctor needs to give him this information. Have it there in the room, like a magazine with big letters in Spanish so that the people will start to read it.*† Because as you say, Latinos are diagnosed late, you know? It will start with teachers. Preschool, kindergartens. Have like conferences with Latino families, you know, bringing everything in Spanish or something.</p>
Health Care Access and Quality	<ul style="list-style-type: none"> <li>• In-person interpreters should be provided whenever there is a concern about child development</li> <li>• Providers should offer longer visits for children who have or are high risk for ASD</li> <li>• Providers should have at-risk or newly diagnosed families meet with a social worker or other person familiar with community resources.</li> <li>• Providers should increase their ASD knowledge and confidence about discussing it with families.</li> </ul>	<p>I think especially if they already know that the kid has autism, then they need – consider their appointments a bit longer so they understand and give family some advice and they should tell them where they can take their kids to get the help they need. [Doctors] don't know exactly what's going on in their family. They [may] have another problem, you know, with [their] other kids. Maybe money or, or maybe it's a single mom.... each family is different, so I think they will [need] help by other resources, like a social worker. When you have a child like that, you need help, you know?</p>
Community Mental Health Stigma	<ul style="list-style-type: none"> <li>• Providers should communicate sensitively about this issue with parents and give them time to come to terms with the information</li> <li>• Providers should involve all family members in discussions about ASD</li> <li>• Providers should offer psychological support to parents and family members of newly diagnosed children.</li> <li>• Providers could connect families of newly diagnosed children with other families of children with ASD.</li> <li>• Information about autism could be incorporated into elementary school curricula so that children and their parents will understand the condition better.</li> </ul>	<p>I would say be very sensitive because this is not an easy thing for her. She's troubling with it. Probably. ... involve the whole family. Everybody's involved because... the other people's gonna interact with the child.†</p>

\* Quotation was translated into English from Spanish.

† Quotation from individual in interview; all other quotations were from focus groups.