

# Latino Parents' Perspectives on Barriers to Autism Diagnosis

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The authors declare that they have no conflict of interest.

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## ABSTRACT

**OBJECTIVE:** Latino children are diagnosed with autism spectrum disorders (ASDs) at older ages and at the point of more severe symptoms. We sought to qualitatively describe community, family, and health care system barriers to ASD diagnosis in Latino children.

**METHODS:** Five focus groups and 4 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 audiorecorded and transcribed. Transcripts were coded by 2 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 as a result of 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, 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, destigmatization 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; health services accessibility; Hispanic Americans; qualitative research

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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.

RECENT ESTIMATES SUGGEST that autism spectrum disorders (ASDs) affect more than 1% of US children over age 3, and rates ASD diagnosis may be increasing.<sup>1</sup> ASDs can be reliably diagnosed,<sup>2</sup> and early diagnosis is associated with improved long-term developmental and family outcomes.<sup>3</sup> However, many children meeting ASD diagnostic criteria are never diagnosed<sup>4</sup> or are diagnosed years after onset of symptoms.<sup>4,5</sup> Delayed diagnosis is a particular problem among Latino children<sup>6,7</sup>: Latino children receive a diagnosis of an ASD 2.5 years later than white non-Latino children.<sup>8</sup> Latino children are also less likely to carry an ASD diagnosis; however, when diag-

nosed, they are more likely to have severe symptoms than white non-Latino children.<sup>4,9,10</sup>

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.<sup>11</sup> Providers may also be less comfortable identifying the early signs of ASD in Latino children.<sup>12</sup> Given known ethnic disparities in health care access and quality generally,<sup>13</sup> as well as ASD services in particular,<sup>14,15</sup> 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.<sup>16–18</sup> To our knowledge, no prior studies have focused on ASD diagnostic delays from the Latino family perspective.

The goals of this study were therefore 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.<sup>19</sup> 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 semistructured interview. Eligible parents spoke English or Spanish and had a child age 2 to 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 sampling<sup>20</sup> to include parents in urban and rural areas, and parents with English or Spanish as the 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 by providing food and child care. Participants who were still unable attend a group as a result of 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 90 minutes. Individual interviews were conducted by a bilingual research assistant at a time and place convenient for the parent.

Verbal informed consent was obtained before interviews or focus groups. Interviews and focus groups followed the same interview guide ([Appendix](#)), which was informed by literature on delayed diagnosis for other developmental and behavioral disorders.<sup>21</sup> The guide had 3 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 audiorecorded 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;

**Table 1.** Focus Group and Interview Participant Demographics (N = 32)\*

Characteristic	Spanish-Language Focus Groups and Interviews (n = 25)†	English-Language Focus Groups and Interviews (n = 7)
Parent gender		
Female	68% (17)	100% (7)
Male	32% (8)	0% (0)
Parent age, y	36 (32–44)	28 (23–37)
Years of education	8 (1–17)	12 (12–16)
No. of children	2 (0–4)	3 (1–8)
Age of child with autism, y	7 (3.3–10.7)	4.6 (3.5–10)
Age of child at diagnosis, y	3.1 (2.4–4.9)  ,¶	2.6 (1.8–3.3)  ,¶
Parent nativity		
Mexico	96% (22)	29% (2)
United States	4% (1)	71% (5)
Years in United States‡	14 (7–25)	28 (28–33)
Acculturation§	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)

\*Data are presented as median (range) or percentage (n).

†One parent in a Spanish-language group did not complete the demographic survey.

‡Assessed only in parents who had not lived in the United States for their entire lives.

§Measured using the Short Acculturation Scale for Hispanics; scale range 1–5<sup>22</sup>; lower score indicates less acculturation.

||Proportion or median calculation based only on participants who had information available.

¶Information obtained via medical chart review; all other data obtained from parent survey.

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