



# Autism Spectrum Disorder and the Hispanic/Latinx Community

## Overview

The rate of people identified with Autism spectrum disorder (ASD) has increased significantly. In the United States, about 1 in 54 children were identified with ASD in 2016, which is a rise from 1 in 110 children ten years before.<sup>2</sup> Even with rising rates and how the Hispanic/Latinx (abbreviated as H/L to preserve space) population is one of the fastest growing populations in the United States, ASD is being identified in the H/L community at a disproportionately lower rate.<sup>3</sup> White children are estimated to be 20% more likely to be identified with ASD (2014).<sup>3</sup> Not having a diagnosis can affect people negatively as they grow up. For one individual it contributed to them feeling misunderstood and losing friendships. “I got better at catching offense on my feet, but I hated living with the anxiety of knowing I might say something offensive at any given moment...”<sup>4</sup> In addition to being underdiagnosed, H/L children are diagnosed with ASD later.<sup>13</sup> There is limited research showing exactly how much later, but a commonly referenced study states that H/L children are diagnosed about 2.5 years later than non-Hispanic children.<sup>5</sup> This is a concern because it is recommended that an ASD diagnosis be made by 3 years of age.<sup>8</sup> This allows for early intervention which is highly advised with ASD. By learning about resources and what ASD can look like, parents can become strong supports for their children. This fact sheet does not list all possible resources but offers some guidance for H/L parents.

## About Autism Spectrum Disorder

ASD is a developmental disability with signs typically appearing in early childhood and lasting throughout an individual’s lifetime.<sup>2</sup> There is not a sole cause for ASD but there are factors which increase the likelihood. Some factors include being born to older parents, genetic factors and using certain prescription drugs while pregnant.<sup>2</sup> ASD is diagnosed based on a child’s behaviors and development.<sup>2</sup> It cannot be identified with medical tests like blood tests.<sup>2</sup> People with ASD often experience challenges with social, emotional, and communication skills.<sup>2</sup> However, not all people experience Autism in the same way as another. Symptoms can include repeating words or actions many times, difficulty adapting to change, avoiding eye contact and/or touch, and losing previous skills.<sup>2</sup>

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Hispanic/Latinx children are diagnosed with Autism Spectrum Disorder about 2.5 years later than non-Hispanic children.

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## Challenges with Diagnosing and Accessing Services

The lower rate and later diagnosis of H/L children is concerning because early diagnosis and intervention can lead to a higher quality of life for individuals with ASD. After receiving a diagnosis, H/L families may still face challenges accessing services. Some factors that affect receiving a diagnosis and accessing services include perception and knowledge of ASD, communication barriers, and lack of access to

services. We will first examine these challenges and then discuss how parents can exercise their rights to help their children.

### *Perceptions and Knowledge About Autism*

Since the H/L community is very diverse, beliefs are not the same across all families. There are some experiences individuals have expressed which can impact identifying ASD and accessing services.

One example is a belief in “mal de ojo”.<sup>6</sup> This refers to an evil look directed at someone perceived as being weaker, such as children and women. It is said to cause illness or disability.<sup>6</sup> This perception can influence caregivers’ response and if they use interventions shown to be effective with ASD. Some H/L parents said they did not know what ASD signs are and thought they were caused by other factors such as family dysfunction.<sup>16</sup> For more information about ASD in Spanish visit the [Autism Society website](#).

Another shared experience is disabilities not being easily accepted in H/L families and being associated with feelings like rejection or embarrassment.<sup>16</sup> Individuals experiencing this may not feel comfortable talking to family members who are often valuable supports. Parents of identified and unidentified children with ASD may experience stress and guilt because they do not feel like they know how to best help their child. It is normal to experience a wide range of emotions. Hearing about others’ experiences can help. In this [video](#), H/L parents talk about how ASD presented in their children and what thoughts and feelings they had. (Audio and captions make this video accessible for both English and Spanish speakers.)

### *Communication Barriers*

Communication barriers can also be a challenge. H/L mothers have shared that information is not always explained enough and if a translator is not present, they can miss a lot of information.<sup>9</sup>

Also, when Spanish materials are provided, they do not always translate well from English.<sup>9</sup>

Families can have trouble communicating with providers for reasons besides language barriers. One overarching issue is discrimination and racism from their service providers.<sup>9</sup> Spanish-speaking parents are asked less about their developmental concerns even if their child is known to be at risk.<sup>16</sup> H/L caregivers can also have trouble connecting with providers and have experienced being treated like they do not know anything.<sup>9</sup> These experiences can make it uncomfortable to ask questions. Language barriers can intensify this discomfort, because families with limited English proficiency report less trust in providers compared to English proficient families.<sup>15</sup>

### *Lack of Access to Services*

A barrier to identifying ASD in H/L children is a lack of access to services.<sup>2</sup> Families may have difficulty finding culturally competent services or live in rural areas where services are scarce. One possible reason why ASD prevalence rates are lower in H/L children is that they are less likely than non-Hispanic children to have health insurance.<sup>7</sup> Another challenge is not being aware of available services or believing a child does not qualify due to immigration status.

Early intervention services are available in every state as part of the Individuals with Disabilities Education Act (IDEA). Early intervention services promote the development of children who have a disability or developmental delay. You can speak to your doctor about whether your child would benefit from early intervention services and they can provide a referral. Children, regardless of immigration status, can qualify for early intervention programs. You can visit [the CDC website](#) to find early intervention services in your state.

## Ways to Address Challenges

Developmental monitoring can help identify ASD earlier. It can be done by caregivers, health care providers, and early educators.<sup>2</sup> Developmental monitoring is a process where children's developmental milestones are watched according to their age to see if they are learning to play, move, and communicate when is typically expected.<sup>2</sup> This is an important practice because many children with ASD show signs before they are two years old, such as not responding to their name at 12 months.<sup>2</sup> The CDC outlines milestones up to the age of 5 years old and provides pictures, videos, and a printable checklist. The CDC website provides this in both [Spanish](#) and [English](#). By noticing delays in milestones, caregivers can identify ASD and seek interventions sooner. Also, it is recommended that all children do an Autism-specific screening tool at their 18-month preventative care appointment. If your doctor has not done this, you can inquire about one being done.

Parents are often not aware of their rights with the school system in the U.S. and in many cases are not told. Also, H/L parents may assume they do not have any rights because of their immigration status. This can lead to hesitation with asking about or pursuing services for their children. It is important to know that public schools cannot require students or parents to disclose their immigration status.<sup>14</sup>

The Individuals with Disabilities Education Act (IDEA) gives parents the legal right to request an evaluation for their child.<sup>1</sup> This can be done by contacting the special education director of their child's school.<sup>1</sup> The school can also determine if a child should be evaluated, but they must obtain written permission from a parent.<sup>1</sup> Also, children who are already receiving special education services must be re-evaluated at least every three years.<sup>12</sup> Another important right to be aware of is that parents can request a translator for IEP meetings and parent-teacher conferences.<sup>11, 12</sup> They also have the right to

request that materials be provided in their preferred language.<sup>11, 12</sup>

The right to request translation services extends beyond schools. According to an executive order signed in 2000, if an agency receives federal funding, they are required to provide assistance to non-English speakers.<sup>10</sup> This can include hospitals, clinics, and health department offices.<sup>10</sup>

The underdiagnosis and later diagnosis of ASD in H/L children can impact their lives as well as parents' lives. Although H/L parents can face additional barriers, they also have their own strengths and rights. Parents play an important role in supporting their children and there are resources available to help.

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## References

1. Autism Society. (n.d.). School Evaluation. Retrieved from <https://www.autism-society.org/what-is/diagnosis/school-evaluation/>
2. Centers for Disease Control and Prevention. (n.d.). Data & Statistics on Autism Spectrum Disorder. Retrieved from <https://www.cdc.gov/ncbddd/autism/data.html>
3. Centers for Disease Control and Prevention. (n.d.). Spotlight On Closing the Racial and Ethnic Gaps in the Identification of Autism Spectrum Disorder. Retrieved from <https://www.cdc.gov/ncbddd/autism/adm-community-report/spotlight-on-closing-racial-gaps.html>
4. Garcia, A. (2017, September 17). Examining why autism is under-

- diagnosed in the Hispanic community. Retrieved from <https://researchautism.org/examining-why-autism-is-under-diagnosed-in-the-hispanic-community/>
5. Mandell, D., Listerud, J., Levy, S., Pinto-Martin, J. (2002) Race differences in the age at diagnosis among Medicaid-eligible children with autism. Retrieved from [https://www.jaacap.org/article/S0890-8567\(09\)60739-5/fulltext](https://www.jaacap.org/article/S0890-8567(09)60739-5/fulltext)
  6. Martinez, K. M. (2015, March 12). Mal de Ojo. Retrieved from [https://doi.org/10.1007/978-1-4419-5659-0\\_476](https://doi.org/10.1007/978-1-4419-5659-0_476)
  7. Palmer, R., Walker, T., Mandell, D., Bayles, B., Miller, C. (2010, February). Explaining low rates of autism among Hispanic schoolchildren in Texas. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2804636/>
  8. Pierce, K., Glatt, S. J., Liptak, G. S., & McIntyre, L. L. (2009). The power and promise of identifying autism early: insights from the search for clinical and biological markers. *Annals of clinical psychiatry: official journal of the American Academy of Clinical Psychiatrists*, 21(3), 132-147.
  9. Shapiro, J., Monzó, L., Rueda, R., Gomez, J., Blacher, J., Taylor, S. (2004, February 1). Alienated Advocacy: Perspectives of Latina Mothers of Young Adults With Developmental Disabilities on Service Systems. Retrieved from <https://meridian-allenpress.com.dist.lib.usu.edu/idd/article/42/1/37/8443/Alienated-Advocacy-Perspectives-of-Latina-Mothers>
  10. United States Government. (n.d.). Overview: Executive Order 13166. Retrieved August 20, 2020, from <https://www.lep.gov/executive-order-13166>
  11. U.S. Department of Education (2018). Protecting students with disabilities. Retrieved from <https://www2.ed.gov/about/offices/list/ocr/504faq.html>
  12. U.S. Department of Justice, & U.S. Department of Education. (2015). Information for Limited English Proficient (LEP) Parents and Guardians and for Schools and School Districts that Communicate with Them. Retrieved from <https://www2.ed.gov/about/offices/list/ocr/docs/dcl-factsheet-lep-parents-201501.pdf>
  13. Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012, June 11). Age at Diagnosis of Autism Spectrum Disorders. Retrieved from [https://www.jpeds.com/article/S0022-3476\(12\)00515-X/fulltext](https://www.jpeds.com/article/S0022-3476(12)00515-X/fulltext)
  14. Washington Office of Superintendent of Public Instruction. (n.d.). Immigrant Student's Rights to Attend Public School. Retrieved from <https://www.k12.wa.us/student-success/access-opportunity-education/migrant-and-bilingual-education/immigrant-student%E2%80%99s-rights-attend-public-schools>
  15. Zuckerman, K., Lindly, O., Reyes, N., Chavez, A., Macias, K., Smith, K., & Reynolds, A. (2017, May 01). Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families. Retrieved from <https://pediatrics.aappublications.org/content/139/5/e20163010>
  16. Zuckerman, K., Sinche, B., Mejia, A., Cobian, M., Becker, T., Nicolaidis, C. (2014). Latino parents' perspectives on

barriers to autism diagnosis. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4006363/>

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