

California Leadership Education In Neurodevelopmental and Related Disabilities

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Barriers to Early Intervention for Latinx Families and Promising Interventions

To the Department of Developmental Services and the Regional Centers,

Executive Summary:

The latest prevalence data from the Centers for Disease Control and Prevention (CDC) reflects California's commendable efforts in early identification of Autism Spectrum Disorder (ASD). It is estimated that 1 in 22 children in California have been identified with ASD, which is significantly higher than the national prevalence data of 1 in 36 children identified with ASD (CDC, 2023). Although there is a significant difference between children in California and the rest of the nation, specific disparities in ASD identification are seen across the country. That is the case seen in boys, who have a higher ASD prevalence than girls.

Latinx children in California are among the groups with the highest prevalence of ASD, suggesting a positive move towards successful education about ASD signs among the different stakeholders, improving health equity in minorities. Nonetheless, just identifying the problem is not enough. Accessing early interventions and special education services is paramount in enhancing children's development. Latinx families have multiple barriers to accessing the previously mentioned services due to reasons ranging from language barriers, lack of ASD awareness, stigmatization of mental and behavioral disorders in Latinx families, distrust in the healthcare system, and lack of culturally tailored interventions by public healthcare providers and public health officials. To address the many barriers in interventions faced by Latinx, we suggest actions at multiple levels of the system. Addressing disability stigma in Latinx families, providing cultural sensitivity training for providers, and health promotion by community members are some of the measures suggested to provide more inclusive and equitable services to our Latinx children.

Description of the Problem:

The delay in autism intervention is attributed to the internalization of public and systemic stigma. The Latinx community places more value on societal norms and interactions with others. In native countries, lack of awareness about the disorder and poor knowledge of autism services influence how people view a child with autism. Labels such as "loco" suggest a belief that discipline is acceptable to handle misbehaviors. Temperaments are considered "boys being boys" rather than developmental concerns. In some studies, parents expressed public "looks" as discriminatory due to the lack of acceptance of an autistic child in the community. Religion is predominantly valued in this community, embracing a "wait to see" attitude to see if behaviors will change over time. "Fatalism" is the concept that parents accept, believing that God gave their child developmental challenges, and unfortunately, no treatment can alter that outcome.

System stigma influences the magnitude of public stigma for a child with autism and reduces access to care due to policies. As a marginalized group, Latinx families already face barriers to access to healthcare. The concept of disability is misunderstood, and the lack of knowledge makes it difficult to accept the condition. There is a false perception of cultural homogeneity where differences are ignored or not accepted. Low funding towards neurodevelopmental disorders can contribute to low health literacy and limited skilled training.

Previous studies have found parents susceptible to embarrassment, rejection, and family burden. Parents avoid health professionals for fear that their parenting skills are being judged and failure to negotiate the logistics of clinical care. Due to racial and ethnic discrimination from professionals in healthcare and education, parents seek diagnosis and treatment for their child with caution.

Solutions/Recommendations:

More/Creative use of Learn the Signs Act Early Campaign: State agencies should expand Spanish language education and screening tools beyond public advertisements to community locations such as: WIC offices, Early Head Start, CAL AIM programs, grocery stores, places of worship, community centers and other places families congregate.

Promotoras de Salud to Increase Education/Awareness: DDS should reimburse for autism education given by promotoras, such as the Parents Taking Action (PTA) program.

Pediatrician's/Screening: Pediatrician's offices should offer Spanish-language education about developmental milestones. Developmental/autism-specific screenings should also be offered in Spanish, and referrals to early intervention should be completed in a timely manner.

Culturally Competent Services: DDS and Regional Centers should require continuing education and offer a higher rate for providing culturally tailored services to specific populations. Providers should be trained in cultural aspects of care, such as: therapeutic alliance, disability knowledge, and family/community makeup.

Conclusion:

Autism is increasing in incidence; however, Latinx children miss out on early intervention. By increasing funding for community education, screenings, and culturally competent services, the stigma associated with autism could be reduced in Latinx families. The healthcare, public health, and school systems are still not prepared to address the multiple barriers to ASD intervention services that Latinx families face. Proven successful health promotion and education programs like the promotoras programs could be beneficial to destigmatizing ASD among Latinx families, building trust in the healthcare system, and improving family advocacy among the Latinx community. Culturally sensitive courses need to be implemented nationwide, starting at a training level (college, residency, fellowships) and having providers complete cultural awareness seminars/training periodically. Lastly, more inclusive ASD screening tools would be of great benefit to our Latinx families in early diagnosis and interventions. It is vital to improve our ASD diagnosis, interventions, and support systems to provide health justice to our children from minority groups like our Latinx children.

References:

- Abercrombie, J., Pann, J., Shin, F., Taylor, E., Brisendine, A. E., Swanson-Holm, R., James, C., Viehweg, S., & Chödrön, G. (2021). Evaluation of the feasibility and perceived value of integrating learn the signs act early. Developmental monitoring resources in early head start. *Early Childhood Education Journal*, 1-13. <https://doi.org/10.1007/s10643-021-01247-5>.
- Alsharaydeh, E. A., Alqudah, M., Lee, R. L. T., & Chan, S. W.-C. (2019). Challenges, coping, and resilience among immigrant parents caring for a child with a disability: An integrative review. *Journal of Nursing Scholarship*, 51(6), 670–679. <https://doi.org/10.1111/jnu.12522>.
- Barrio, B., Hsiao, Y., Prishker, N. & Terry, C. (2019). The impact of culture on parental perceptions about autism spectrum disorders: Striving for culturally competent practices. *Multicultural Learning and Teaching*, 14(1), 1-9. <https://doi.org/10.1515/mlt-2016-0010>.
- Burkett, K., Kamimura-Nishimura, K. I., Suarez-Cano, G., Ferreira-Corso, L., Jacquez, F., & Vaughn, L. M. (2022). Latino-to-Latino: Promotores' beliefs on engaging Latino participants in autism research. *Journal of Racial and Ethnic Health Disparities*, 9(4), 1125–1134. <https://doi.org/10.1007/s40615-021-01053-0>
- De Leon, S. J. (2020). Raising Children with Autism in Guatemala: Caregiver Perceptions of Stress and Support using Mixed Methods. *ProQuest Dissertations Publishing*.
- DuBay, M., Watson, L. R., & Zhang, W. (2018). In search of culturally appropriate autism interventions: Perspectives of Latino caregivers. *Journal of Autism and Developmental Disorders*, 48(5), 1623–1639. <https://doi.org/10.1007/s10803-017-3394-8>
- Gevarter, C., Najar, A. M., Flake, J., Tapia-Alvidrez, F., & Lucero, A. (2022). Naturalistic communication training for early intervention providers and Latinx parents of children with signs of autism. *Journal of Developmental and Physical Disabilities*, 34(1), 147–169. <https://doi.org/10.1007/s10882-021-09794-w>
- Guerrero, M. G. B., & Sobotka, S. A. (2022). Understanding the barriers to receiving autism diagnoses for Hispanic and Latinx families. *Pediatric Annals*, 51(4), e167–e171. <https://doi.org/10.3928/19382359-20220322-03>
- Hall-Lande, J., McGuire Buck, D., Srinivasavaradan, D., Brown, K. H., Chödrön, G. S., & Weber, S. (2022). Promoting family engagement and early identification of developmental delays: The role of act early ambassadors. *Zero to Three*, 43(1). 28-37.

- IDEA. (2023). *OSEP fast facts: Children identified with intellectual disability*. Individuals with Disabilities Education Act. <https://sites.ed.gov/idea/osep-fast-facts-children-identified-with-intellectual-disability/>
- Khanlou, N., Haque, N., Sheehan, S., & Jones, G. (2015). It is an issue of not knowing where to go: Service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities. *Journal of Immigrant and Minority Health*, 17(6), 1840–1847. <https://doi.org/10.1007/s10903-014-0122-8>
- Lopez, K., Marroquin, J. M., & Gutierrez, C. (2020). Methods to decrease disparities in age of autism diagnosis and treatment access among Latinx children. *Social Work*, 65(2), 140-148. <https://doi.org/10.1093/sw/swaa012>
- Maenner, M. J., Shaw, K. A., Bakian, A. V., Bilder, D. A., Durkin, M. S., Esler, A., Furnier, S. M., Hallas, L., Hall-Lande, J., Hudson, A., Hughes, M. M., Patrick, M., Pierce, K., Poynter, J. N., Salinas, A., Shenouda, J., Vehorn, A., Warren, Z., Constantino, J. N., ... Cogswell, M. E. (2021). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *MMWR. Surveillance Summaries*, 70(11), 1–16. <https://doi.org/10.15585/MMWR.SS7011A1>
- Magaña, S., Lopez, K., de Sayu, R. P., & Miranda, E. (2014). Use of promotoras de salud in interventions with Latino families of children with IDD. In R. Hodapp (Ed.) *International Review of Research in Developmental Disabilities*, 47, 39-75. London, England: Academic Press. <https://doi.org/10.1016/B978-0-12-800278-0.00002-6>
- Miller, M., Passarelli, M., Zucker, S., Ake, W., Martini-Carvell, K., & Dworkin, P. (2023). Help me grow: A model of targeted universalism to advance equity and promote the well-being of all children. *Social Innovations Journal*, 20. <https://socialinnovationsjournal.com/index.php/sij/article/view/6595>.
- National Center on Birth Defects and Developmental Disabilities. (2023). *2020 autism and Developmental Disabilities Monitoring (ADDM) network surveillance summaries*. Centers for Disease Control and Prevention. <https://stacks.cdc.gov/view/cdc/126222>
- Nevison, P. (2020). California autism prevalence by county and race/ethnicity: Declining trends among wealthy whites. *Journal of Autism and Developmental Disorders*, 50(11), 4011–4021. <https://doi.org/10.1007/s10803-020-04460-0>

- Paula, C. S., Cukier, S., Cunha, G. R., Irarrázaval, M., Montiel-Nava, C., Garcia, R., Rosoli, A., Valdez, D., Bordini, D., Shih, A., Garrido, G., & Rattazzi, A. (2020). Challenges, priorities, barriers to care, and stigma in families of people with autism: Similarities and differences among six Latin American countries. *Autism : The International Journal of Research and Practice*, 24(8), 2228–2242. <https://doi.org/10.1177/1362361320940073>.
- Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood*, 3(1), 52–60. <https://doi.org/10.1089/aut.2020.0043>
- Rivard, M., Millau, M., Mello, C., Clément, C., Mejia-Cardenas, C., Boulé, M., & Magnan, C. (2021). Immigrant families of children with autism disorder’s perceptions of early intensive behavioral intervention services. *Journal of Developmental and Physical Disabilities*, 33(4), 633–651. <https://doi.org/10.1007/s10882-020-09764-8>
- Shaw, K. A., Bilder, D. A., McArthur, D., Williams, A. R., Amoakohene, E., Bakian, A. V., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Pas, E. T., Salinas, A., Warren, Z., Williams, S., Esler, A., Grzybowski, A., Ladd-Acosta, C. M., Patrick, M., Zahorodny, W., ... Maenner, M. J. (2023). Early identification of autism spectrum disorder among children aged 4 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *MMWR. Surveillance Summaries*, 72(1), 1–15. <https://doi.org/10.15585/mmwr.ss7201a1>
- Solgi, M., Reeder, J. A., Alderman, S. L., & Zuckerman, K. E. (2023). An intervention to increase detection of developmental delays in special supplemental nutrition program for women, infants, and children. *Academic Pediatrics*, 23(3), 646–650. <https://doi.org/10.1016/j.acap.2023.01.003>.
- Son, E., Magaña, S., Pedraza, F. D. M., & Parish, S. L. (2020). Providers’ guidance to parents and service use for Latino children with developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 125(1), 64–75. <https://doi.org/10.1352/1944-7558-125.1.64>
- State of California & Department of Developmental Services. (2021). Purchase of Service Report. <https://www.dds.ca.gov/rc/dashboard/purchase-of-service-report/>
- Troxel, M., Linas, K., Jacobstein, D., Biel, M., Soto, S. H., Lorenzo-Hubert, I., Dos-Santos, S., Mendez, R., & Anthony, B. J. (2018). Implementing autism screening for Latino children in primary care: Perspectives from parents and providers. *Journal of Health Disparities Research and Practice*, 12(2), 88–105. <https://digitalscholarship.unlv.edu/cgi/viewcontent.cgi?article=1853&context=jhdrp>.

Vega, D., PhD., Arellano, J. I., & Carrillo, G. L. (2016). The Under-Identification of Autism among Latino Youth: Improving Culturally Competent Training in School Psychology Programs. *Trainers' Forum*, 34(1), 42-53.

<http://libproxy.usc.edu/login?url=https://www.proquest.com/scholarly-journals/under-identification-autism-among-latino-youth/docview/2032395527/se-2>

Zuckerman, K. E., Chavez, A. E., Wilson, L., Unger, K., Reuland, C., Ramsey, K., King, M., Scholz, J., & Fombonne, E. (2021). Improving autism and developmental screening and referral in US primary care practices serving Latinos. *Autism*, 25(1), 288-299.

<https://doi.org/10.1177/1362361320957461>

Zuckerman, K.E., Sinche, B., Meija, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic Pediatrics*, 14(3), 301-308.

<https://doi.org/10.1016/j.acap.2013.12.004>