

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.

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