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Entre la Duda y El Miedo: Health Disparities Among Latino Children and Youth with Developmental Disabilities

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Executive Summary

Latino children with developmental disabilities are significantly more likely to be underdiagnosed, misdiagnosed, or diagnosed later than their non-Latino peers. They face persistent barriers to timely referrals, evaluations, and interventions, which are essential for optimal developmental outcomes. Limited access to quality primary care services and inconsistent family–provider collaboration often delay early detection and treatment. Many Latino families encounter healthcare systems that are not fully equipped to deliver culturally and linguistically responsive care, leading to reduced follow-up and lower participation in intervention programs.

Furthermore, gaps in insurance coverage and inconsistent Medicaid implementation across states restrict access to specialized therapies and early intervention services. The issue is compounded by a lack of coordination among health, education, and social service systems, resulting in fragmented care that undermines children’s long-term development and well-being. Additionally, the underrepresentation of Latino children in clinical trials and health research limits the availability of culturally informed data and evidence-based practices tailored to their needs. To ensure equitable health outcomes, policy reforms must prioritize accessible primary care, culturally competent provider training, Medicaid expansion, and inclusive clinical research that reflects the diversity of the U.S. child population.

Background

Latino Children

The U.S. Census Bureau defines *Latino or Hispanic* as individuals of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.¹ For this issue brief, *children* are defined as individuals aged 3 months to 24 years, reflecting the period during which early intervention, pediatric, adolescent, and transitional health services are most critical. Latino children comprise approximately 25 percent of all children under age 18 in the United States, making them the largest and fastest-growing child population nationwide.

Healthcare Providers

In this brief, healthcare providers are licensed professionals authorized by the state to deliver medical, behavioral, or therapeutic services. The focus is on providers who offer direct and intervention-based care to children with developmental disabilities, including Developmental and Behavioral Pediatricians, Behavioral Health Specialists, Neuropsychologists, Speech-language pathologists, applied behavior analysis (ABA) therapists, and other licensed specialists involved in a child’s care plan.²

Low-Income.

Low-income refers to children and families whose household incomes fall at or below eligibility thresholds for public health insurance programs such as Medicaid and the Children’s Health Insurance Program (CHIP). Income level is a critical determinant of insurance coverage, healthcare access, and continuity of services.

Developmental Disabilities

According to the Centers for Disease Control and Prevention (CDC), *developmental disabilities* are conditions that result in impairments in physical, learning, language, or behavioral functioning. These conditions originate during the developmental period, may affect daily functioning, and typically persist across the lifespan. Developmental disabilities include autism spectrum disorder, Down syndrome, fragile X syndrome, and related conditions.³

Latinos comprise 20% of children in the United States and are the most significant and fastest-growing minority group among children.⁴ In the United States, one in six children is affected by a form of developmental disability such as autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), cerebral palsy, and Down syndrome.⁵ Latino children with developmental disabilities (DD) experience disproportionately low access to essential services—referrals, evaluations, and interventions—that are critical for long-term health and functioning. This access gap leads to delayed diagnoses, reduced therapy use, and diminished quality of life for both children and caregivers. Latino children from low-income immigrant households face additional barriers to healthcare access, deriving from both language and cultural barriers and healthcare providers’ lack of culturally competent care. Structural inequities related to insurance coverage, provider availability, language access, and system navigation place these children at heightened risk for delayed diagnoses, interrupted care, and poorer health outcomes—beyond the challenges associated with their developmental conditions alone. These gaps underscore the urgent need for policy and system-level interventions that address both insurance access and care delivery capacity for this population.

Problem Analysis

Latino children who are less likely to receive specialized services face many barriers due to financial, cultural, and linguistic backgrounds that limit their capacity to obtain needed healthcare services and resources.⁶ These factors often impede effective engagement with primary care and timely provider intervention. When these barriers go unaddressed, they restrict access to referrals, diagnostic evaluations, and follow-up care, weakening the role of primary care as an entry point to specialized services. Together, financial, linguistic, and cultural barriers perpetuate delayed care, which leads to increased system mistrust, and continued underutilization of healthcare services and resources.

Access to Quality Primary Care Services

Access to quality primary care services plays a vital role for Latino children with developmental disabilities to obtain needed care. Texas researchers examined parental awareness of their child’s health coverage status and found that almost 75% of children lack a Primary Care Provider (PCP), making them more likely to lack preventive care services.⁷ Though public insurance programs such as Medicaid and the Children’s Health Insurance Programs (CHIP) are available at low or no cost to these families, Latino children continue to be one of the highest demographics of uninsured children in the United States at a 9.7% rate.⁸ Low-income Latino children with DD who come from immigrant households have significantly higher barriers to healthcare coverage because of English proficiency. Language barriers and limited access to language services significantly hinder parents’ and caregivers’ ability to navigate the complex healthcare insurance system and secure necessary, affordable coverage. Therefore, it is noted that many of these children are eligible for federal programs yet are not enrolled. Enrolling eligible children to receive healthcare coverage is a vital step in securing early diagnosis and intervention for better development and quality of life.

When Latino Children are unable to access primary care services, this leads to the inability to receive early-on diagnosis and interventions that are crucial to foundational development and well-being for Latino Children. Latino children have a 3.3% higher prevalence of having a more severe form of autism compared to 2.7% of their white counterparts.⁹ Many Latino children diagnosed with a disability, such as ASD, are still less likely to receive needed specialized services such as behavioral therapy or behavioral analysis (ABA), occupational therapy, and social skills training.¹⁰ Over one-fourth of all family caregivers to children with DD have experienced trouble in paying for ASD services prior to 3 months or more, or shared that experiencing high service copays was a barrier for their children to receive needed care.¹⁰ Lack of healthcare coverage leading the financial challenges prevents many families from accessing appropriate and timely care needed to address the needs of their children.

Family and Healthcare Provider Intervention

Family caregivers, such as parents, play a crucial role in seeking the medical attention needed to address these children's needs. Obtaining needed healthcare services for Latino children begins with families' ability to detect signs of developmental concerns and raise these concerns with the child's healthcare provider.¹⁰ Latino families require additional educational outreach and support to equip them in the de-stigmatization of the existence of developmental disabilities, which can enhance the diagnostic and intervention process early on.¹¹ A cross-sectional study reviewing health disparities within ASD shared how parents of Latino children reported the lack of access to a healthcare provider, a healthcare provider not spending enough time with their child, a healthcare provider not willing to listen, the healthcare provider being insensitive to family values and customs, or not treating family caregivers as partners when it comes to the care of the child.¹² The United States healthcare system structure and provider biases contribute to racial and/or income disparities within the DD space, which then impact the educational input and resources affecting the way low-income Latino families seek developmental care for these children.¹³

Healthcare providers, specifically pediatricians, play a significant role in a child's development by providing necessary referrals, interventions, and treatments related to their patients' overall health education and expected outcomes. However, pediatricians have reported that they do not feel fully equipped to provide the necessary care for this population, which is one of their most significant unmet needs.¹⁴ Shared decision-making requires both parents and healthcare providers to assess the child's needs best. Latino families are less likely to report their shared decision-making experience compared to white families, especially those from non-English-speaking and low-income households. Language barriers between families and healthcare providers impede and delay diagnosis and treatment, limiting access to necessary interventions. Latino parents are less likely to identify signs of developmental disabilities due to lack of knowledge, leading to fewer diagnoses being reported. Latino families often turn to complementary health approaches, such as special diets or supplements, to address the health concerns of their autistic children, yet do not disclose such information to their child's provider. By not disclosing such information, this hinders the shared decision-making process.¹⁷

Latino families and caregivers are other contributing members to a child's development and intervention, especially when navigating resources needed to address their child's medical conditions. However, understanding what it entails to have a child with a form of developmental disability is often viewed as taboo among Latino households. Studies have shown that for most Latino parents, 54% believed that vaccines cause autism or were less likely to endorse the idea that genes and familial medical history are what contribute to the causes of DD, leading to a reduction of service use.¹⁵ This further demonstrates that the gap within the patient-provider relationship is such that families are not receiving adequate information from treatment providers. Furthermore, the stigma viewed from the broader Latino community perceives disabilities as shameful and questions the credibility of the diagnosis, leading to families feeling pressured to conceal their child's behaviors.

Latino children with developmental disabilities experience persistent and interconnected barriers to care that reflect broader structural inequities within the U.S. healthcare system. Limited access to primary care, gaps in insurance enrollment, language barriers, financial hardship, provider bias, and cultural stigma collectively delay diagnosis and

restrict access to essential services. Not only do these children require specialized medical care related to their conditions, but overall, as children with developmental disabilities continue to age, they are at a higher risk of developing poor health outcomes and unmet healthcare needs, leading to early mortality.¹⁶ Addressing these disparities through a health equity lens requires policy-level interventions that expand language-accessible services, strengthen Medicaid and CHIP outreach and enrollment efforts, mandate culturally responsive and family-centered provider training, and reduce financial burdens associated with specialized therapies. Equitable policies that prioritize early screening, inclusive communication, and shared decision-making are critical to ensuring that Latino children with developmental disabilities receive timely, high-quality care and have the opportunity to achieve optimal developmental outcomes.

Recommendations

Insurance Coverage and Medicaid Implementation

During the first Trump Administration, the “chilling effect” phenomenon occurred, where mixed-status families, meaning citizen children living with one immigrant parent or household member. Many feared that the sharing of Medicaid data with federal agencies and the risk of deportation would increase the number of uninsured Latino children.¹⁷ Furthermore, the “Big Beautiful Bill” will cut almost \$1 trillion from Medicaid and CHIP and will lead to restrictions on state budgets on Medicaid, leading to the loss of health insurance coverage for one of the most vulnerable populations in the United States.

To address the gap in health disparities between low-income Latino children who seek healthcare services for their special needs, states can improve access by less frequent Medicaid renewal requirements and higher Medicaid reimbursement rates for both moderate- and high-complexity pediatric office visits.¹⁸ Policymakers interested in ensuring adequate healthcare access for these vulnerable children should consider the effects of increasing the frequency of eligibility renewals and of cutting provider reimbursement rates.

The expansion of healthcare services within health policies that further exacerbate DD screening timelines and requirements, access, and cost of diagnosis and treatments would increase the level of care and support for both children and families.¹⁹ In addition, expanding healthcare coverage for non-office-based care, such as telehealth, improves communication within the patient-provider relationship and reduces disparities.

Investing in Community-Based Programs

Community programs have played a pivotal role in bridging the communication and trust gap between family caregivers and healthcare providers. Investing federal dollars in community-based programs such as Promotoras de Salud (Community Health Workers) or ECHO (Extension for Community Healthcare Outcomes) programs helps share the needed knowledge and resources across the network to meet the needs of these children. Assistant Professor Kristina Lopez from Arizona State University shares how community-based programs have equipped Latina mothers with the necessary information on autism literacy, which has demonstrated improved communication skills in their children.²²

Conclusion

Our healthcare system must create the necessary adjustments and changes to best accommodate access for Latino children with developmental disabilities. Latino families raising children with DD continue to face significant delays in accessing and using interventional services compared to their white counterparts—delays that carry serious consequences for children and caregivers alike. Limited and delayed access contributes to poorer quality of life, increased caregiver stress, and higher long-term medical costs. These challenges are further compounded when therapy interventions are not culturally adapted, leading to lower participation, reduced effectiveness, or complete disengagement from services. Failure to prioritize this issue will deepen inequities, strain public health and education systems, and perpetuate avoidable economic and social costs for generations. For policymakers, investing in culturally responsive care, equitable research representation, and timely access to services is not only a matter of

health equity but a strategic imperative to improve long-term outcomes, reduce systemic burdens, and ensure that all children have the opportunity to reach their full potential.

Endnotes

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