Beyond Awareness: Supporting Families of Children with Developmental Disabilities

March 16, 2026 9:00 AM Irang Kim, PhD, MSW
ikim@tulane.edu

Irang Kim, PhD, MSW

Developmental disabilities include, but are not limited to, conditions such as autism, cerebral palsy, Down syndrome, and intellectual disabilities. These conditions affect physical, learning, language, or behavioral development and often require coordinated services across the health, education, and social systems.

In recent decades, awareness of developmental disabilities, particularly autism, has grown significantly. Public conversations around neurodiversity, early intervention, and inclusive education have become more visible. However, for many families raising children with developmental disabilities, awareness alone does not address the daily challenges they face in accessing services and support.

My research focuses on families of children with autism and other developmental disabilities, with particular attention to immigrant and culturally diverse communities. Across multiple studies, a consistent theme has emerged: receiving a diagnosis is often just the beginning of a long and complicated journey.

Diagnosis is Only the First Step

Early diagnosis and intervention are widely recognized as critical for improving developmental outcomes. In theory, once a child receives a diagnosis, families should be connected to services that support their child’s development. In reality, however, many families struggle to navigate what comes next.

In a needs assessment study I conducted with Asian immigrant families raising children with autism, we found significant gaps in how families access early intervention and community services. Although early intervention services are designed to support children soon after developmental concerns are identified, only about 30% of families in our study reported being referred to early intervention by clinicians. Most families reported that they had to find services themselves. Many parents described feeling overwhelmed by the complexity of the service system and uncertain about which resources were available or how to access them. These findings reflect a broader issue: a diagnosis does not automatically lead to effective service navigation.

Structural Barriers for Immigrant Families

For immigrant families, navigating developmental disability services can be particularly challenging. Parents often encounter barriers such as language differences, unfamiliarity with healthcare and education systems, and cultural differences in how disability is understood or discussed. Parents struggle to find culturally and linguistically appropriate services or providers who understand their family’s cultural context. As a result, immigrant families are at risk of experiencing delayed access to services or underutilizing available supports, even when those services exist.

Culturally Responsive Solutions

Addressing these challenges requires more than simply expanding services. It also requires designing supports that are culturally responsive and accessible to diverse communities. One approach my colleagues and I have explored is the cultural adaptation of parent education programs. Through a pilot study funded by the Organization for Autism Research, we culturally adapted Parents Taking Action, a peer-led parent education program for Korean immigrant families raising autistic children. Peer-led programs can be particularly powerful because they create opportunities for parents to learn from others who share similar experiences, languages, and cultural backgrounds. Parents in the program reported that connecting with other families helped them better understand available services, advocate for their children, and feel less isolated in the process.

These types of community-based interventions recognize that families often rely on social networks and culturally familiar resources when navigating complex systems.

Looking Toward the Future

As developmental disabilities become more widely recognized, the next challenge is ensuring that families can access the services they need in ways that are clear, equitable, and culturally responsive. This includes improving coordination between healthcare providers, social workers, schools, and community organizations so that families receive guidance immediately after a diagnosis.

Emerging technologies may offer new possibilities. For example, digital navigation tools could help families identify available services, understand eligibility requirements, and receive personalized guidance about next steps after a diagnosis. However, technology alone cannot solve these challenges. Solutions must be developed in partnership with the communities they aim to serve and must take cultural and linguistic diversity into account.

Dr. Irang Kim is an Assistant Professor at Tulane University School of Social Work. She specializes in practice, policy, and research related to the health and well-being of families of individuals with autism and developmental disabilities (DDs). Her study

is focused on two areas: 1) identifying and addressing disparities affecting children with autism and other DDs in underrepresented communities; and 2) developing empirically based, culturally relevant interventions for caregivers of young children with autism.