



# PERSPECTIVES OF MARYLAND ASIAN AMERICAN CAREGIVERS RAISING CHILDREN WITH DEVELOPMENTAL DISABILITIES

**A NEEDS ASSESSMENT CONDUCTED WITH THE SUPPORT OF THE MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL AND THE UNIVERSITY OF MARYLAND SCHOOL OF SOCIAL WORK**

## KEY SURVEY FINDINGS & RECOMMENDATIONS

*We are an undeserved community - no one believes that Asian children could be anything less than "smart."*

Caregivers of children with developmental disabilities must use multiple systems to find care for their children, but we do not know a lot about the specific needs of Asian American families. We surveyed 73 parents who identified as Chinese, Korean, Indian, Japanese, Vietnamese, Filipino, and Bangladeshi. Their children had autism, Attention Deficit Hyperactivity Disorder, Down syndrome, or other intellectual and developmental disabilities.

### (1) LISTEN TO PARENTS' CONCERN ABOUT POSSIBLE DEVELOPMENTAL DELAYS AND ACT QUICKLY TO SCREEN AND REFER CHILDREN

Parents said it took an average of 12 months between noticing developmental delays and getting a diagnosis for their child. Most parents told healthcare professionals about their concerns, but only about one-third of professionals conducted a developmental screening or referred the child to a specialist.

*I asked myself multiple times: what if I knew earlier and took my daughter to therapy earlier?*

*I am VERY active in the [developmental disability] community... many [Asian parents] rely on me for the resources and information.*

### (2) CONNECT PARENTS WITH ADVOCATES FROM THEIR OWN COMMUNITY

Most parents had not received services from parent advocates, but 71% of those who had found parents advocates to be helpful sources of information and support.

### (3) REDUCE KEY BARRIERS TO SERVICE ACCESS

Some services, like dental care and respite care, were not commonly used. Also, nearly half of parents paid for some therapeutic services out-of-pocket. Parents who did not speak English had additional challenges communicating with their child's providers and accessing supports.

*It is difficult to find out and apply for information on benefits....It would be helpful if you provide language support [in my native language] for it. I feel overwhelmed because of the extensive medical costs...*

### (4) INCREASE COMMUNITY AWARENESS OF DEVELOPMENTAL DISABILITIES

*People in the community need help to give my children more tolerance than discrimination.*

While many parents said their community members try to help their child and family, 65% also felt their community had little information or knowledge about developmental disabilities. Some parents believed their community members: (a) think that individuals with developmental disabilities will "grow out of it;" (b) are uncomfortable around their children; (c) feel that developmental disabilities are a result of bad parenting or lack of discipline; or (d) use hurtful words to describe their children.

### (5) BUILD ON THE STRENGTHS OF EACH FAMILY AND THEIR ETHNIC COMMUNITY

Despite the challenges that parents described, 79% said they recognized their child's strengths as well. Local communities and organizations, service providers, and other advocates can be important allies in efforts to empower and include children with developmental disabilities and their families in all areas of community life.

*[My son] is who he is and I wouldn't change that for the world. I think if I continue to support and help him - he will achieve spectacular things.*

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**FOR MORE INFORMATION, PLEASE CONTACT:**

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