

RESEARCH & PRACTICE BRIEF

Needs Assessment of Maryland Asian American Caregivers Raising Children with Developmental Disabilities



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UNIVERSITY of MARYLAND
SCHOOL OF SOCIAL WORK

Who conducted the needs assessment?

A research team at the University of Maryland School of Social Work (UMSSW) conducted the needs assessment with the support of the Maryland Developmental Disabilities Council and the UMSSW. The team, led by Dr. Sarah Dababnah, Dr. Irang Kim, and Ms. Yao Wang, worked with an expert advisory board composed of national leaders on developmental disability research and practice to better understand the needs of Asian American families in Maryland.

Why did we survey Asian American families in Maryland?

Despite an increase in Asian Americans with developmental disabilities, there is little known about Asian American children with developmental disabilities and their families nationally, as well as specifically in Maryland. Parents raising children with developmental disabilities must navigate multiple systems to access appropriate health and community services. Parents who immigrate to the United States also face additional challenges due to language or other barriers. However, there is not a lot of research on Asian American families. Thus, healthcare professionals, teachers, and other professionals do not have sufficient information to understand how to best support families in obtaining a diagnosis or using services.

What did we ask in our survey?

“I’m glad to see this research. We are an undeserved community - no one believes that Asian children could be anything less than “smart.” My husband and I are the children of immigrants, we’re highly educated. So a [developmental disability] diagnosis...hit us like a ton of bricks. This wasn’t the future we have envisioned. It’s the kind of diagnosis that crumbles you and humbles you. It simultaneously challenged and strengthened my faith in God.”

Our survey asked parents more information about themselves and their children, including the child’s diagnosis, their household income, and the parent’s English proficiency. Then, parents answered questions about the process for their child to receive a developmental disability diagnosis, parents’ ways of gathering information, their child’s service use, parents’ coping processes, and parents’ perceptions of community views about developmental disabilities. We also gave parents space to share any additional information. After the COVID-19 pandemic began, we added four questions on parent employment and child service use related to the pandemic.

Who participated in the survey?

Between October 2019 – July 2020, 73 Asian American parents of children with developmental disabilities in Maryland completed the survey. About half of the parents who participated were Chinese; the remaining participants were Korean (20%), Indian (7%), Japanese (7%), Vietnamese (6%), Filipino (6%), or Bangladeshi (1%). Most of the participants were married (95%), mothers (88%), high-income (over 50% had incomes of \$100,000 or more), had a college education (nearly 80% had an undergraduate degree or more), and lived in either Howard County (41%) or Montgomery County (36%). Only one in five of the participants were born in the United States, although most reported they knew English well.

The parents answered questions about their children, who had autism (58%), Attention Deficit Hyperactivity Disorder (27%), a developmental delay (18%), an intellectual disability (15%), Down syndrome (14%), or Cerebral Palsy (1%). Most of the children were male. Three-fourths of the children were between 5-12 years old, although some parents of young children and adolescents participated. Many children had co-occurring conditions, such as anxiety, sleep problems, gastrointestinal issues, vision or hearing challenges, or depression. Almost all of the children were born in the United States. Most of the children were insured through private or public options, but 3% reported their children did not have insurance or they were unsure.

What did we learn from parents about developmental disability screening and diagnosis?

- **Parents reported an average 12-month gap between noticing developmental delays and getting a diagnosis for their child.** On average, parents had early concerns about their child's development (28 months old), but their children were not diagnosed until 40 months old.

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

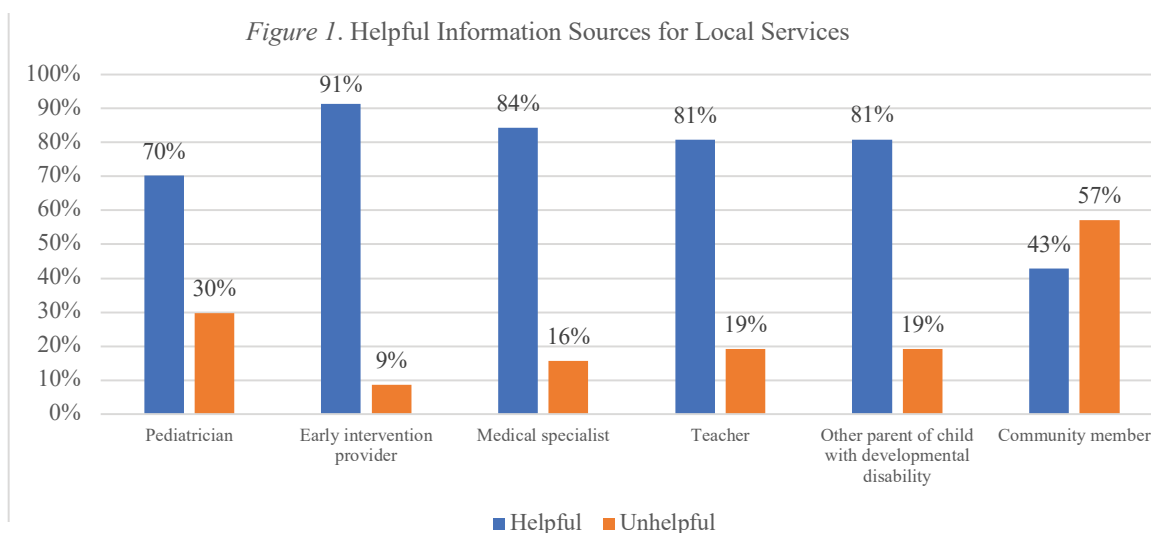
- **Most parents told healthcare professionals about their concerns, but the professionals' did not always act quickly to evaluate or refer the child.** Nearly three-fourths of the parents said they raised their concerns about their child's development to their child's healthcare provider. In response to parents' concerns, only about one-third of parents said the professionals conducted a developmental screener or referred the child to a specialist. Notable percentages of participants reported the professional responded by telling the parent it was too early to identify developmental concerns (29%), the child's developmental was typical (17%), or the child would "grow out of it" (14%). More than one in five of the participants reported they did not receive a referral to the professional who diagnosed their child.
- **Parents encountered many barriers to obtaining a diagnosis for their child.** As they tried to obtain assistance for their child, 62% of the respondents said they had trouble understanding how the healthcare system worked, getting help to coordinate care, or obtaining a timely evaluation. Most participants (89%) reported they trusted professionals' advice. Yet, 19% felt that stigma related to disabilities made them reluctant to follow up on developmental concerns.

***"For Asian parents who are new to American culture, due to cultural difference regarding [developmental disabilities] between Asian and American, it usually takes longer time for parents to acknowledge the situation and seek evaluation and support....
I have heard that some Asian American parents are still denying [the diagnosis] and their children do not get services and therapy they need."***

- **Parents who did not speak English had additional challenges communicating with their child's providers.** Of those who responded to questions about interpretation, 36% of the respondents said that language interpreters were unavailable when needed, and 41% reported interpreters did not help them to understand what the professionals were saying. Nearly one-third (30%) of the parents reported professionals said their child's developmental delays were because parents spoke a language other than English at home.
- **Most parents received help, but it was a stressful process.** While over three-fourths (79%) of the parents reported they ultimately were able to access need medical, therapeutic and community supports, 72% also said the diagnostic process caused family stress.
- **Parents want professionals to increase their knowledge of developmental disabilities and related supports.** Nearly all of the respondents recommended doctors, nurses and other health professionals demonstrate more knowledge about developmental disabilities, and that these professionals communicate more with caregivers about the steps to obtain a diagnosis and related information. Most parents wished health professionals would act faster when parents have developmental concerns about their children; provide and train interpreters on developmental disabilities and the diagnostic process; provide assistance to families to make specialist appointments; and, give developmental checklists at routine check-ups.

How did parents find information about developmental disabilities and related supports?

- **Parents identified many helpful and unhelpful people for information about local services and supports in their communities.** About 38% of parents did not have knowledge about developmental disabilities before their child was diagnosed. Parents identified many sources of helpful information to meet their children needs, including their child's early intervention coordinator, pediatricians/primary care providers, medical specialists, other parents of children with developmental disabilities, and the child's teacher (see Figure 1). However, a larger number of parents said community members were not helpful in identifying services in their communities, compared to those who said they were helpful. Similarly, some parents reported their child's pediatrician, child's teacher, and other parents of children were unhelpful in finding community services.



- **Social media and local organizations are also important sources for information.** Parents used various methods to gather information about their child's diagnosis and available services: social media, local developmental disability support organizations, the child's school, and reading materials outside of social media. Few parents reported finding information from national developmental disability organizations or from organizations specific to their ethnic group.

"I am VERY active in the [developmental disability] community and I am almost always the only person of color in the disability events. I know a lot of Asian parents and families with children with developmental disabilities. But they do not participate in the events organized by the disability groups and many rely on me for the resources and information."

- **Parent advocates and other community supports are not readily available, yet can be helpful sources of information and support.** Eighty percent of parents recommended television, radio, and newspapers feature more stories about developmental disabilities in the parents' primary language. Nearly 80% of parents had no experience with a parent advocate; however, of those who did, 71% found them to be helpful.

What services did parents report their children used?

- **Most parents reported accessing some type of service for their children, including public early intervention and special education.** Most parents (88%) reported their children had received special education services, and 65% of respondents accessed early intervention services through the Maryland Infants and Toddlers Program. Many parents (71%) also reported their children received speech and language therapy.
- **Dental care and respite care were underutilized.** Just over one-third of the respondents reported using dental services (37%) or respite care (7%) for their children, citing barriers such as lack of awareness of the service, ineligibility, unavailability in their area or in their preferred language, being on the waitlist, cost, and distance.
- **Nearly half of parents paid for some therapeutic services out-of-pocket.** Parents reported their children's services were funded through private insurance (58%), out-of-pocket by parents (46%), Medicaid (26%), or a Medicaid waiver (4%). In the open-ended question about what parents need to support their children, most listed more financial support.

How has the COVID-19 pandemic impacted parents' employment and children's service access?

“During COVID-19 period, my children must stay at home and I have to spend more time taking care of them. Prices are rising sharply now, we have to reduce expenditure in order to get through the difficult time.”

Of the 25 people who completed the survey with COVID-19 questions, 20% reported the pandemic had no impact on their employment. Yet, 64% reported they switched to working from home, 12% lost their jobs, and 4% had reduced work hours. Some parents expressed concern about increased discrimination against Asian Americans during the pandemic. When questioned about the primary impact of the pandemic on their household, 24% reported no benefits. Nearly half said they had more time with family, and 12% said they were able to give their children more breaks at home. Some reported less stressful days and school pressure. Lastly, just over half of respondents said their child had received alternative services for those stopped due to COVID-19, but parents' satisfaction with these services were mixed.

“I do worry, not just about my child, but Asian American community as a whole because there are incidents that Asian Americans are abused verbally or physically being attacked or robbed because of the COVID-19 outbreak.”



How did the parents feel their community viewed developmental disabilities?

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

Many respondents (65%) felt their community had little information or knowledge about developmental disabilities. Over half (60%) said community members try to help their child and family. Yet, 59% of the participants also said that people in their community think that individuals with developmental disabilities will “grow out of it,” 42% that community members are uncomfortable around their child with a developmental disability, and 36% that developmental disabilities are something of which to be ashamed. About one in four parents reported they perceived their community members think developmental disabilities are a result of bad parenting or lack of discipline. Similarly, 24% said that people in their community use hurtful words to describe children with developmental disabilities, such as “stupid.”

What are some recommendations from this needs assessment?

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.

- 1. Listen to parents and act quickly.** The majority of parents reported they trusted their providers’ advice, yet experienced delays in obtaining a timely developmental evaluation. Thus, providers should listen to parents’ concerns and act quickly to refer children for evaluations. In particular, providers should be aware that cultural and language barriers might make it more difficult for providers to recognize developmental delays or understand parents’ concerns; or for parents to navigate the healthcare system, coordinate care, or overcome disability-related stigma.

“We feel very fortunate to have the language, cultural and financial resources to navigate our family life, but we believe others, particularly minority populations, who may not have the same resources be given more information and support.”



- 2. Connect parents with advocates from their own community.** Parent advocates, along with healthcare professionals, teachers, community members, and organizations all play an important role in assisting families of children with developmental disabilities. Professionals and organizations who support children with developmental disabilities, along with individuals and organizations specific to families' ethnic groups, can work together to connect families to services, increase their access to information from a variety of sources, and empower children and their families to engage in community life.
- 3. Reduce key barriers to service access.** Given costs, distance, lack of translators, and other service barriers make it difficult for children to obtain necessary services, more financial supports, in-home services, and culturally relevant programs are needed.
- 4. Increase community awareness of developmental disabilities.** Along with positive supports that parents mentioned from their community, parents also experienced stigma and other challenges within their community related to their child's developmental disability. Much more work is needed to increase community knowledge of the value and joy that children with developmental disabilities bring to their families, as well as to their communities at large.

“There are days and moments where I find it beyond challenging, but [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.”

- 5. Build on the strengths of each family and community.** We found some differences based on English proficiency, which demonstrate the need to identify families who might need additional support. Additionally, most families are especially vulnerable to financial burden and disruptions of therapies and other supports during the pandemic. However, the needs assessment also revealed families' resilience to stressors and commitment to support their children in partnership with their providers and community members.

Please visit our Facebook page (<https://www.facebook.com/MarylandAANS/>) to request more information, or contact: Sarah Dababnah, PhD, MPH, MSW, Associate Professor, University of Maryland School of Social Work at sdababnah@ssw.umaryland.edu.

