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

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Background

The prevalence of children diagnosed with developmental disabilities (DDs), currently about one in six, has increased in the US (Baio et al., 2018; Zablotsky et al., 2019). Raising children with DDs is associated with positive outcomes for parents, such as personal growth and improved family cohesion (Yoong & Koritsas, 2012; Faso et al., 2013). However, parents of children with DDs also experience high levels of stress related in part to navigating community services, due to a variety of reasons such as long waiting lists and high service costs (Ooi et al., 2016).

Studies have found that early intervention improves long-term developmental outcomes, such as improved language abilities, adaptive skills, and social behaviors across the lifespan (Anderson et al., 2014; Clark et al., 2018; Dawson et al., 2012). Early diagnosis and intervention are beneficial not only for children with DDs, but also for caregivers’ well-being (Giarelli & Fisher, 2016; Zwaigenbaum et al., 2015). However, multiple studies highlight racial and ethnic disparities in DD health care and service use, including in diagnosis and early intervention (Dababnah et al., 2018; Magaña et al., 2012; Magaña et al., 2016). Children of immigrants are particularly vulnerable: compared to children born in the US to White mothers, children of foreign-born mothers are at higher risk for being diagnosed with DDs (Becerra et al., 2014). Yet, while the literature focused on historically underserved communities is growing, there is little known about Asian children with DDs and their families.

The Asian population is the fastest-growing group in the US, increasing 72% between 2000 to 2015 (López et al., 2017). Accordingly, there has been an increase in Asian Americans with DDs (Rice et al., 2010). Maryland has a significant population of Asian Americans, as the US Census Bureau (2019) reported that 6.7% (n=405,060) of Maryland’s population was Asian. The largest Asian ethnic populations in Maryland are Indian, Chinese, Korean, Filipino, Vietnamese, and Japanese (Statistical Atlas, 2018).

Despite their increasing population, Asian American families of children with DDs have been largely invisible in practice and research. For example, no Asian American caregivers of children with autism in Maryland were included in the 2017 National Survey of Child Health (NSCH) data. The NSCH is a national sample and provides rich data on children’s lives, including physical and mental health, access to quality health care, and child’s family and social context. In addition, a recent review of research focused on East Asian parents of children with DDs revealed that existing studies used mostly qualitative methods, had small samples, were concentrated only in large metropolitan areas, and broadly explored caregiving experiences (rather than specific topics such as diagnostic processes or professional relationships; Kim, Wang, & Dababnah, 2020). To our knowledge, there are no rigorous quantitative studies which thoroughly evaluate Asian American families’ experiences as they navigate service systems for their children with DDs.
In order to begin to fill in the large gaps of knowledge related to Asian American families of children with DDs, we conducted a needs assessment of Maryland families, with the support of the Maryland Developmental Disabilities Council. The current project was a unique opportunity to understand the strengths and needs of this population; their experiences in the diagnostic process; navigation of community services and healthcare; barriers and facilitators of service use; and other factors that may impact Asian Americans children and their families of children in Maryland. Specifically, we aimed to achieve three primary objectives: 1) develop a survey to determine the facilitators and barriers of the diagnostic process and service use of Asian American parents of children with DDs; 2) build relationships with key stakeholders, including self-advocates, caregivers, providers, and other advocates of children with DDs and their families in Maryland to reach underserved Asian American communities; and 3) collect, analyze, and disseminate data to understand service needs, strengths, and community inclusion of Asian American parents of children with DDs.
Survey Procedures

We took several steps to assess the needs of Asian American families raising children with DDs in Maryland. Below, we describe our survey development, translation, recruitment, and data collection.

**SURVEY DEVELOPMENT AND TRANSLATION.** We took a comprehensive approach to develop our survey. First, we convened an advisory board of national leaders in DD research (see Page 3). In our initial meetings, we solicited advice on possible survey items. Several of the advisors provided survey questions they had used in other studies designed to understand needs of caregivers raising children with autism and other DDs. Once we had a draft survey, we shared it with the entire advisory board, who provided additional feedback. Then, we shared the draft survey with the Maryland Developmental Disabilities Council staff, who reviewed and provided us with additional helpful feedback. Finally, we requested feedback from two Asian American parents of children with DDs. In addition to items used in other national DD surveys (which included items on the child’s diagnostic process and barriers; ways of information gathering; service use; parents’ coping processes; and parent beliefs and community views about DDs), our final survey included additional questions on English proficiency, and open-ended questions on additional needs they wanted to share.

After we finalized the survey, we professionally translated the survey and a recruitment flyer into four different languages (see Appendix A for English-language recruitment flyer). We prioritized targeting Chinese, Filipino, Indian, Japanese, Korean, and Vietnamese caregivers, the six largest Asian ethnic groups in Maryland (Statistical Atlas, 2018). Given English is widely spoken in India and the Philippines, we translated the survey and flyer into Chinese, Japanese, Korean, and Vietnamese. Bilingual speakers in each language reviewed the English and translated surveys and flyers, and revised translations as necessary.

**RECRUITMENT.** Once we received ethics approval from the University of Maryland Baltimore Institutional Review Board, we started recruiting survey participants in September 2019. In order to complete the survey, participants must have met all of the following criteria: 1) primary caregiver of a child with a DD (aged 0-18) living in Maryland; and 2) self-identified Asian American. Our survey was available in five different languages in Qualtrics, a secure survey portal. We collected data mainly through Qualtrics, but we also provided paper surveys to participants when requested.

We used several approaches to recruit participants. First, we reached out to local agencies or organizations which provide services or information to families or individuals with DDs, including early intervention services. We made a list of agencies by county, with the goal to reach organizations in each region in Maryland. We broadly searched organizations serving individuals with DDs, as well as those focusing on specific DDs such as Down syndrome, intellectual disabilities, autism, and cerebral palsy. We contacted each organization by phone and email, and provided the
recruitment flyer and an informational letter. We followed up with agencies several times if we did not receive a reply. In some cases, we were able to advertise the study in person through local events hosted by DD organizations (for example, see Appendix B). Ultimately, we contacted 278 service agencies and organizations by email or phone.

Our second recruitment strategy was to target public schools in Maryland, with the primary goal to ensure that we reached individuals across Maryland. We contacted special educators and other public school system representatives across Maryland. When requested, we completed their approval process in order to distribute flyers to their school community. We distributed flyers through various means to local parents through special education teachers, school websites, social media, and listservs.

Third, we broadly searched Asian American-specific service organizations, religious institutions, language schools and other related groups with large Asian American members. We maintained careful records of all outreach efforts, in order to ensure we specifically contacted a range of ethnic organizations. In addition to general Asian American-serving organizations, and those serving our primary Asian ethnic target groups (i.e., Chinese, Filipino, Indian, Korean, Japanese, Vietnamese), we also contacted organizations specifically serving the Burmese/Myanmarese, Cambodian, Nepalese, Pakistani, and Thai communities (for example, see Appendix C). We contacted around 150 individuals and Asian-serving organizations. In several instances, we met in person with organization staff to explain the study purpose and procedures. In Spring 2020, we planned to attend various in-person events hosted by local Asian organizations. Unfortunately, due to the COVID-19 pandemic, all but one was canceled. However, the one we attended in February 2020 was well-attended and received media coverage in a local Chinese-language newspaper (see Appendices D-E for event flyer and media coverage).

Lastly, we utilized our own connections and local communities to distribute study information. We created a Facebook page to post study information. When we received approval, we also posted flyers in local Asian grocery stores, as well as public libraries. Finally, we distributed information to personal contacts and professional colleagues when appropriate.

**DATA COLLECTION.** The online survey was open to participants between September 2019 and July 2020. Participants received $20 to complete the survey. Given our broad outreach, we had a substantial numbers of false responses to our online survey (e.g., respondents from outside of Maryland). We implemented several strategies to screen data collected through Qualtrics. First, we embedded two questions twice to see if answers matched. Second, we excluded responses that took less than 20 minutes to complete. Third, we removed surveys that did not have a Maryland internet protocol (IP) address. (Note, for those responses in the proximity of Maryland, such as the District of Columbia, we reviewed responses manually to see if they fit inclusion criteria). We reviewed all survey responses that met the three criteria individually to check their validity. After we were confident that the data were valid, we sent a $20 gift card to the email address the respondent provided.
Survey Results

DESCRIPTION OF PARTICIPANTS

Between October 2019 and July 2020, 73 parents participated in the survey, including 25 who completed the questionnaires inclusive of COVID-19 items added in May 2020. We note that throughout this report, we report the valid percentages (i.e., the percent of people who responded, thus excluding missing data). The survey was available in five languages, and parents completed the survey in English (60%), Chinese (21%), Korean (14%), Japanese (4%), and Vietnamese (1%). We collected information on the participants themselves and their children, summarized below and in Table 1.

PARENT CHARACTERISTICS. The majority of respondents (88%) identified themselves as the mother of a child with a DD, whereas the remainder were fathers (12%). Nearly all of the participants were married or living with a partner (95%). The average parent age was 41 years. The participants mostly had higher incomes (over 50% had incomes of $100,000 or more) and education (nearly 80% had an undergraduate degree or more). While participants represented ten Maryland counties, most lived in either Howard County (41%) or Montgomery County (36%).

Only one-fifth of the participants were born in the U.S. Most participants were Chinese (53%), although a sizeable number of Koreans (21%) also participated. The remaining participants were Indian (7%), Japanese (7%), Filipino (6%), Vietnamese (6%), and Bangladeshi (1%). While nearly 90% of the respondents indicated their native language was not English, the majority of respondents indicated they spoke, read, and wrote English well.

CHILD CHARACTERISTICS. Over half of the children had an autism diagnosis (58%). Parents also identified their children had Attention Deficit Hyperactivity Disorder (ADHD; 27%), a developmental delay (18%), an intellectual disability (15%), Down syndrome (14%), or cerebral palsy (1%). Most of the children were male (69%) and were eight years old on average. Three-fourths of children were between ages 5-12 years old, although some parents of young children ages 0-4 (12%) and adolescents ages 13-18 (12%) participated. Notable percentages of the children had co-occurring conditions, such as anxiety (22%), sleep problems (19%), gastrointestinal issues (16%), vision or hearing challenges (10% and 7%, respectively), or depression (8%). Almost all the children (92%) were born in the US. Most of the children were insured, including through the parent’s employer-provided insurance (60%), Medicaid (16%), private insurance purchased directly from the insurer (12%), insurance purchased on the Maryland Health Connection (10%), or TriCare (3%). About 3% of parents did not have insurance for their children or were unsure.
Of the 25 people who completed the survey with COVID-19 questions, 7% reported the pandemic had no impact on their employment. Yet, more than two-thirds (64%) of parents reported they switched to working from home, 12% lost their jobs, and 4% had reduced work hours. When questioned about the primary impact of the pandemic on their household, 24% reported no benefits. Nearly half (48%) said they had more time with family, and 12% said they were able to give their children more breaks at home. Smaller proportions reported less stressful days (8%) and absence of school pressure (4%).
Child’s Diagnostic Process and Barriers

Nearly three-fourths of the parents reported having concerns about their children’s development pre-diagnosis and discussing their concerns with a healthcare professional (see Table 2). Comparably fewer of the parents noted their spouse/partner (51%); doctor, nurse, or other professional (e.g., teacher; 57%); or family members (36%) had concerns about the child’s development. Respondents had early concerns (average of 28 months) about their child’s development, such as language delays (63%) and social communication (58%). In response to parents’ concerns, some professionals conducted a developmental screener (32%) or referred the child to a specialist (39%), but 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 (25%) participants reported they did not receive a referral to the professional who diagnosed their child. The professionals who commonly referred children for evaluations included primary care providers (41%), early intervention providers (15%), teachers (9%), social workers (4%), specialists (e.g., neonatologist; 4%), or other professionals (1%).

Table 2. Child Pre-Diagnostic Process

<table>
<thead>
<tr>
<th>Diagnostic Process and Barriers</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver concerns about child’s development</strong></td>
<td></td>
</tr>
<tr>
<td>Had concerns, and expressed them to a healthcare professional</td>
<td>54 (76.1)</td>
</tr>
<tr>
<td>Had concerns, but did not express them to a healthcare professional</td>
<td>5 (7.0)</td>
</tr>
<tr>
<td>No concerns pre-diagnosis</td>
<td>12 (16.9)</td>
</tr>
<tr>
<td><strong>Timing of caregiver’s first developmental concern</strong></td>
<td></td>
</tr>
<tr>
<td>At birth</td>
<td>8 (13.6)</td>
</tr>
<tr>
<td>After birth</td>
<td>51 (86.4)</td>
</tr>
<tr>
<td><strong>Average age of caregiver’s first developmental concern</strong></td>
<td>28.2 months</td>
</tr>
<tr>
<td><strong>First developmental delays caregivers noticed</strong></td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>37 (62.7)</td>
</tr>
<tr>
<td>Social communication</td>
<td>34 (57.6)</td>
</tr>
<tr>
<td>Disruptive behavior</td>
<td>11 (18.6)</td>
</tr>
<tr>
<td>Motor</td>
<td>11 (18.6)</td>
</tr>
<tr>
<td>Daily activities</td>
<td>8 (13.6)</td>
</tr>
<tr>
<td>Feeding/eating</td>
<td>8 (13.6)</td>
</tr>
<tr>
<td>Temperament</td>
<td>8 (13.6)</td>
</tr>
<tr>
<td><strong>Professional’s response to caregiver’s concerns</strong></td>
<td></td>
</tr>
<tr>
<td>Made a referral to a specialist</td>
<td>23 (39.0)</td>
</tr>
<tr>
<td>Conducted a developmental screener</td>
<td>19 (32.2)</td>
</tr>
<tr>
<td>Told caregiver it was too early to tell if anything was wrong</td>
<td>17 (28.8)</td>
</tr>
<tr>
<td>Told caregiver the child’s development was typical</td>
<td>10 (16.9)</td>
</tr>
<tr>
<td><strong>Professional who referred child for diagnostic evaluation</strong></td>
<td></td>
</tr>
<tr>
<td>Did not receive a referral</td>
<td>17 (25.0)</td>
</tr>
<tr>
<td>Primary care physician or pediatrician</td>
<td>28 (41.2)</td>
</tr>
<tr>
<td>Early intervention provider</td>
<td>10 (14.7)</td>
</tr>
<tr>
<td>Teacher</td>
<td>6 (8.8)</td>
</tr>
<tr>
<td>Social worker</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Specialist</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.4)</td>
</tr>
</tbody>
</table>

Notes:*This average excludes those concerned at birth; **More than one response was allowed; thus percentages might not equal 100.
Ultimately, parents reported that children were diagnosed on average at 40 months old (excluding children diagnosed at birth). Nearly all of the parents noted the professional who diagnosed their child gave them some support post-diagnosis, such as giving them information about available services. Most parents followed up on their providers’ recommendations, although 10% did not know what to do with the information they received. A majority (79%) said they understood their child’s strengths as well as challenges when their child was diagnosed.

Parents identified several barriers to their child obtaining a DD diagnosis and related supports (see Figure 1). About 61% of the parents did not have prior knowledge about DDs. In seeking help, 62% of the respondents had trouble understanding how the healthcare system worked, getting needed 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. Parents faced other logistical issues as well, such as uncomfortable visits for the child (30%), long distance to evaluation (24%), and the evaluation’s expense (25%). Of those parents 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. 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.

Nearly all of the respondents recommended doctors, nurses and other health professionals demonstrate more knowledge about DDs; that professionals communicate more with caregivers about the steps to obtain a DD diagnosis; and medical clinics provide more DD-related information. Of the choices parents received of possible methods to improve the diagnostic methods, respondents most commonly (98%) indicated they wished health professional should act faster when parents have child developmental concerns. However, they also frequently cited clinics should have interpreters available when needed (97%), provide assistance to families to make specialist appointments (95%), give checklist of DD signs at routine check-ups (92%), and train interpreters on DDs and the diagnostic process (90%).

**Figure 1. Caregivers Reporting Diagnostic Barriers**

- **Stress of diagnostic process**: 72%
- **Difficult to understand the health care system**: 62%
- **Did not know where to go for help**: 48%
- **No care coordination**: 46%
- **Poor quality of needed interpreters**: 41%
- **Unavailability of needed interpreters**: 36%
- **Timeliness of DD evaluation**: 35%
- **Provider attributing delays to use of non-English language**: 30%
- **Discomfort of appointments for child**: 25%
- **Cost of DD evaluation**: 24%
- **Family travel for DD evaluation**: 22%
- **No prior DD knowledge**: 21%
- **Unable to access updated medical information and…**: 19%
- **DD stigma in the community**: 19%
- **Distrust of providers**: 11%
- **Fear of asking for help due to legal issues**: 8%

**What do caregivers recommend to health professionals to improve the diagnostic process?**

- Act faster when caregivers have child developmental concerns
- Provide interpreters when needed, especially those trained on DDs and the diagnostic process
- Offer assistance to families to make specialist appointments
- Give checklists of DD signs at routine check-ups
Caregivers’ Information Gathering

As parents began to learn more about their child’s diagnosis, they looked to different people for information and support (see Figure 2). Nearly all of the parents (91%) said their child’s early intervention coordinator or therapist was helpful to meet their child’s needs, whereas large percentages of the parents likewise said medical specialists (84%), other parents of children with DDs (81%), the child’s teacher (81%), other therapists (77%), and pediatricians/primary care providers (70%) were helpful. Smaller proportions of the respondents reported community members (43%) were helpful in identifying services in their communities, whereas 57% reported community members were not helpful. Similarly, notable proportions of parents reported their child’s pediatrician/primary care provider (30%), other therapists (23%), the child’s teacher (19%), and other parents of children with DDs (19%) were unhelpful in finding community services.

Parents used various methods to gather information about their child’s diagnosis and available services. The most common information source was social media (68%). Approximately 46% of respondents also said they found information through local DD support organizations, the child’s school (45%), and reading materials outside of social media (42%). Smaller numbers of parents reported finding information from national DD organizations (26%), and only 15% of parents found information from organizations specific to their ethnic group.

![Figure 2. Helpful Information Sources for Local Services](image-url)
Parents provided suggestions to improve community-based information sources and supports. Eighty percent of parents recommended television, radio, and newspapers have more stories about DDs in the parents’ primary language. Most parents (79%) had no experience with a DD parent advocate; however, of those who did, 71% found them to be helpful. A similar proportion (68%) of the respondents did not have any experience with a DD community health worker; while of those who did, just over half (52%) found them helpful.

**Overall Service and Medication Use**

The majority of parents (88%) said their children had received special education services, and 65% also had used early intervention services through the Maryland Infants and Toddlers Program. Many parents (69%) reported their child received some type of therapy, including those in school. The most reported service currently used was speech and language therapy (72%; see Figure 3). Some parents also said their children received recreational services (e.g., swimming, dance; 39%), occupational therapy (38%), dental care (37%), mental health counseling (28%), physical therapy (25%), applied behavior analysis (24%), case management (19%), assistive communication technology (17%), and social skills training (16%). Few parents reported use of dieticians (13%), neurologists (11%), respite care providers (7%), residential services (4%), and vocational training (2%). The children’s services were funded through private insurance (58%), out-of-pocket by parents (46%), Medicaid (26%), or a Medicaid waiver (4%).
When questioned about reasons their child did not receive services, participants chose multiple explanations. Most commonly, parents reported not needing the services, or to a lesser extent, ineligibility for a service. However, notable percentages of the respondents were unaware of listed services (e.g., 30% were unaware of case management services; see Figure 4). Small proportions of caregivers said needed services were unavailable in their area; not in preferred language; or, far from their homes. Some caregivers reported their child had not received needed services due to being on the waitlist or cost.

Notably, services often considered to be universally appropriate for children had low reported numbers of use. For example, only 37% of respondents said their child accessed dental care. Comparably, 14% said they were not aware of the service for their children; 5% said dental care was unavailable in their area; 3% said it was unavailable in their preferred language; and 3% cited the cost as a barrier to accessing the service. In another example, only a small number of parents (7%) reported using respite care. Those who did not access respite care cited barriers such as lack of awareness of the service (21%), ineligibility (6%), unavailability in their area (2%), or cost (2%).

![Figure 4. Percentage of Caregivers Unaware of Services for Their Children](image-url)
The COVID-19 pandemic also impacted service access. Of the 25 respondents who responded to the survey with questions about the pandemic, 30% said they stopped recreational activities due to COVID-19, and 5-30% of respondents said they stopped most of the remaining services their child received prior to the pandemic. Overall, just over half (52%) of respondents said they had received alternative services for those stopped due to COVID-19.

Less than one-third of parents reported using medications or treatments for DD symptoms for their children. About 35% said their children used prescription medications, 26% used multivitamins, 9% herbal supplements, and 6% over-the-counter medications. Parents did not commonly cite use of dietary treatments (e.g., gluten-free diets; 14%), chiropractic or massage therapy (3%), traditional healers (1%), or acupuncture (1%).

**Parental Coping Methods**

We used the 28-item Brief COPE (Carver, 1997) to better understand parents’ use of various coping methods. The most cited coping method was acceptance (e.g., “I’ve learning to live with [stress].”). Parents’ also often reported efforts to plan and actively address problem situations (e.g., taking action to make the situation better), positively reframe stressful situations, and use informational support (e.g., getting help and advice from others). To a lesser extent, respondents said they used self-distraction (e.g., watching TV), religion/spirituality (e.g., praying, meditating), and emotional support from others to cope with stressors. Methods that parents cited on average using a little bit included venting, self-blame, and humor. The least commonly report methods were behavioral disengagement (e.g., “giving up trying to deal with it”), denial (e.g., telling oneself “this isn’t real”), and substance use.

**Community Views of DDs**

Parents reported on their perceptions of their community’s view on DDs (see Figure 5). Three-fourths of the respondents said people in their community viewed DDs as a medical condition, and 55% felt their community had little information or knowledge about DDs. Over half (65%) of respondents said community members try to help their child and family, 56% reported that their community members think individuals with DDs have special abilities, and 37% felt their community members want to learn about DDs. Yet, half of the participants said that people in their community think that individuals with DDs will “grow out of it,” 42% that community members are uncomfortable around their child with a DD, and 36% that DDs are something of which to be ashamed. One in four participants reported they perceived their community members think DDs 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 DDs, such as “stupid.” Only a small percentage (10%) of respondents said that people in their community think that DDs only happen in the US.
Caregivers’ Perspectives on Child and Family Needs

In addition to the questionnaires, we provided parents an open space to write what they and their children need. Most parents (n=61) provided a response. The most common parent need was financial support. Parents discussed financial burdens related to paying for private therapies and related services, and hoped for more information on services such as financial planning. One parent noted that due to the COVID-19 pandemic, “Prices are rising sharply now, we have to reduce expenditures in order to get through the difficult time.” Others discussed the impact that financial pressures had on the time they could spend with their child, as one said, “…if I can afford to work only one job, I would definitely spend time with her. Poor girl has so little time with Mommy.” Some parents noted that only a narrow range of services are covered by their medical insurance.

Besides financial support, parents frequently mentioned the need for increased information about developmental disabilities in general, as well as specifically about available services and supports. For example, one parent felt more widespread awareness of developmental delays and early intervention would be beneficial, saying, “I asked myself multiple times: what if I knew earlier and took my daughter to therapy earlier?”

Parents also raised concerns about how to support their child in the future. One parent’s despair was evident in this comment, “I need someone to fix…this nightmare and hell we are living through. I need to know my child will be okay when I’m no longer able to care for him.” Parents expressed worries about their child’s transition to adulthood, as one described:

The most pressing need is life beyond high school. Many parents say leaving HS [high school] is like falling off a cliff - the kids just stay at home after HS. There is a high rate of unemployment (75%) in the DD community. There are some college programs but they are segregated and do not lead to any employment or job skills. There are inclusive college options outside Maryland but it is not available in MD. We need inclusive college programs and more job training in MD.

Many parents wanted more options to accommodate their child’s needs and strengths, such as in-home care, alternative communication devices, care coordination, and one-on-one supports. One parent noted waiting lists and distance are barriers to obtaining services, saying “I feel there are resources and support for us in Howard County, and MD/DC, but it is far, hard to ask for and get, and a lot of work. The diagnosis and lack of immediate support was very crushing.” Finally, some parents emphasized that while their child accessed some therapies, they were not frequent enough. For example, one said, “My son may need minimum of five hours per week of speech therapy but he is getting only one hour per week. He needs ABA therapy to manage his behavioral changes but there is not enough support through public systems.”
Some parents highlighted that while they were grateful to receive school-based services, they felt school services were insufficient for their child’s needs. As one parent said, “We appreciate the support from public schools. But the public school employees do not give info about out of school services because they worry parents may demand the government to pay for those services. Our kids DO need more than what the public schools offer.” Others mentioned challenges with the school system after moving to the US from Asia, remote schooling due to the COVID-19 pandemic, and limited special educators and other specialists within schools.

Besides academic supports and therapeutic services, many parents desired more opportunities for their child to engage in recreational activities and socialize with peers. Many parents specifically requested additional inclusive community activities that they could do as a family. Some parents wanted more family leisure time to strengthen their relationship with their partners and their children, including those children who were typically developing. Parents also mentioned the need for affordable respite care, particularly given remote schooling and being far away from family support in Asia.

Some parents mentioned the need for advocates and peer mentors to guide them through the service system. One parent noted her isolation as one of the few Asian parent advocates, saying:

I am VERY active in the [DD] 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 DD. But they do not participate in the events organized by the disability groups and many rely on me for the resources and information. Frankly, I get tired of helping the Asian families sometimes. I can’t change the world by myself; they need to do their part as well.
The previous parent’s comment revealed another common theme we identified in the open-ended responses, the need for cultural and linguistic supports. Several parents desired support in their native languages. For example, one parent said, “As a Korean-speaking Korean, there is a limit to getting along with the American parent community of children with disabilities, and it is not easy to get information.” Another parent spoke more about cultural differences, saying, “For Asian parents who are new to American culture, due to cultural differences regarding DD between Asian and American, it usually takes longer time for parents to acknowledge the situation and seek evaluation and support.” Parents recommended expanding knowledge and information through various channels, as one said, “I think it’s important to spread awareness to non-English speaking (or ESL) Asians in the US and use the media they are exposed to spread that awareness (e.g., foreign language cable channels, newspapers, Facebook, etc.). With awareness, they may become better community supporters.”
Some parents responded to the survey after the COVID-19 pandemic began, which included an additional open-ended question about any related worries they had. Of the 20 people who responded to this question, nine did not have significant concerns. The remaining 11 described concerns such as canceled activities and therapies, and their child’s increased vulnerability to the virus due to being immunocompromised. Several discussed their worries about the negative impact on their child’s social and academic skills due to remote schooling and disrupted therapies. One parent specifically discussed concerns related to being an Asian American, saying, “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. FBI has even issued a warning about this.”

Finally, many parents emphasized the many strengths their child had, and the value they gained from raising a child with a DD. One parent said, “Looking back all those year coming along, I personally appreciate the advent of my child. I am glad that I learned and grew a lot from this procedure. Hope, Faith and Love.” Another described how parents change careers to DD-related jobs due to their experience as a parent. Some described appreciation for others’ support to build on their child’s strengths, as one parent said:

> I’m thankful for this country and everything all the support, programs, people offer to my child and help her make significant progress. Yes, she still has DD and it will never go away. But all I wish for is she will lead a happy and healthy life. I’m positive that a lot can be done to make this goal comes closer.

While parents overall seemed to recognize their child’s strengths, some cautioned that their child experienced discrimination from others for both for their DD, as well as for their ethnicity. Several parents were happy to see a study focusing on the Asian American community given the discrimination they perceived from their communities. One parent explained:

> 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 [DD] 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.

Many parents talked about lack of acceptance within their community; thus, more community awareness is needed: “People in the community need help to give my children more tolerance than discrimination.” One parent summarized her dreams for inclusion and acceptance:

> While in this “normal” world, my son’s [DD] is considered a disability, there are times I think the fact that he just processes things differently isn’t abnormal. It’s [because] we as a society deem things to be normal and want things done “normally.” My son is really intelligent and beats to his own drum. There are days and moments where I find it beyond challenging, but he 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!
Summary and Recommendations

To our knowledge, this project was the first systematic needs assessment of Asian American families raising children with DDs in Maryland. While we identified considerable strengths within this population, the survey also revealed parents’ perspectives on barriers they face to access services and gain community support. Our findings were largely consistent with studies inclusive of other ethnic and racial minority groups, which have found significant disparities in DD diagnoses and service access related to race, ethnicity, income, and nativity (e.g., see Becerra et al., 2014; Dababnah et al., 2018). It is important to keep in mind that the parents who participated in our survey were mostly women, high-income, and well-educated. Furthermore, most of the children had insurance coverage and were US citizens. Thus, the challenges our respondents detailed might be magnified in groups that typically have poorer access to care, such as children from low-income households, uninsured children, or children without US citizenship. Thus, more research is needed to better understand the needs of Asian American families who are historically underserved in the US healthcare system. Additionally, more work is needed to understand potential variations within Asian American groups, based on ethnicity, income, or other factors.

The needs assessment highlighted the many strengths of Asian American children with DDs and their families, and the opportunity for local communities and organizations, service providers, and other advocates to be important allies in efforts to empower and include children with DD and their families in all areas of community life. Based on our needs assessment, we recommend service providers, community members, and other key stakeholders:

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.

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 DDs. Professionals and organizations who support children with DDs, 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 DDs bring to their families, as well as to their communities at large.

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 COVID-19 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.
Dissemination Plans

Moving forward, the results of this survey provide DD professionals, advocates, and other stakeholders with a summary of the strengths and needs of Asian American families raising children with DDs in Maryland. To complement this full report, we will distribute a shorter research and practice brief to providers through community partners that facilitated data collection and participant recruitment efforts, as well as other interested organizations. We will also disseminate one-page summaries in 15 languages aimed at parents and other lay audiences. For purposes of this project, we created a Facebook page, which will allow us to share our findings on social media. Finally, we will present our findings to academic audiences through local and national academic conferences, as well as peer-reviewed scientific journals.
References


Can you check yes to all of these questions?

☐ Do you live in Maryland?
☐ Do you have a child under age 18?
☐ Are you Asian or Asian American?
☐ Does your child have a developmental disability (for example, ADHD, autism spectrum disorder, Down syndrome, intellectual disability, learning disorder, blindness, seizures)?

If so, please participate in a research study to help us understand your family’s needs and how you use community and health care services. We are specifically focused on Asian American families, given they have received little attention in past.

We invite you to complete a 45-60 minute survey, either online or on paper. You will receive $20 for completing the survey.

You can access the survey here at https://tinyurl.com/y3zaopxl.

If you would like have more information, please contact Irang Kim at irang.kim@ssw.umaryland.edu or (410) 706-7927.

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Appendix B

Photo of Research Team Members Irang Kim and Yao Wang at 2019 Howard County Autism Society Walk and Run Race
Appendix C
Maryland Burmese Community Network Facebook Post

Maryland Burmese Community Network
@marylandburmesecommunitynetwork

Home
Posts
Reviews
Photos
About
Community
Create a Page

Maryland Burmese Community Network
February 11

If you are Burmese family in the Maryland and your children are diagnosed as developmental disabilities? We are trying to reach out to the families and they will fill out the survey, we will provide $20 amazon gift card for them as compensation. FYI to Burmese community. မိဘတ်များသည်လူမှုများတွင် ဦးချိချက်များသည် ကျွန်ုပ်တို့ကို ရှာဖွေရန်ဖြစ်ပါသည်။ အရာများဖြစ်ပါသည်ရှိယူဆရန်အတွက် ကျွန်ုပ်တို့ကို ထိန်းသိမ်းပါသည်။

See Translation

Asian American Needs Survey

Can you check yes to all of these questions?

☐ Do you live in Maryland?
☐ Do you have a child under age 18?
☐ Are you Asian or Asian American?
☐ Does your child have a developmental disability (for example, ADHD, autism spectrum disorder, Down syndrome, intellectual disability, learning disorder, blindness, seizures)?

If yes, please fill out this survey form and email at [email]

amazon gift card $20 အားယူရန် ခေါ်င်သိမ်းပါသည်။

See Translation
The Village Initiative Presents:

Community Conversation:
Parenting Children with Special Needs

Join our conversation with Asian parents!

Speaker: Dr. Sarah Dababnah, Assistant Professor at the University of Maryland School of Social Work

Time: Saturday, February 15, 2020 from 2 – 4 pm

Location: Chinese Culture and Community Service Center, Inc.
9366 Gaither Road, Gaithersburg, MD 20877

- Presentation on parenting children with special needs
- Introduction of local community resources for families of children with developmental disabilities
- Dialogue with local service providers
- Survey on the needs of Asian American families raising children with developmental disabilities

Questions: Email village.initiative.md@gmail.com

Sign Up: Click Here; Or call (240) 393-5950

Childcare will be provided with request.

Sponsored by the Village Initiative of CCACC-Pan Asian Volunteer Health Clinic & Chinese American Parent Association, Montgomery County
Asian American Health Initiative, Montgomery County
Appendix E

Media Coverage in China Press Weekly Featuring Dr. Sarah Dababnah

亚裔记者协会吁媒体公正报道新冠病毐新闻

华府华人团体举办公益讲座
关注华裔特殊儿童教育

华府华人联合会在广州驻波士顿办事处交涉物资

中美大华府赶集歌手音乐会

优美的歌曲惹人醉

支持亚裔记者协会

【记者报道】

Appendix E

Media Coverage in China Press Weekly Featuring Dr. Sarah Dababnah

亚裔记者协会（AAJ）指出，近日爆发的新冠病毒（COVID-19）疫情引发全球关注。在此背景下，亚裔记者协会呼吁媒体公正报道新冠病毐新闻，以帮助华裔社群了解实时情况，避免不必要的恐慌。

据报道，中国媒体在报道新冠病毐新闻时，存在一定程度的偏向和不实报道。为了纠正这种现象，亚裔记者协会呼吁媒体在报道时应遵循客观、公正的原则，不夸大其词，不增加不必要的恐慌。

亚裔记者协会指出，媒体在报道病毐新闻时，应注重事实的准确性，避免在报道中加入过多的主观情感色彩。同时，媒体还应注重病毐的科学性报道，以提供给读者准确的病毐信息。

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