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

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Expert Advisory Board

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.

Table 1. Children and Parent Characteristics (*N*=73)

Child Characteristic	*N (%)*	*Parent Characteristic*	*N (%)*
Born in US	67 (91.8)	**Born in US**	15 (20.3)
Child Age		**Parent Ethnicity***	
Early Childhood (0-4)	9 (12.3)	Chinese	39 (53.4)
Young School Age (5-9)	38 (52.1)	Korean	15 (20.5)
Middle Childhood (10-12)	17 (23.3)	Indian	5 (6.8)
Adolescent (13-18)	9 (12.3)	Japanese	5 (6.8)
Child Diagnosis*		Filipino	4 (5.5)
Autism	42 (57.5)	Vietnamese	4 (5.5)
ADHD	20 (27.4)	Bangladeshi	1 (1.4)
Developmental Delay	13 (17.8)	**Education Level**	
Intellectual Disability	11 (15.1)	High School	4 (5.5)
Down syndrome	10 (13.7)	Some College	3 (4.1)
Cerebral Palsy	1 (1.4)	Associate Degree	7 (9.6)
Co-occurring Condition*		Undergraduate Degree	15 (20.5)
Anxiety	16 (21.9)	Graduate Degree	43 (58.9)
Sleep problems	14 (19.2)	**Household Income**	
Gastrointestinal symptoms	12 (16.4)	$0-24,999	8 (11.0)
Vision impairment	7 (9.6)	$25,000-49,999	6 (8.2)
Depression	6 (8.2)	$50,000-74,999	9 (12.3)
Hearing impairment	5 (6.8)	$75,000-99,999	12 (16.4)
		$100,000-149,999	19 (26.0)
		$150,000 and over	19 (26.0)

Note: *More than one response was allowed; thus percentages might not equal 100%.

HOUSEHOLD IMPACT OF COVID-19 PANDEMIC. 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

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

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.

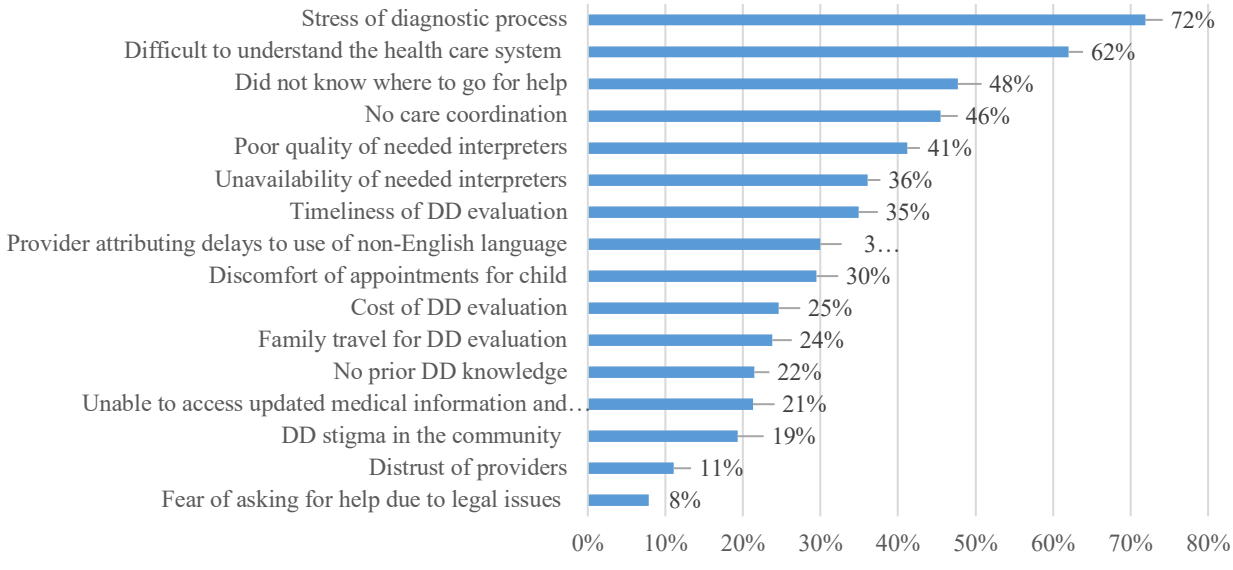
Parents identified several barriers to their child obtaining a DD diagnosis and related supports (see Figure 1). About 61% of the parents did not have prior knowledge about DDs. In seeking help, 62% of the respondents had trouble understanding how the healthcare system worked, getting needed help to 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 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%).

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

Figure 1. Caregivers Reporting Diagnostic Barriers

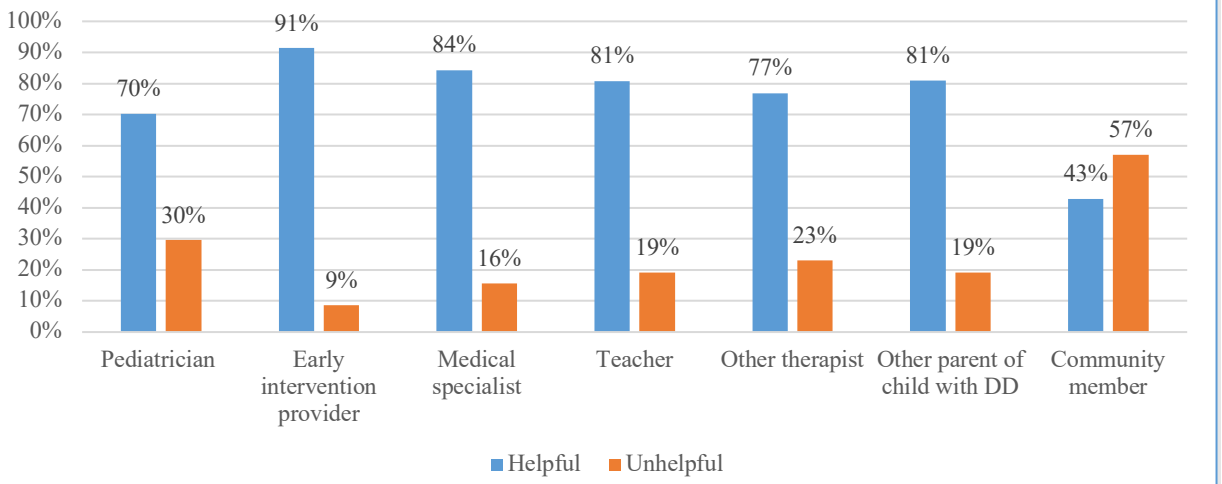


Caregivers' Information Gathering

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



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.

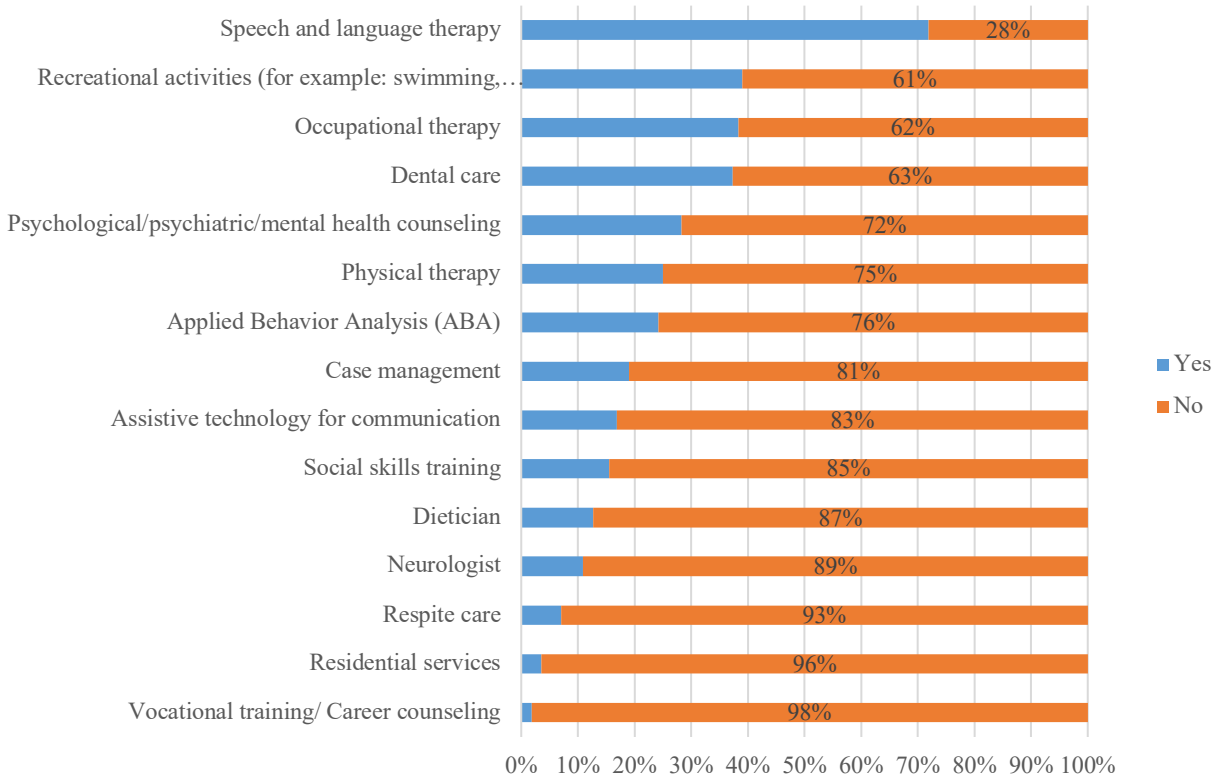
What do caregivers recommend to improve community-based information sources and supports?

- Television, radio, and newspapers should have more stories about DDs in the caregivers' primary languages.
- DD parent advocates can be helpful sources of information and support.

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%).

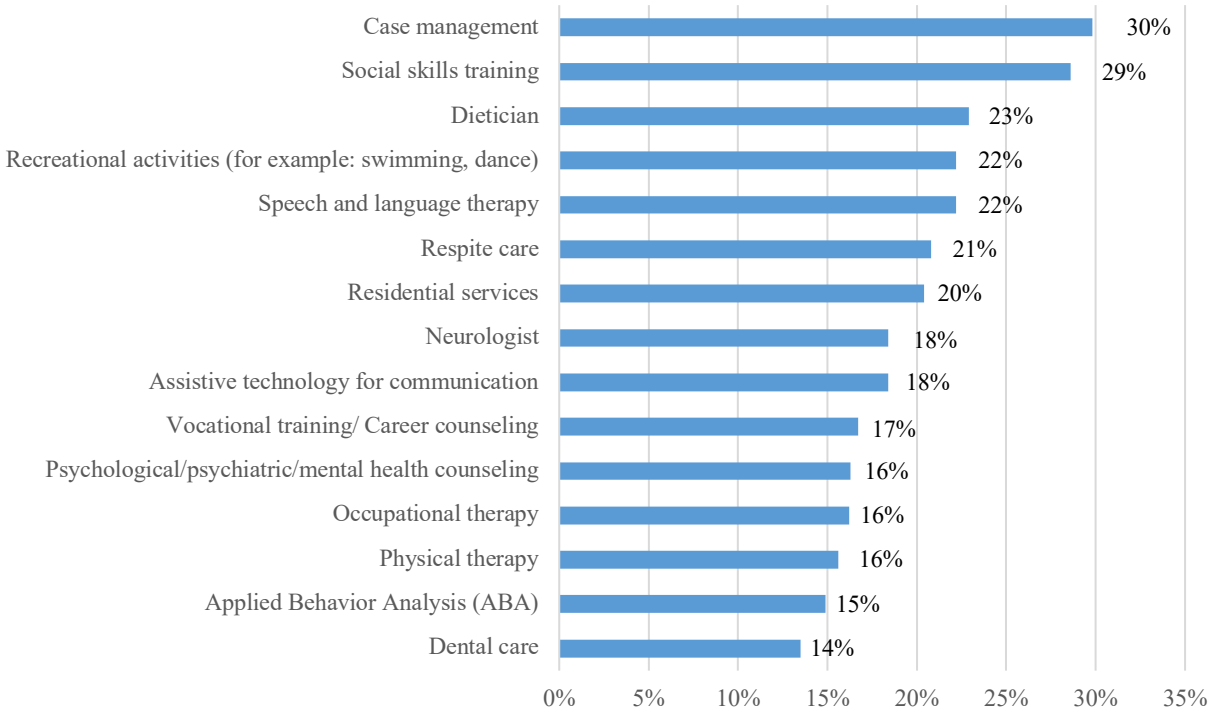
Figure 3. Use of Services



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



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%).

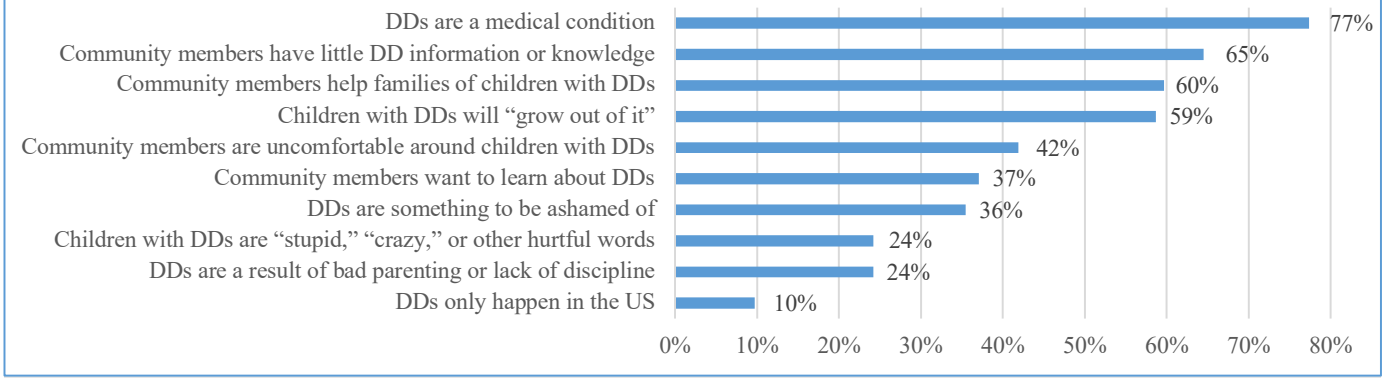
Parental Coping Methods

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.

Figure 5. Caregiver Perceptions of Community's View of DDs



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.

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Appendix A

English-Language Recruitment Flyer

Asian American Needs Survey

<u>Can you check yes to all of these questions?</u>

☐ 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.

(Scan this QR code and start the survey!)

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

Funding made possible by University *of* Maryland School of Social Work; Maryland Developmental Disabilities Council — Empowerment · Opportunity · Inclusion

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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

Appendix D
Chinese American Event Flyer

UNIVERSITY of MARYLAND
SCHOOL OF SOCIAL WORK

The Village Initiative Presents:

VILLAGE INITIATIVE

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.

CCACC- PAYHC
泛亞義務門診

CAPA·MC MARYLAND
Education & Community

Asian American Health Initiative
Together To Build A Healthy Community

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毒新闻

■侨报记者萧芸报道

亚裔记者协会（AAJA）指出，近日爆发的新型冠状病毒（COVID-19）疫情引发全球关注。与此同时，毫无根据的谣言也通过各种渠道传播并引发恐慌，催生了多国多地针对亚裔的歧视现象，甚至在全美多地出现了仇外和针对亚裔的霸凌事件。该协会于14日呼吁广大新闻工作者，在对新型冠状病毒疫情进行报道时，更加注意行文、修辞及报道内容的准确度。

AAJA在声明中称，民众对该病毒的担忧与日俱增，同时对亚裔的敌意和歧视也在加剧，“自疫情爆发以来，已经出现了仇外心理和种族主义的现象。”

在美国和亚洲拥有1500多名成员的亚裔记者协会认为，媒体应有负责任的报导准则，并恳请媒体在将图片等素材附加到报道中时，选择更加谨慎，以正视听。

该声明并抨击了使用唐人街或戴口罩的亚洲人作为新冠病毒疫情相关报道通用配图的媒体。声明指出，除非照片经过适当的选择并与报道内容相关，否则这类图片很容易加强其他族裔对华裔及唐人街的刻板偏见，甚至助长了恐慌情绪，让其他族裔民众把亚裔当做病毒的携带、传播者。此类图片的频繁使用，导致亚裔在佩戴口罩时被无端的异样目光审视，甚至遭受辱骂、攻击。

尽管目前全美只有15例确诊病例，但恐慌臆测的心态仍在迅速蔓延。该协会还敦促广大记者不要使用“武汉病毒”（Wuhan virus）这样的字眼，因为这不是官方指定用词，可能会让该病毒起源的中国城市武汉蒙上负面烙印。

马里兰大学社工系助理教授芭芭娜（Sarah Dababnah）介绍儿童发展障碍。

华府华人团体举办公益讲座 关注华裔特殊儿童教育

【侨报记者吴哲2月15日华盛顿报道】由华府地区华裔团体发起的“关爱村”公益项目于2月15日在美京华人活动中心推出《小区对话：父母如何教导有特殊需要的孩子》活动，成功开展针对华裔特殊教育群体的公益讲座，为有需要的华裔家庭提供帮助。

“关爱村”项目是由泛亚义务门诊、蒙郡华人家长会和马里兰大学美国亚裔研究项目组这三个社区团体发起的公益项目，通过公益讲座为华裔社区提供帮助。本次讲座邀请了马里兰大学社工系的助理教授芭芭娜（Sarah Dababnah）讲述特殊儿童的教育方式，并邀请了社区相关教育机构的专业人士，与华裔家长分享照顾特殊儿童的经验。

芭芭娜在讲座中介绍了包括自闭症、唐氏综合症、脑麻痹和智力发展障碍等常见的儿童发展障碍（DD），对各项发展障碍作出理论阐述。芭芭娜表示，可以通过应用行为分析法、结构教学法和语言针对治疗等各项训练来治疗儿童发展障碍，此外一些药物和食疗方法对于自闭症等障碍也颇有疗效。

据芭芭娜介绍，儿童小于三岁的家长可以联系马州政府，若大于三岁则可以通过学校来获得相关服务。除了联系学校，本地华裔家长可以向马州政府申请加入MEDICAID WAIVER项目，然后使用MEDICAID或个人保险来获得儿童障碍的专业治疗。芭芭娜建议家长在家时要耐心跟孩子沟通，陪孩子玩耍，帮助孩子与同龄人交朋友。除此之外，更要注意自己的精神健康，创造和谐的家庭环境，为特殊儿童成长提供良好条件。

随后，美京华人活动中心健康服务部代表Kate Lu介绍了“关爱村”项目的由来，并鼓励华裔家长参加项目的同时提供相关个人家庭信息，以便政府可以更好地满足华裔家庭的需求。

来自蒙郡华人家长会的代表杨成华（Julie Yang）表示，蒙郡每个高中都设有特殊教育专业咨询，建议有需求的家长与老师保持紧密联系，共同应对特殊教育难题。另外，她鼓励在场家长带孩子参加马州青少年特殊奥运会，通过体育运动更好地融入社会。

此外，公校华语专员沈余秀雯（Lily Shen）、精神科医生邵晓萍、儿科精神科医生张拉艳等教育与医学专业人士也现场介绍了他们在特殊教育领域的相关服务经验。

蒙郡华人家长会代表杨成华（Julie Yang）介绍特殊教育服务。

助力抗疫 广州联谊会与广州驻波士顿办事处交接物资

交接仪式参与者合影。（周颖摄）

【侨报记者周颖2月16日麻州报道】2月16日下午2时，波士顿广州联谊会与广州驻波士顿办事处在麻州昆西市举办了抗疫救灾物品交接仪式，以确保将近日由广州联谊会成员和波士顿华人一同筹集的价值6268.76美元抗疫物资第一时间运抵广州市急需医疗物资的医院和地区。

广州联谊会会长柏志刚在交接仪式上表示，中国目前出现新冠肺炎疫情，六万多同胞被感染，更有逾1500人失去了生命，为了在关键时刻尽力帮助祖（籍）国，充分体现广州联谊会“一方有难八方支援”的宗旨，该会很快决定以接龙的方式展开援助活动，所有筹款均用于购买医疗物资，并由广州市政府驻波士顿办事处签收，款项和物件也都在网站上及时公示，流程公开透明。据柏志刚称，广州联谊会已经通过筹款购买了价值6268.76美元的医疗物资，其中包括30盒一次性手套、20盒一次性鞋套、15枝红外耳温枪、40个护目镜以及近60盒N95口罩等。

交接仪式上，广州驻波士顿办事处项目主任胡劲和联络员张梦茹对医疗物资核对并签字，并表示16日就已经将部分物资发往了广州。胡劲说，波士顿广州联谊会和广州驻波士顿办事处此前曾签订过合作备忘录，此次中国疫情爆发，办事处受广州市政府委托在波士顿寻找医疗物资，得到了广州联谊会的大力支持。胡劲表示，办事处目前采取收到多少物资就寄出多少物资的策略，让救援物资尽早抵达急需的地区、医疗机构。

柏志刚（左）切蛋糕庆祝抗疫物资交接顺利。（周颖摄）

张福全讲话。（周颖摄）

广州联谊会首任会长张福全表示，自协会发起捐款以来，当地华人十分热心，发生了许多感人的故事。不少会员出门扫货，尽可能多地购买医疗物资，也有不少此前没有捐款渠道的联谊会以外的华人也纷纷出手相助。张福全说，现在第一批物资已经就绪，该会并将用余款继续购买医疗物资，驰援抗疫。

柏志刚告诉记者，许多广州联谊会成员和昆西居民均为草根阶层，能够在短时间内收到这么多捐款令人十分感动。广州联谊会歌舞团代表周佩贞表示，歌舞团团员们也十分热心，共捐出了1500美元。

大华府赶集歌手音乐会 优美歌曲惹人醉

【侨报记者吴哲2月15日华盛顿报道】大华府赶集歌手年度音乐会于2月15日在马州北贝塞斯达卫理公会教堂成功举办，成员们合唱了许多充满台湾风情的优美歌曲，吸引了许多民众前往观赏。

音乐会由台湾知名音乐艺术家、马里兰大学音乐博士沈新钦担任音乐总监，本地钢琴艺术家黄筱佩任钢琴演奏，还有来自台湾的陈沁瑜、陈建国、黄腾宽等表演者分别担任打击、大提琴和键盘手。他们与合唱团其他歌手一起为观众演奏了《台湾是宝岛》《风平浪静》《最后的住家》等许多动听曲目。其中，《将进酒》由台湾民族音乐家张弦文编曲，由赶集合唱团歌手们演唱，嗓音浑厚、气势恢宏，令人印象深刻。歌手们也演唱了不少基督教歌曲，获得在场“老外”观众的阵阵掌声。

赶集歌手合唱团（VS/VS）创始人沈新钦介绍，赶集合唱团2014年组团，至今已有6年。合唱团正如其名，来自不同地区的团员们平时各有工作，只能周末抽空聚会演练，时间匆忙、正如赶集，但大家都因合唱的魅力聚集到一起。

沈新钦表示，合唱团成员大多来自台湾，在合唱音乐中融入了一些台湾元素。此外，合唱团也在传统台湾歌曲之外尝试客家话、英文、西班牙语的歌曲，融入了更多古今中外文化元素，争取每个乐季筹备全新曲目，献给大华府的观众。


大华府赶集歌手合唱音乐会。

南北卡华人工商总会组织云讲座 会计师网上支招指导民众报税

【侨报记者王昊北卡报道】一年一度的报税季已经开始。为服务华人社区，帮助南北卡当地华人了解正确报税的相关信息，南北卡华人工商总会于2月15日组织了税务在线讲座，由北卡三角区著名会计师朱明君主讲。是次讲座亦是一次“云讲座”的尝试。

朱明君利用自己的专业知识，向民众普及税务相关知识，旨在帮助北卡三角区的华人正确报税，合法省税。她主要从投资出租房涉及的税务、外国人在美国投资房产的税务问题、海外金融资产申报，以及退休计划等几个方面进行了详尽的分析和介绍。

在投资出租房涉及的税务方面，朱明君深入浅出地讲了出租房租赁收入的定义及类型、租赁费用包含项、折旧算法和租金被动损失相关的税务问题。比如租赁费用包括广告、车旅费、清洁和维护、佣金、折旧、保险、利息（其他）等。折旧的一般算法为美国住宅折旧一般以27.5年计算，炉具、冰箱和电器为5年，办公家具和设备为7年。出租人每年都应该从租金收入中减去正确的房子折旧金额。即使出租人不减这部分折旧，在出租房出售报税时，出租房的成本价值也会因折旧金额的抵扣而降低。

关于外国人在美国投资房产的税务问题，朱明君详细地讲解了租金所得税代扣代缴、免征预提，以及出售房产的税务问题。

对于新移民以及很多在美国居住多年并有海外金融资产的居民来说，海外金融资产申报就是关乎这些人的一个重要问题。同时，朱明君还对收到外国礼物和馈赠报告如何交税，以及FBAR(Fin114表格）进行了详细讲解。

在这次税务讲座中，朱明君还讲到了退休计划，其介绍了社会安全养老金、401k, 403(b)、Traditional IRA和Roth IRA以及小企业主四个退休计划。