Brief Report: Impact of the COVID-19 Pandemic on Asian American Families with Children with Developmental Disabilities

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Accepted: 19 July 2021 / Published online: 1 September 2021

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Abstract

Discrimination against Asians and Asian Americans increased during the COVID-19 pandemic. Yet, even prior to the pandemic, little research explored the experiences of Asian American families of children with autism and other developmental disabilities. This brief report summarizes the results of a survey conducted between May and July 2020, in the immediate aftermath of state and local lockdowns due to the pandemic. Twenty-five Asian American caregivers of children with autism and other developmental disabilities completed the survey and reported on the pandemic's impact on their household. Most of the caregivers were mothers, immigrants, Chinese, raising children with autism, and highly educated. Participants' primary concerns were the disruption of their children's educational and therapeutic services. We discuss research limitations and implications.

Keywords Asian · Asian American · Autism · Developmental Disabilities · Caregiver · Parent

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Coronavirus Disease 2019 (COVID-19) has affected every aspect of one's lives, including health and economies worldwide. Social distancing is a primary strategy to prevent virus spread, which has resulted in school closures, working from home, and limited face-to-face interactions. These changes add additional burdens to parents, as they serve as teachers at home, while continuing to be responsible for household tasks and employment demands (Fontanesi et al., 2020). Accordingly, national surveys have revealed negative impacts on child and parent psychological well-being, behavioral health, and economic security (Gassman-Pines et al., 2020; Patrick et al., 2020).

The move to remote and hybrid learning models has disproportionately impacted children with Autism Spectrum Disorder (hereafter, autism) and their families (Colizzi et al., 2020). The shift to remote schooling has often resulted in the discontinuation of in-person therapies and educational supports, and increased burden on parents to deliver not only teaching support, but therapies as well. Emerging research has reported that compared to parents of typically developing children, parents of children with autism have experienced increased anxiety and depression during the COVID-19 pandemic (Wang et al., 2021; Willner et al., 2020).

Well before the COVID-19 pandemic began, decades of studies have found that parents of children with autism and other developmental disabilities (DDs) experience higher levels of parenting stress compared to typically developing children or children with other special needs (Gupta, 2007; Padden & James, 2017). Furthermore, studies have identified racial and ethnic differences in parenting stress among parents of children with autism and other DDs (Dababnah et al., 2021; DeLambo et al., 2011). In addition, there are significant racial, linguistic, and socioeconomic disparities in the quality of and access to care (Mandell et al., 2009; Smith et al., 2020), which complicate parents' efforts to navigate complex healthcare systems to address multiple child developmental and behavioral difficulties. For example, children with autism with immigrant parents received later diagnostic evaluations, as well as fewer hours of services, compared to children with nonimmigrant parents (St. Amant et al., 2018; Valicenti-McDermott et al., 2012).

Asian Americans are the fastest growing racial group in the US, making up about 6% of the population (US Census Bureau, 2019). Researchers project a 101% increase in the Asian American population from 2016 to 2060 (Vespa et al., 2020). The six largest Asian American ethnic groups include Chinese, Filipinos, Indians, Japanese, Koreans and Vietnamese (Hoeffel et al., 2012). While the Japanese population is decreasing, the Bangladeshi, Bhutanese, Burmese, Mongolian, Nepalese, Pakistani, and Singaporean communities in the US are growing (Budiman et al., 2019). Accordingly, along with the rise in autism and other DDs generally (17.8%), the number of Asian Americans raising children with DDs have also increased (Rice et al., 2010).

Despite the increase in the Asian population in the US, research and practice have largely excluded Asian American families of children with autism and other DDs. For example, national statistics on Asian Americans with DDs are often aggregated with other racial groups, rather than having a separate category (e.g., see Zablotzky et al., 2017). A recent scoping review of research focused on East Asian Americans of children with autism found that parents had limited knowledge about autism

and expressed shame and self-blame about their child's diagnosis (Kim et al., 2020). The review identified only a small body of mostly qualitative studies concentrated in large urban areas, which suggests a need for research that examines Asian Americans' experiences accessing and using child DD supports.

Research focusing on Asian Americans raising children with autism and other DDs is even more urgent during the COVID-19 pandemic. The spike in discrimination and hate crimes against Asian Americans has been widely reported (e.g., see Lee & Waters, 2021; Pew Research Center, 2020). Thus, along with the increased burden on parents of children with DDs overall, Asian American parents raising children with autism and other DDs might face additional stressors. Given the contextual risks that Asian American parents of children with DDs may experience due to the intersection of race, ethnicity, and DDs, the purpose of study is to understand the effects of the COVID-19 pandemic on Asian American parents of children with autism and other DDs.

Methods

Procedures

This study received ethics approval from the University of Maryland Baltimore Institutional Review Board. The research was part of a larger project exploring the experiences of Asian American caregivers of children with DDs in Maryland, which we describe in detail in a separate article. Maryland is an ethnically and racially diverse US state, with an Asian population slightly higher than the national average (6.7% in Maryland versus 5.9% nationally; US Census Bureau, 2019). The largest Asian ethnic groups in Maryland are Chinese, Filipino, Indian, Vietnamese, Korean, and Japanese. Yet, consistent with the limited studies on Asian Americans with DDs nationally, we could not identify research conducted in Maryland focused on this growing population.

We developed our survey in collaboration with a national advisory board of DD experts and two Asian American parents of children with DDs. Once we finalized the English-language survey, we professionally translated the survey into Mandarin, Korean, Japanese, and Vietnamese. Native speakers of these languages then reviewed the translated surveys and compared them to the English versions. In May 2020, we modified the survey to include additional questions focusing on the impact of the COVID-19 pandemic on participants and their children.

Recruitment

Participants in the study met the following inclusion criteria: (1) primary caregiver of a child with a DD (aged 0–18) living in Maryland; and (2) self-identified Asian or Asian American. We employed three strategies to distribute study information, which targeted (1) local agencies or organizations providing services or information to individuals with DDs and/or their families; (2) public schools; and (3) Asian

American-specific service organizations, religious institutions, language schools and other related groups with large Asian American members. In addition, we created a Facebook page to distribute study information online. Before the COVID-19 pandemic in the US, we intended to hold multiple in-person events to recruit survey respondents. After March 2020, we were limited to remote recruitment and data collection. While we offered to mail surveys to those who wished to participate using a paper version, only three parents requested hard copies, and two returned them.

Measure

The entire original survey contained 78 questions and took approximately one hour to complete. We added five questions to assess the impact of COVID-19 related to household employment, child service use, unexpected benefits from the pandemic, and concerns of discrimination. Two questions had multiple choices, from which respondents could choose one primary response. These questions stated: (1) How has the COVID-19 pandemic in the community affected your job or the job of someone in your household? (2) Are there unexpected benefits to the COVID-19 pandemic for you and your household? A third COVID-related item asked parents to indicate which needed child services were discontinued due to the pandemic. A fourth item questioned if parents had arranged alternative services for their children, asking “Do you have any alternative services for those that you stopped due to COVID-19? If so, please specify which ones, and your satisfaction with these services.” Finally, the survey included an open-ended question, “Are you worried about your child/children with DDs and how others may treat them because of the COVID-19 outbreak?” We note that some parents also included COVID-related responses in an open-ended question originally in the survey, which asked, “What do you and your child need (for example: information, financial support, child care, family leisure time, and so on)?”.

Data Collection

Participants completed the online survey containing the COVID-19-related questions between May and July 2020. The survey was available in five languages (English, Mandarin, Korean, Japanese and Vietnamese). We collected data through Qualtrics, a secure survey portal. We provided a hard copy survey upon participants’ request. We did not collect any identifying information. Participants received \$20 to complete the survey. The survey directed online survey participants to a separate Qualtrics survey to provide their email or mailing address for the \$20 compensation, in order to maintain separation between the data and any identifiable information.

Data Analysis

We conducted all quantitative data analyses using STATA version 14. We analyzed the COVID-19-related quantitative questions using descriptive statistics. We used a thematic analysis to explore the open-ended responses in NVIVO 12. We sought to

identify any themes based on parent or child characteristics, including child's DD diagnosis, child's age, child's insurance status, parent's relationship to the child, parent's ethnicity, number of years parent has lived in the US, and parent's educational level.

Results

Participants

Twenty-five parents responded to the survey with the COVID-19 questions (see Table 1). Most of these respondents were female (88%) and born outside of the US (64%). For those born outside the US, they reported living in the US for nearly two decades on average (ranging from 5 to 40 years; $SD=9.6$). The majority of parents were Chinese (52%), although Korean (20%), Japanese (12%), Indian (8%), and Vietnamese (3%) parents also participated. While the majority of the participants (72%) responded to the English-language survey, seven participants (28%) chose to complete the survey in either Korean, Mandarin, or Japanese. Most participants (68%) rated their English proficiency as “very good” (68%) or “good” (20%), while 12% participants reported that they were “not good at all” in English. The sample was overwhelmingly highly educated (72% reported they had graduate degrees) and had high household incomes (over half had incomes greater than \$100,000).

Parents reported on their children, nearly all whom were born on the US (96%). Their children were mostly male (68%) and ranged in age from 2 to 16 years old (average of 8 years; $SD=3.7$). Over half of the children had autism (52%); parents also reported their children had developmental delays (32%), Attention Deficit Hyperactivity Disorder (32%), Down syndrome (16%), intellectual disability (12%), and cerebral palsy (4%). Common child co-occurring conditions included anxiety (32%) and gastrointestinal issues (24%). Nearly all of the children had some type of healthcare insurance, including 64% with employer- or union-provided coverage and 20% with Medicaid.

Household Impact and Unexpected Benefits

The most common primary impact on their household employment was the shift to working from home (64%; see Table 2). A smaller percentage reported job loss (12%) or reduced work hours (4%). One-fifth of the respondents said there had been no impact. Parents also identified unexpected benefits to the COVID-19 pandemic, the most common being more family time (48%). Others reported the ability to give children more frequent breaks (12%), less stressful morning and evening routines (8%), absence of school pressures (4%), and more completed chores (4%). Nearly one in four parents reported no benefits. We did not find a clear relationship between household impact and unexpected benefits.

Table 1 Child and Parent Characteristics ($N=25$)

Child Characteristic	N (%)
Born in the US	24 (96.0)
Gender	
Male	17 (68.0)
Female	8 (32.0)
Age (in years)	8 (ranging from 2–16, SD=3.7)
Child Diagnosis*	
Autism	13 (52.0)
ADHD	8 (32.0)
Cerebral Palsy	1 (4.0)
Developmental Delay	8 (32.0)
Down Syndrome	4 (16.0)
Intellectual Disability	3 (12.0)
Co-occurring Condition*	
Anxiety	8 (32.0)
Depression	2 (8.0)
Gastrointestinal symptoms	6 (24.0)
Hearing impairment	3 (12.0)
Sleep problems	4 (16.0)
Vision impairment	5 (20.0)
Child Insurance Coverage*	
Through an employer or union	16 (64.0)
Medicaid	5 (20.0)
Directly from an insurance company	3 (12.0)
Maryland Health Connection	3 (12.0)
Military healthcare	1 (4.0)
No insurance	1 (4.0)
Parent Characteristic	N (%)
Born in the US	9 (36.0)
Years living in the US if born outside the US	19 (ranging from 5–40, SD=9.6)
Relationship to the Child	
Mother	22 (88.0)
Father	3 (12.0)
Age (in years)	41 (ranging from 32–50, SD=5.4)
Parent Ethnicity	
Chinese	13 (52.0)
Korean	5 (20.0)
Indian	2 (8.0)
Japanese	3 (12.0)
Vietnamese	2 (3.0)
Education Level	
Associate Degree	1 (4.0)
Undergraduate Degree	6 (24.0)
Graduate Degree	18 (72.0)

Table 1 (continued)

Household Income	
\$0–24,999	2 (8.0)
\$25,000–49,999	1 (4.0)
\$50,000–74,999	5 (20.0)
\$75,000–99,999	6 (24.0)
\$100,000–149,999	5 (20.0)
\$150,000 and over	6 (24.0)
Self-Rated English Proficiency	
Not good at all	3 (12.0)
Good	5 (20.0)
Very good	17 (68.0)
Survey Language	
English	18 (72.0)
Korean	3 (12.0)
Mandarin	3 (12.0)
Japanese	1 (4.0)

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

Disrupted and Alternative Services

Approximately one in three parents who reported their children needed recreational activities reported these activities ceased due to the COVID-19 pandemic (see Table 3). Between 7–18% of the respondents also reported their children's needed dental care, social skills training, counseling, applied behavioral analysis, speech-language therapy, special education, physical therapy, respite care, and occupational

Table 2 COVID-19 Impact on Household ($N=25$)

	N (%)
Primary change in household employment	
No change	5 (20.0)
Someone in household who generally has a job outside the home is now working from home	16 (64.0)
Someone in household has lost their job	3 (12.0)
Someone in household has fewer work hours than before	1 (4.0)
Primary unexpected benefit	
No benefits	6 (24.0)
More time with family	12 (48.0)
Ability to give children more frequent breaks	3 (12.0)
Less stressful morning and evening routines	2 (8.0)
Absence of school pressure	1 (4.0)
Completion of chores	1 (4.0)
Absence of social pressures	0 (0.0)

Table 3 COVID-19 Impact on Child Service Use ($N=25$)

Service	Stopped Due to COVID-19; N (%)
Recreational Activities	6 (35.3)
Dental Care	2 (18.2)
Social Skills Training	2 (15.4)
Counseling	2 (15.4)
Applied Behavioral Analysis	2 (14.3)
Speech-Language Therapy	3 (15.0)
Physical Therapy	1 (11.1)
Special Education	2 (10.5)
Respite Care	1 (10.0)
Occupational Therapy	1 (6.7)
Assistive Technology	0
Case Management	0
Neurology	0
Nutrition	0
Residential	0

Note. The denominator of each percentage varies, as we calculated over the number of parents who reported their child needed the service

therapy were discontinued. No parents reported necessary assistive technology, case management, neurology, nutrition, or residential services stopped due to the pandemic.

Nearly half of the parents ($n=12$; 48%) reported they had not been able to receive alternative services for those cancelled due to the pandemic, which parents listed as including applied behavior analysis, recreational activities, and speech-language therapies. Of those parents who reported their child had received alternative services ($n=13$; 52%), including social skills training, and speech-language, occupational, and physical therapies, their satisfaction varied. Two parents expressed satisfaction with online speech-language and physical therapies. Others reported dissatisfaction with telehealth in comparison to face-to-face services in general, or about speech-language therapy in particular.

Pandemic-Related Concerns

Along with an open-ended question to write any remaining child or family needs, or other issues the participants wanted to share, after the pandemic began we specifically asked if parents had any concerns related to the treatment of their children due to the COVID-19 outbreak. Two parents, both raising children with autism, talked about their worries related to increased discrimination against Asians and Asian Americans during the COVID-19 pandemic. One father of a 14-year old mentioned concerns about “increased irrational fears,” and a mother of a 10-year old said:

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.

Other participants said they were not worried about how their child would be treated because their children were at home, rather than in school or in the community. For example, one father of an 8-year old child with Down syndrome said, “No [concerns], my children had essentially no contact with other people during the COVID-19.” One mother of an 11-year old child with autism expressed hopefulness, saying, “I am afraid not much. The world is just simply a mirror of yourself. If I do not think in this way, then the world around us will be like that. Maybe I am too optimistic.” Finally, in response to the question about the treatment of their children, some parents, mostly those raising young children ranging from 2 to 5 years old, said they did not have any pandemic-related concerns.

The majority of parents’ COVID-19-related worries were associated with their child’s education due to school closures, disrupted therapies, and cancelled activities. One mother of a 12-year-old child with Down syndrome summarized, “I am not worried about how others treat my child due to the pandemic. I am concerned that my child is missing out of the activities that give him the opportunities to stay physically active, improve his social skills, and learn.” Others focused on the drop-off of educational skills, as a mother of a 9-year old child with Down syndrome said, “We need our son to continue building basic academic skills so he doesn’t fall too far behind during virtual learning this fall.” Some parents commented specifically on the discontinuation of therapies and recreational activities. One mother of a 9-year-old child with autism mentioned only her child’s summer and extracurricular activities (e.g., swimming), but not therapies, were cancelled. However, several other parents noted their child was not receiving therapies during the pandemic. Parents requested more one-on-one, in-person, and home-based support from therapists and other professionals, as well as “access to more activities that we can do to help our child in the absence of a therapist.” Parents also had concerns about the lack of social interaction, as one mother of an 8-year-old child with autism explained her child’s “social skills are getting harder to keep during this stay at home time.” Notably, all of the parents who described concerns regarding regression in social skills were raising school-age children with autism. A couple of parents described health-related concerns due to “weak lungs” or “weak immunity.” Finally, one parent had financial concerns related to the pandemic, saying “Prices are rising sharply now, we have to reduce expenditure in order to get through the difficult time.”

Discussion

This study expands on the limited research on Asian American children with autism and other DDs, uniquely capturing the experiences and sentiments of their parents during the tumultuous period of the emergence of COVID-19 in the US, which resulted in school closures and the simultaneous increase in reports of racial discrimination. While nearly all of the children were born in the US, the majority of the parents in the sample were immigrants. Although most of the

parents held advanced academic degrees, immigrant families with children with special health care needs such as autism and other DDs frequently benefit from additional support services to navigate complex medical and education systems and access community resources (Linton et al., 2019).

Over 60% of the respondents endorsed the shift to telework as the main impact on the household employment, which may be a reflection of the educational attainment and nature of the occupations of the parents in this sample. Fewer parents reported job loss or reduction in work hours. In contrast, the pandemic has had a disproportionate impact on low-wage, hourly workers, many of whom do not have the ability to work from home (Kinder & Ross, 2020). We thus recommend that providers inquire about access to services and basic needs as some families may need assistance in connecting with the appropriate resources needed to mitigate the health and economic challenges brought about by the pandemic (Patrick et al., 2020).

The majority of the respondents cited unexpected benefits from the pandemic, with over half endorsing increased family time. However, a quarter of the parents did not note any benefits from the pandemic. This may relate to hardships experienced by some families such as health and economic stressors, as well as possible learning or behavioral challenges in their child that may have heightened during this period. Yet, despite the hardships experienced by families during the pandemic, one parent conveyed hopefulness and optimism in an open-ended response. This positive outlook, along with those who reported unexpected benefits from the pandemic, may serve as markers of resilience, a trait which has been associated with immigrants (Linton et al., 2019) and has been found to decrease caregiver burden in caring for a child with a disability (Alsharaydeh et al., 2019).

In our study, the parents primarily endorsed concerns related to school and clinic closures, including disrupted therapies and social activities. The most common service the children stopped receiving during the pandemic were recreational activities, although some reported the cessation of other essential services such as dental care, social skills training, and counseling. Yet, nearly half of the respondents were unable to arrange alternative services for those that were halted due to the pandemic. Other research has documented that COVID-19 has resulted in significant disruption of therapy services for children with autism, which has led to increased behavioral challenges and parental stress (White et al., 2021).

Among the parents who had arranged alternative services, satisfaction was mixed. As some children may struggle to engage in virtual sessions, some parents expressed a desire for resumption of in-person therapies. On the other hand, some respondents were concerned about potential COVID-19 exposure for their child and other family members, with one parent noting concerns about "weak immunity," and thus were more inclined to pursue remote services. Clinicians should consider providing both remote and in-person service options when feasible. Furthermore, given that parents of children with autism in our study shared worries about child regression in social skills, there is clearly much work needed to mitigate some of the impacts on children and families as children return to school and in-person therapies.

Despite the well-documented incidents of hate crimes and other discrimination against Asian Americans in the wake of the COVID-19 pandemic, and continuing

today, few parents noted discrimination as a primary concern. This finding could be related in part to many parents working from home, which along with their children being out of school, contributed to reduced community exposure to discrimination. Few parent concerns related to the pandemic in general could be due to child age as well, as young children's interactions with others could be limited mostly to family members and childcare providers. Yet, as states begin to ease restrictions and more children transition back to in-person classes and childcare, it will be important for providers to also inquire about the parent's and child's emotional well-being. These inquiries should include questions about experiences of discrimination during the pandemic, as research has found discrimination is associated with poorer mental and physical health in Asians (Lee & Waters, 2021).

Limitations

The findings of this brief report should be contextualized within its limitations. First, the small sample was composed primarily of highly educated mothers in Maryland. The sample size also did not allow for rigorous analyses to differentiate findings based on a variety of likely relevant factors, such as child diagnosis, age, and ethnicity. One potential reason for our small, highly educated sample were our recruitment methods, which due to the COVID-19 pandemic, relied solely on remote outreach and online data collection. Low-income populations are less likely to have internet access (Pew Research Council, 2021), which limited individuals' ability to receive the recruitment flyer and access our survey. While we offered to mail paper surveys, only three parents post-pandemic requested a hard copy. However, pre-pandemic, we successfully recruited more socioeconomically diverse parents during our one in-person event. Thus, we suggest researchers offer an array of opportunities for individuals to participate, including both in-person and online options.

We collected the COVID-19-related data during a three-month period shortly following the initial pandemic lockdowns in March 2020. It is likely that the concerns parents expressed in this study have only intensified during the extended period of school closures, job losses, and other pandemic-related impacts on children, parents, and communities.

Implications and Conclusion

Clearly, we need much more research to understand the needs of a rapidly growing Asian American population in the US. While we did not find clear themes based on child and parent characteristics, except those related to child diagnosis and age, we urge future research with larger samples to explore potential differences within the ethnically diverse Asian American population. This study offers only a brief snapshot of Asian Americans' experiences raising children with autism and other DDs in the immediate aftermath of the COVID-19-related lockdowns and closures in the US. Despite the high socioeconomic status of the sample overall, parents expressed challenges related to the cessation of DD-related

services, including limited satisfaction with telehealth or the ability to arrange alternative services. Our sample was not large enough to compare differences by socioeconomic status or other demographic characteristics. Yet, it is likely that for parents with additional burdens related to inflexible job schedules, low wages, language barriers, or other factors associated with low socioeconomic status, the concerns parents described in this study would be magnified. Thus, along with coordinated efforts among schools, healthcare providers and social services to support the needs of children with DDs (Aishworiya & Kang, 2020), it is critical for service providers to also remain cognizant of the unique challenges faced by Asian Americans during this time. Likewise, it is equally important to be attuned to their strengths, so that providers can better build upon families' resilience.

The COVID-19 pandemic has laid bare many fault lines in our country's willingness to come together to address racial, ethnic, and socioeconomic disparities and injustices. For children with autism and other DDs in racial and ethnic minority families, the dual challenges to combat racism and access appropriate services are even more daunting. Thus, as autism and DD providers begin to improve telehealth and other services in the aftermath of the pandemic, we hope that the field also takes the opportunity to create services that are more responsive to an increasingly culturally diverse population of children and families.

Funding This study was supported by grants from the Maryland Developmental Disabilities Council and the University of Maryland School of Social Work (PI: Dababnah).

Declarations

Ethics Approval This study was approved by the University of Maryland Baltimore Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to Participate Before beginning the online survey, participants were provided with information outlining their rights as a participant in this study. In order to participate in the anonymous survey, participants were required to check a box that they understood their rights and consented to participate. For those who completed paper copies of the survey, we obtained verbal consent.

Consent for Publication We did not collect identifiable information from human subjects in this study and thus have not reported any identifying information in the manuscript.

Conflicts of Interest The authors have no relevant financial or non-financial interests to disclose.

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