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# PARENTAL STRESS IN ASIAN AMERICAN AND NON-ASIAN AMERICAN FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES DURING COVID-19

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## SUBMITTED TO SCRIPPS COLLEGE IN PARTIAL FULFILLMENT OF THE DEGREE OF BACHELOR OF ARTS

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#### **Abstract**

Past research has found higher levels of parental stress in Asian American families of children with developmental disabilities as compared to their non-Asian counterparts. This study examined whether this trend remains in the setting of the COVID-19 global pandemic, as well as considering the relationships between parental stress and COVID-19 stressors, the experience of discrimination during the pandemic, the type and severity of developmental disability, and child age. This study used a sequential explanatory mixed methods approach to quantitatively measure parental stress in 48 Asian American and 62 non-Asian American parents, and qualitatively collect data regarding the specific personal experiences of a subset of these families during the COVID-19 pandemic. As expected, the Asian American parents demonstrated higher levels of parental stress than the non-Asian American parents, and all parents perceived the COVID-19 pandemic as a stressful experience that has significantly impacted both themselves and their children with developmental disabilities. This research has important implications for supporting and advocating for Asian American and non-Asian American families of children with developmental disabilities in times of crisis.

# Parental Stress in Asian American and Non-Asian American Families of Children with Developmental Disabilities During COVID-19

"The most humbling experience in life." "Having my heart outside my body." A life turned upside down instantly." "Exhausting sacrifice which brings innumerable blessings." These were some of the responses that parents provided when asked by a blogger to describe parenting in six words (Pacheco, 2013). Though short, these statements perfectly demonstrate the complexities of parenthood. While being a parent can be extremely rewarding and fulfilling, parenthood is more often than not accompanied by stress.

In addition to reducing general parental well-being, parental stress can have a multitude of negative consequences on child development. As Bronfenbrenner's ecological systems theory suggests, family dynamics are one of many factors that can influence the development of a child (1994). For example, parents who have high stress levels are often less affectionate and responsive with their children than parents with lower stress levels and are more likely to engage in domineering parenting practices (McLoyd, 1990). High parental stress levels are also correlated with problematic internalizing and externalizing behaviors (Liu & Wang, 2015) and difficulties empathizing or understanding the perspectives of others (Guajardo et al., 2008) in children. Critically, the inverse is also true—just as parental stress can harm both parents and children, treating parental stress can help both parents and children. Interventions designed to target parental stress have been shown to augment the effects of therapy for children. For example, children receiving therapy for antisocial and aggressive behavior experienced greater therapeutic change when their parents additionally completed a parent problem-solving intervention (Kazdin & Whitley, 2003). Evidently, parental stress is important to address, for the sake of both parent and child outcomes.

Many factors can influence levels of parental stress, such as having a child with special needs, the family's culture, or living during a global pandemic. This study examined parental stress of parents of children with developmental disabilities during the COVID-19 pandemic, as well as compared how these parental stress levels differ in Asian American and non-Asian American parents. A sequential explanatory mixed methods design was used, in which the initial quantitative survey phase explored the statistical relationships between parental stress, COVID-19 stressors, discrimination, ethnicity, and developmental disability. The following qualitative multiple case study phase expanded on the data from the quantitative phase and provided detailed descriptions of a subset of these parents' specific personal experiences.

#### **Developmental Disabilities and Parental Stress**

To understand parental stress in parents of children with developmental disabilities, it is crucial to first define the term "developmental disabilities." In the United States, approximately 17% of children aged 3-17 have at least one developmental disability (Zablotsky et al., 2019). These developmental disabilities include: attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy, hearing loss, intellectual disability, learning disability, and vision impairment (Centers for Disease Control and Prevention, 2019). Rates of these developmental disabilities vary by factors such as gender, ethnicity, and region, but the overall rate of developmental disabilities in the U.S. has been increasing over the years (Zablotsky et al., 2019). As such, the task of learning about and addressing the needs of children with developmental disabilities is ever more pressing.

Parenting a child with a developmental disability comes with its own set of special challenges. Parents of children with developmental disabilities often have to deal with extremely high care demands, activity constraints, employment limitations, and increased financial

difficulties (Kuo et al., 2011; McCann et al., 2012). Perhaps unsurprisingly, parents of children with developmental disabilities generally experience higher levels of parental stress than parents of neurotypical children (children without developmental disabilities), regardless of socioeconomic status (Dyson, 1991; Dyson, 1997; Gupta, 2007). Research has also shown that parental stress tends to be higher in families of children with developmental disabilities such as ADHD, ASD, cerebral palsy, and mental retardation than in families of children with chronic medical conditions such as asthma or HIV-infection, mainly due to the low reinforcement and high behavioral problems that are often associated with developmental disabilities (Gupta, 2007).

Furthermore, parental stress levels of parents of children with developmental disabilities can look very different depending on a variety of factors. For example, the specific developmental disability and special needs patterns of a child can influence levels of parental stress (Gupta, 2007; Holroyd & McArthur, 1976; Spratt et al., 2007). Gupta (2007) found that parental stress in relation to child misbehavior tends to be higher for parents of children with ADHD than parents of children with other developmental disabilities, such as ASD, cerebral palsy and mental retardation. This is likely because children with ADHD often demonstrate high distractibility, low adaptability, and demanding behavior (Gupta, 2007). Holroyd and McArthur's (1976) research showed that mothers of children with ASD experience more stress than mothers of children with Down's syndrome. This is likely because children with ASD engage in more disruptive behaviors than children with Down's syndrome; hyperactive, repetitive, and fearful behaviors are common among children with ASD (Ngashangva & Dutt, 2015). Further emphasizing the role of child behavioral issues in determining parental stress, having a child with both behavioral difficulties and cognitive impairments, or only behavioral difficulties, is correlated with higher levels of parental stress than having a child with only

cognitive impairments (Spratt et al., 2007). As ADHD and ASD are often associated with challenging behaviors (Gupta, 2007; Ngashangya & Dutt, 2015), it would make sense that these specific conditions are better predictors of parental stress than other developmental disabilities. Additionally, children with more severe intellectual disabilities engage in more problem behaviors—such as temper tantrums, violence, or self- injurious behaviors—than children with borderline, mild, or moderate intellectual disabilities (Ngashangva & Dutt, 2015). It would likely follow that disability severity is correlated with parental stress.

Parent and family characteristics also play a role in these parental stress levels. For example, family conflict, marital strain, and ineffective parental coping strategies can compound parental stress in families of children with developmental disabilities (Biswas et al., 2015; Jones & Passey, 2005; Kersch et al., 2006). Parent age influences parental stress as well (Baxter et al., 2000; Ha et al., 2008; Konstantareas & Homatidis, 1989; Nereo et al., 2003). That is, younger parents of children with learning disabilities have struggled more with child adjustment problems and experienced greater parental stress than parents who were over 40 years old, likely due to a lower level of confidence in their parenting abilities (Konstantareas & Homatidis, 1989). Correspondingly, older parents of disabled children experience less parental stress and mental health problems than younger parents of disabled children (Ha et al., 2008). Longitudinal studies have found that parental stress of parents of children with special needs decreases as children get older, likely due to increased parental experience, greater child independence, and fewer child behavioral issues over the years (Baxter et al., 2000; Nereo et al., 2003). These demographic factors seem to augment parental stress in families of children with developmental disabilities; however, research should also consider the influence of cultural factors that pertain to parenting.

Culture and ethnicity can impact parental stress levels of parents of children with developmental disabilities. While most of the research regarding parental stress of parents of children with developmental disabilities focuses on White parents, some researchers have examined these patterns in other cultures. Pruchno et al. (1997) compared African American and White mothers of children with chronic disabilities, analyzing the mothers' age, education, income, living arrangements, physical health, caregiving burden, and satisfaction. They found that race did not actually predict caregiving burden or satisfaction; instead, sociocultural, interpersonal, situational, temporal, and personal contexts were responsible for differences in caregiving burden and satisfaction (Pruchno et al., 1997). Meanwhile, other research has examined the differences between Hispanic parents and non-Hispanic White parents with a family member with mental retardation, using surveys and interviews to explore cultural differences in family characteristics, religious values, support resources, and caregiver burden (Heller et al., 1994). Hispanic parents reported having high religiosity and believing that it was their religious duty to care for the family member with mental retardation. Consequently, they actually reported being less burdened by having a family member with mental retardation than the White parents (Heller et al., 1994).

DeLambo et al. (2010) have also endeavored to compare the parental stress levels of Asian American and non-Asian American (White, Black, Latino, and Native American) parents of children with developmental disabilities, also taking the ages of children and parents into account. They found that while both the Asian and non-Asian American parents experienced high and comparable levels of parental stress, the Asian American parents experienced higher parental stress in relation to their child's characteristics of developmental disability, primarily due to frustrations with their child's inability to adapt. Additionally, child age was only

associated with parental stress for the non-Asian American parents. While having an older child was correlated with lower parental stress for the non-Asian American parents, as previous studies have also found (Baxter et al., 2000; Nereo et al., 2003), this effect was not found for the Asian American parents (DeLambo et al., 2010). DeLambo et al. noted that this finding could possibly be attributed to Asian American parents' tendency to be actively involved throughout their children's lives due to the collectivist nature of many Asian cultures, as opposed to parents in other cultures that train their children to be independent and consequently might experience a decrease in stress as their child grows older. In light of these heightened parental stress levels among Asian American parents of children with developmental disabilities, it seems that research examining this population is particularly vital. Yet even ten years later, DeLambo et al.'s research remains the only study to focus on parental stress levels in this particular group. Clearly, there is a need for additional research that further explores developmental disabilities and parental stress in the Asian American community.

#### The Asian American Community, Developmental Disabilities, and Parental Stress

The Asian American community refers to individuals in the U.S. who descend from any of the over 20 countries in East, Southeast, and South Asia. Currently, the cultures that make up most of the Asian American population in the U.S. are Chinese, Indian, Filipino, Vietnamese, Korean, and Japanese American (López et al., 2017). It is incredibly important to understand that the label "Asian American" applies to an extremely diverse group of people with varying experiences, beliefs, and values; therefore, research about the "Asian American community" does not necessarily generalize to every Asian American person.

Despite their status as the fastest growing ethnic group in the U.S. (López et al., 2017), Asian Americans are underrepresented in research about developmental disabilities and parental stress. This is in part due to the fact that Asian Americans have the lowest rates of disabilities of all ethnic groups in the U.S, with only 6.4% of Asian Americans having at least one severe disability, although this might be partially due to underreporting (Waldman & Perlman, 2015). Yet, as demonstrated in the finding that Asian American parents experience higher levels of parental stress due to the behaviors and characteristics of their children with developmental disabilities than other cultural groups (DeLambo et al., 2010), it is extremely important to address parental stress and developmental disabilities within this diverse ethnic community.

Several reasons can potentially explain why Asian American parents experience such high parental stress regarding developmental disability. Within the Asian American community, there are many different negative cultural stigmas and religious beliefs around disabilities that can foster feelings of shame and prevent families of children with developmental disabilities from receiving the help they need (Baker et al., 2010; Chiang & Hadadian, 2007; Gabel & Taylor, 2004; Jegatheesan et al., 2010; Saetermoe et al., 2001; Wynaden et al., 2005; Yan et al., 2017). Indeed, Asian American adults are more likely than African, European, and Latinx American adults to stigmatize disability (Saetermoe et al., 2001). In the Hmong and Mien Southeast Asian American communities, there is a cultural belief that a child's developmental disability can be the result of a mistake made by a parent or ancestor (Baker et al., 2010). The idea of karma as a cause of disability is also seen in Indian Hindu communities (Gabel & Taylor, 2004). Similarly, karma and ancestral curses are often believed to be the causes of developmental disabilities in Chinese cultures (Chiang & Hadadian, 2007). According to Confucian beliefs, parents are responsible for training their children, so having a child with a developmental disability could be seen as a failure of the parent (Ho, 1986). Shame associated with dissimilarity may be particularly salient in Asian cultures that center the importance of family honor and

social conformity (Yan et al., 2017). Meanwhile, South Asian Muslim parents of children with ASD often take offense to being told their child has autism by experts and try to raise their children as normally as possible, in accordance with Islamic doctrine (Jegatheesan et al., 2010). Because of these various cultural beliefs regarding developmental disability, there is a fear that the stigma surrounding developmental disability will be placed on the family. Given the importance of conformity due to the collectivist quality of many Asian cultures (Fung et al., 2018), this experience can be especially stressful for Asian American families. Therefore, desires to conform and preferences for "normality" contextualize the degree to which Asian American parents of children with such disabilities are stressed.

In addition to cultural stigma and religious beliefs in the Asian American community, parental ethnotheories can help explain why having a child with a developmental disability can be such a stressful experience for Asian American parents. Developed by Harkness and Super (1996), the concept of "parental ethnotheories" refers to the ways in which culture informs parenting and beliefs about how a child should behave. If the way the "ideal child" in Asian cultures acts is especially incongruous with the way a child with a developmental disability might act, it would make sense that Asian American parents might experience higher stress levels. In many Asian American cultures, children are expected to be obedient and respect their elders, a concept sometimes referred to as filial piety (Ho, 1986; Shek & Chan, 1999). Asian American parents are more likely to agree that emotions should be suppressed than White parents (Butler et al., 2007), and Chinese American parents have been found to highly value parental control (Lin & Fu, 1990). Asian Americans also tend to value group harmony more than other ethnic groups, which can translate to a stronger desire for a harmonious and conflict-free family (Fung et al., 2018).

Affect preferences in parenting may also influence experiences of distress for parents of children with disabilities. Whereas other cultural groups tend to most value high-arousal positive affect such as expressions of excitement, Asian Americans tend to most value low-arousal positive affect such as calmness (Tsai et al., 2006). Tsai et al.'s research compared actual and ideal affect in Asian Americans and European Americans by having participants respond to a list of different affective states with a rating of how much they would like to feel it and how much they actually feel it. They found that ideal and actual affect were not strongly correlated, meaning that the affective states individuals experience do not necessarily reflect their affect preferences. However, controlling for actual affect, European American participants valued high-arousal positive affect more than the Asian American participants. Similarly, the Asian American participants valued low-arousal positive affect more than the European American participants (Tsai et al., 2006).

This affect preference could suggest that Asian Americans have a greater desire for calm children. Because children with developmental disabilities have more trouble with emotional regulation and social functioning (Ashburner et al., 2010; Maedgen & Carlson, 2010), it is often more difficult for them to conform to the culturally valued behaviors of child obedience, filial piety, emotion suppression, cooperation, and calmness. Consequently, Asian American parents of children with developmental disabilities might experience such high parental stress because the common behaviors of children with developmental disabilities are more incongruous with their culture's ethnotheories of how a child should behave than, for example, Italian or Mexican ethnotheories of how a child should behave. Asian Americans have also been found to consider negative affect and the negative aspects of a situation more than European Americans (Wirtz et al., 2009). Similarly, they are less likely to perceive and portray their children in a positive light

(Miller et al., 1996). These tendencies could also possibly lead to higher stress levels; however, researchers have yet to explore parental ethnotheories as correlates of parental stress, especially in the context of a global pandemic.

Another possible contributor to the high parental stress levels of Asian American parents of children with developmental disabilities are barriers to psychological support. There is a severe underutilization of mental health services by the Asian American community (Abe-Kim et al., 2007), meaning that Asian American parents might be less likely to join a support group for parents of children with special needs or seek professional help to reduce their stress. Wynaden et al. (2005) examined the various factors that affect Asian American's access to mental health care by interviewing Asian American community members, community leaders, and health-care professionals. They found that, in addition to the cultural stigma around disabilities, there is also a stigma around general help-seeking and mental health issues in many Asian cultures. Language barriers, the cultural belief that people should suppress emotions and avoid discussing personal issues outside of the family, and the scarcity of culturally-specific services can also prevent stressed Asian Americans from receiving help (Wynaden et al., 2005).

Alongside these barriers, the issues and needs of the Asian American community are often obscured by their model minority status. The term "model minority" refers to a demographic group whose members are commonly perceived as having few problems and being more socioeconomically successful than the general population (Chaudhary et al., 2012). This myth can hide the struggles of Asian American parents and their children with special needs, leading to limited societal awareness and resources that address this issue. Additionally, research has shown that Asian Americans who more highly endorse positive model minority stereotypes about Asian Americans hold more negative attitudes toward help seeking and show higher

psychological distress (Ho & Jackson, 2001). Therefore, the model minority myth can contribute to stress while simultaneously preventing parents from seeking help to reduce it.

However, there are many differences in parental stress in families of children with developmental disabilities within the Asian American community itself. As previously mentioned, the Asian American community is extremely diverse and therefore the various cultural stigmas and religious beliefs about disability, parental ethnotheories, and help-seeking behaviors described above do not necessarily apply to all Asian American parents. For example, more acculturated Asian Americans are less likely to engage in authoritarian parenting practices and more likely to experience greater psychological well-being than less acculturated Asian American parents (Yu et al., 2016). Similarly, Asian Americans who were born in the U.S. are less likely to stigmatize disability than Asian-born Asian Americans (Saetermoe, 2001). Another study interviewed first-generation Asian American parents of children with disabilities in San Francisco and found that, unlike many of the Asian American parents in previous studies, these parents readily sought outside support and did not believe their child's disability was due to past wrongdoings or bad karma (Nguyen & Hughes, 2013). Additionally, while there are several similarities between the many Asian subcultures, the already limited body of research regarding Asian American parental stress and attitudes toward disabilities overwhelmingly focuses on East Asian families and consequently cannot necessarily be generalized to all Asian American communities.

Therefore, it is important to keep in mind that factors such as acculturation level, location, time, and ethnic subgroup can influence parental stress levels in families of children with developmental disabilities within the Asian American community. Still, the previously discussed cultural stigmas, parental ethnotheories, affect preferences, barriers to psychological

support, and model minority status can help explain why the parental stress levels of these Asian American families as a group might be especially high.

#### Parental Stress and Developmental Disabilities During COVID-19

Past research has shown that the parental stress levels of parents of children with special needs have been compounded during times of national stress and trauma, such as Hurricane Katrina (Rath et al., 2007). A similar trend could have occurred during the current coronavirus pandemic. COVID-19 has caused numerous stressful changes to people's daily lives, such as the shift to working from home, temporary or permanent unemployment, home-schooling, lack of physical contact with relatives and friends, and uncertainty and fear about a dangerous virus (World Health Organization, 2020). A recent study using the COVID-19 Stress Scale found a 28% surge in anxiety and a 22% surge in depressive symptoms among a general population sample from the U.S. and Canada (Taylor et al., 2020b). Researchers have even identified a "COVID stress syndrome" that certain particularly fearful individuals have developed in response to the virus (Taylor et al., 2020a). Given this increased stress in the general population, it is probable that parents have also experienced rising stress levels.

COVID-19 has led to increased parental stress and even potential for child abuse, especially in parents who receive financial assistance or have high anxiety/depressive symptoms (Brown et al., 2020). Parental burnout has also increased during the pandemic (Griffith, 2020). These increases are likely due to changes in routine for both parents and children, the stresses of home-schooling and working at home, fears about COVID-19, and physical and social isolation for both parents and children (Imran et al., 2020). Parents also have less access to social support, an important protective factor for parental stress (Respler-Herman et al., 2012). If such changes have been recorded in parents of neurotypical children, it is highly likely that parents of children

with developmental disabilities are experiencing even greater challenges and stress. The school closures are especially harmful for children with special needs, as they are not receiving the same level of support from schools, might not be able to receive in-person therapy or attend social skill groups, and are especially affected by the disruption in routine, which many children with ASD highly value (Lee, 2020). The stresses of homeschooling are likely augmented for parents of children with developmental disabilities, as these children tend to require more supervision and assistance.

No previous research has specifically examined parental stress of Asian American families of children with developmental disabilities during the coronavirus pandemic, but it is likely that these parents have experienced COVID-19 differently than their non-Asian American counterparts. On one hand, it is possible that certain COVID-19-related stressors might not have as significant of an impact on Asian American families due to cultural tendencies toward collectivism rather than individualism (Fung et al., 2018). It is possible that because many Asian American parents are more used to being highly involved in their children's lives and do not desire independent children as strongly as parents in individualist cultures (Fung et al., 2018), they would experience less distress about having to spend more time and effort caring for their children due to school closures. Certain, though not all, Asian American ethnic subgroups also tend to be more highly educated and socioeconomically successful than the general population (Pew Research Center, 2013), which could mitigate the overall effects of COVID-19-related layoffs and unemployment in this group. According to the Centers for Disease Control and Prevention (2020), COVID cases and hospitalization rates are slightly higher for Asian Americans than White Americans, but lower than Native Americans, Black Americans, and Latinx Americans.

Conversely, Asian Americans might be more vulnerable to the effects of the pandemic in other respects. Some Asian Americans (especially Chinese/East Asian Americans) have experienced COVID-19-related racism and discrimination during the pandemic due to people thinking that they are infected with or responsible for the virus (Le et al., 2020; Yang et al., 2020). There is a well-supported link between racial discrimination and worse mental health, both in general (Vines et al., 2017) and within the Asian American community specifically (Gee et al., 2009). It is therefore likely that anti-Asian COVID-19-related discrimination has affected many Asian Americans' psychological well-being during the pandemic. In addition, concern about future COVID-19-related stigma and discrimination could possibly lead to additional anxiety about post-pandemic situations such as reentering the job market, returning to school, and increased public social interactions (Misra et al., 2020). In these ways, COVID-19-related discrimination can reduce general mental health and well-being, which can render Asian American parents and children even more vulnerable to the negative effects of the pandemic and potentially lead to higher levels of stress.

In addition to COVID-19-related discrimination, there are a few other factors that might differentially affect Asian Americans during the pandemic. For example, COVID-19-related challenges such as working at home and homeschooling have been found to be even more taxing in crowded households (Cluver et al., 2020). As Asian Americans are more likely to live in more crowded households and multigenerational homes (Pew Research Center, 2013), it is possible that they are especially burdened by the pandemic. Furthermore, the response of the U.S. government and much of the American population to COVID-19 can be described as fairly individualistic, with many people refusing to participate in collective prevention measures such as social distancing or wearing a mask (Bazzi et al., 2020; Bian et al., 2020). Due to the

collectivist nature of many Asian cultures, Asian Americans might find this response especially frustrating. Lastly, if, as DeLambo et al. (2010) suggest, Asian Americans' higher levels of parental stress in families of children with developmental disabilities is primarily due to parents' frustrations regarding their child's issues with adapting to environmental changes, then these frustrations might be heightened during a pandemic where adaptability is demanded. Overall, while these speculations can be made, much more must be learned about the parental stress levels of Asian American and non-Asian American parents of children with developmental disabilities during COVID-19.

#### **Present Research**

Given the lack of research pertinent to parental stress during the COVID-19 pandemic for parents of children with developmental disabilities, the purpose of this research was to learn about COVID-19 parental stress levels and compare the experiences of Asian American and non-Asian American parents. Brofenbrenner's ecological systems theory, which posits that a variety of factors work at different structural levels and interact with each other to determine the unique ecological environment and experiences of an individual (1994), can help demonstrate the importance of the interactions between culture, developmental disability, and COVID-19 in relation to parental stress. The hierarchy of contexts in the ecological systems theory, from the most immediately related to the individual to the most removed, are: the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem. If the individual at the center is a parent, the microsystem might include features of their child, such as having a child with a developmental disability. The macrosystem includes overarching patterns in which the parent lives, such as the family's cultural context. The chronosystem includes changes to the parent's environment, such as the many changes to daily life that the COVID-19 pandemic has

caused. Together, these qualities of the microsystem, macrosystem, and chronosystem interact and create the context in which the parent lives. In other words, the factors of having a child with a developmental disability, living in an Asian American culture context, and experiencing COVID-19-related changes can work together and influence the specific level of parental stress that a parent experiences.

Consistent with the general increase in parental stress during the COVID-19 pandemic (Brown et al., 2020) and higher parental stress levels in families of children with developmental disabilities compared to families of neurotypical children (Dyson, 1991; Dyson, 1997; Gupta, 2007), it was expected that most parents of children with developmental disabilities are experiencing high levels of parental stress. The present research addressed and explored this issue by measuring parental stress levels in Asian American parents of children with developmental disabilities, as well as their non-Asian counterparts, during the COVID-19 pandemic. A sequential explanatory mixed methods approach (summarized in Figure 1) was especially salient to capture the statistical relationships between parental stress and COVID-19 as well as the cultural nuance of parental stress during the pandemic. This means that, in addition to the quantitative measure of parental stress, a subset of the parents was also interviewed about their specific personal experiences. The decision to use a mixed methods design was driven by the researcher's epistemological worldview, pragmatism, which emphasizes empirical humility and using multiple methods to address research questions. However, as other mixed methods researchers have also done (Creswell & Clark, 2018), alternative worldviews helped inform analyses at different points in the current research. Specifically, a postpositivist perspective was used when analyzing the quantitative data from Phase 1, while a constructivist lens was used to interpret the qualitative data from Phase 2.

The initial quantitative phase of the research examined the relationships between parental stress, experience of discrimination, child age, stress change since the pandemic happened, developmental disability severity, developmental disability type, and ethnicity. In light of the extant literature (DeLambo et al., 2010; Gee et al., 2009; Gupta, 2007; Holroyd & McArthur, 1976; Misra et al., 2020; Ngashangva & Dutt, 2015; Spratt et al., 2007; Taylor et al., 2020b; Vines et al., 2017), the following hypotheses were tested in this quantitative phase:

- Parents will report that their stress has increased since the COVID-19 pandemic happened.
- For Asian American and non-Asian American parents, a greater exposure to COVID-19-related stressors will be positively correlated with parental stress levels.
- Asian American parents and non-Asian American parents will not have significantly different COVID-19-related stressors.
- Asian American parents will demonstrate, on average, more experiences of discrimination than non-Asian American parents.
- Experience of discrimination will be positively correlated with parental stress.
- Child age will be negatively correlated with parental stress such that parents with younger children will report increased levels of parental stress.
- Parental stress will vary by the severity and type of developmental disability the child has. ADHD and ASD will more positively predict parental stress than other types of developmental disabilities. Severe disabilities will more positively predict parental stress than mild or moderate disabilities.

 Asian American parents will show higher levels of parental stress than non-Asian American parents.

Following the quantitative phase, a qualitative multiple case study phase of equivalent status was driven by the following research question: how have Asian American and non-Asian American parents of children with developmental disabilities experienced the COVID-19 pandemic, and how can these parents be supported in the future? Using a semi-structured interview approach, this phase facilitated a more in-depth look at a few parents' personal experiences during the pandemic and helped identify specific areas of need or potential resources to support families of children with developmental disabilities during a global pandemic.

#### Method

#### Phase 1

#### **Participants**

The participants in this study were Asian American and non-Asian American parents of children aged 18 or under with developmental disabilities. Past research comparing parental stress levels in Asian American and non-Asian American parents of children with developmental disabilities found a moderate effect size (DeLambo et al., 2010); therefore, I expected to identify moderate effects in the statistical analyses for the current study. Consequently, according to Cohen (1992), an appropriate sample size for a desired power of 0.80 with a of 0.05 and a multiple regression model with seven variables would be 102 participants. Therefore, the sample for the current study (N = 110; Asian American parents: n = 48, non-Asian American parents: n = 62) was sufficient for the analyses to be conducted. Only one parent per family was able to participate, and they were required to speak English to complete the survey. Participants with multiple children with a developmental disability could participate but were asked to provide

information about only one of their children. Participants, who self-selected int the study, were conveniently sampled via recruitment through various organizations, Facebook groups, school district mailing lists, and support groups for parents of children with special needs. Additionally, the Asian American parents were recruited from organizations that specifically cater to Asian American families of children with special needs. Participants were offered \$15 an hour as compensation for participating, enough for one hour of babysitting.

Of the 48 Asian American parents, participants identified as Indian American (n = 16), Korean American (n = 9), Filipino American (n = 8), Chinese American (n = 6), Japanese American (n = 5), Taiwanese American (n = 2), and multi-ethnic (n = 2). Almost all these parents were born in another country. Only 5 of the Asian American parents included here were fathers; the other 43 were mothers. Parents' ages ranged from 33 to 61 (M = 43.15, SD = 6.93), and their children's ages ranged from 3 to 18 (M = 9.48, SD = 4.22). Their children's diagnoses included ASD (25, 52.08%), a combination of multiple developmental disabilities (15, 31.25%), ADHD (2, 4.17%), intellectual disability (1, 2.08%), learning disability (1, 2.08%) or a disability not listed in the survey (4, 8.33%), such as "speech impediment." Though many of these parents had children with multiple disabilities, 36 had a child with ASD, 3 had a child with ADHD, 1 had a child with both ASD and ADHD, and 8 had a child with neither of these conditions.

Of the 62 non-Asian American parents, participants identified as White or European American (n = 39), Latinx or Latina/o American (n = 12), Black or African American (n = 7), multiracial (n = 2), or "other" (n = 2). In this sample, there were 12 fathers and 49 mothers. These parents' ages ranged from 27 to 61 (M = 41.11, SD = 7.42), and their children's ages ranged from 2 to 18 (M = 9.90, SD = 4.51). Their children's diagnoses included a combination of multiple developmental disabilities (27, 43.55%), ASD (13, 20.97%), learning disability (11,

17.74%), ADHD (3, 4.84%), intellectual disability (3, 4.84%), cerebral palsy (2, 3.23%), or a disability not listed in the survey (3, 4.84%). Of these parents, 19 had a child with ASD, 11 had a child with ADHD, 12 had a child with both ASD and ADHD, and 20 had a child with neither.

#### Materials

This study took the form of an online survey that assessed parents' parental stress levels, experience of discrimination during COVID-19, stress change since the COVID-19 pandemic happened, COVID-19 stressors, ethnicity, their child's age, and the severity and type of developmental disability their child has.

Demographics. Participants selected their ethnicity ("Latinx or Latina/o American", "White or European American", "Black or African American", Asian or Asian American", "Native Hawaiian or Pacific Islander", "Native American", "Multiracial", or "Other"). They also typed in their specific country/countries of descent and the country they were born in. Lastly, they indicated their highest level of education completed, their age and gender, their relationship status and partner's gender, the number of children they have, and the age and gender of their child with a developmental disability.

**Parental Stress.** Parents completed a parental stress scale with 22 items. Half of these items were taken from the Parental Stress Scale developed by Berry and Jones (1995). Berry and Jones' original scale includes 18 items that assess parents' perceptions and feelings about parenting and addresses both positive and negative themes of parenthood. It demonstrated satisfactory internal reliability (Cronbach's  $\alpha = .83$ ) and reliability over time (test-retest correlation = .81). Research analyzing major parenting stress measures found that the Parental Stress Scale has good construct validity, as determined by its correlations with a number of related constructs, such as family functioning or parental loneliness, and ability to differentiate

between parents of juvenile offender and non-offender children (Holly et al., 2019). It has also demonstrated excellent content validity and validity generalization, as well as adequate treatment sensitivity (Holly et al., 2019). To keep the parental stress measure used in the current study relatively brief and prevent participant fatigue, only 11 of the 18 items on the Parental Stress Scale were used here.

In addition to the 11 items from the Parental Stress Scale, the 21-item scale used in this study also included 11 items from the 3rd Edition Parenting Stress Index developed by Abidin (1995). The Parenting Stress Index is broken into two sections—one assesses parental stress in relation to characteristics of the parent, while the other assesses parental stress in relation to characteristics of the child. To gain insight into parental stress in relation to child characteristics, the 11 items used in the current measure were taken from the "child domain" section. This child domain of the Parenting Stress Index includes items relating to six areas of child characteristics: hyperactivity, adaptability, reinforcement of the parent, demandingness, mood, and acceptability; the 11 Parenting Stress Index items used in the current parental stress measure represent all of these sections. The child domain of the Parenting Stress Index has been found to have excellent internal reliability (Cronbach's  $\alpha = .91-.93$ ) and construct validity, as determined by its associations with related parent and child social, emotional, and health outcomes and its demonstrated ability to differentiate between mothers of children with and without ASD (Holly et al., 2019). The Parenting Stress Index is also credited with excellent content validity, validity generalization, and treatment sensitivity (Holly et al., 2019). Furthermore, there is a positive correlation between scores on the Parenting Stress Index and the Parental Stress Scale (Pontoppidan et al., 2018).

Overall, the 11 items from the Parental Stress Scale (Berry & Jones, 1995) and the 11 items from the Parenting Stress Index (Abidin, 1995) that formed the current scale were expected to provide a comprehensive measure of participants' parental stress by assessing both general perceptions of parenting and parenting stress in relation to child characteristics. In the current study, this scale was found to have a good internal consistency (Cronbach's α of .83). Some examples of items that parents responded to in the current 22-item scale are: "The behavior of my child is often embarrassing or stressful to me.", "I enjoy spending time with my child.", and "It seems my child is a little different from what I expected, which bothers me sometimes." Parents were asked to indicate the extent to which they agree with each item using a 5-point scale (1- "strongly disagree", 5- "strongly agree"). The full parental stress measure is included in Appendix A. Each parent's responses to the 22 items were compiled to create a single numerical parental stress score.

Experience of Discrimination during COVID-19. Participants completed Yang et al.'s adapted version of the 5-item Everyday Discrimination Scale to measure discrimination against Asian Americans during COVID-19 (2020). Yang et al. found that this scale had a good internal consistency (Cronbach's  $\alpha$  = .93). This scale was primarily based on the 5-item shortened Everyday Discrimination Scale (Sternthal et al., 2011), which asks participants to rate how often they have experienced five types of discrimination in their everyday life. This original 5-item shortened Everyday Discrimination Scale (Cronbach's  $\alpha$  = .77) uses the items "You are treated with less courtesy/respect than other people", "You receive poorer service than others at restaurants or stores", "People act as if they are afraid of you", "You are threatened or harassed", and "People act as if they think you are not smart" (Sternthal et al., 2011). However, to better reflect anti-Asian bias during COVID-19, Yang et al. replaced the item "People act as if they

think you are not smart" with the item "People act as if you are dangerous" (2020). Participants were asked to think about their experiences during the pandemic and respond to the 5 items using a 5-point scale (1- "Never", 5- "A lot"). In the present study, this scale demonstrated a good internal consistency (Cronbach's  $\alpha = .88$ ). This scale can be found in Appendix B.

Stress Change Since Pandemic Happened. Participants were explicitly asked "how has your stress level changed from before the pandemic to during the pandemic?" Given the lack of pre-pandemic data regarding the stress levels of the parents in this sample, a direct comparison of stress levels before and after the pandemic was not possible. This question was written for the current study to measure parents' perceptions of if and how COVID-19 has affected their stress in a general manner. Though this measure was purely based on self-reports and did not assess participants' stress change comprehensively, it provided general insight on whether the pandemic has increased or decreased the stress of these parents as a group. Participants responded to this question using a 7-point scale (1-"decreased greatly", 7-"increased greatly").

COVID-19 Stressors. To assess exposure to COVID-19-related stressors, participants completed Park et al.'s newly developed COVID-19 Stressors measure (2020). Park et al.'s questionnaire contains a checklist of 23 COVID-19 stressors, such as "changes to daily work routine" or "risk of loved ones becoming infected." This list includes eight infection-related stressors, ten activity-related stressors, and five financial/resource-related stressors, based on previous work during SARS and the early months of COVID-19. Participants checked off which of these 23 COVID-19 stressors they have experienced in the last week. As the COVID-19 Stressors measure is relatively new and was developed during a pandemic, the authors did not provide psychometric information about this scale. However, this scale seems to have adequate construct validity, as demonstrated by its correlations with age, gender, financial strain, and

caregiver status (Park et al., 2020). Furthermore, in relation to the use of this scale in the current study, this measure demonstrated good internal reliability (Cronbach's  $\alpha$  = .83), as presented along with the rest of the data from Phase 1. The full COVID-19 Stressors scale is provided in Appendix C.

Child's Developmental Disability. Participants selected their child's specific developmental disability/disabilities from the following list: "attention deficit hyperactivity disorder (ADHD)", "autism spectrum disorder (ASD)", "cerebral palsy", "hearing loss", "intellectual disability", "learning disability", "vision impairment", or "other". If they selected "other", they had the option to write in their child's developmental disability/multiple disabilities. Lastly, they selected the approximate severity of their child's developmental disability ("mild", "moderate", or "severe").

#### Procedure

The participants completed an online survey. First participants gave their informed consent. Next, they completed the various measures described above in the following order: parental stress, experience of discrimination during COVID-19, stress change since the pandemic happened, COVID-19 stressors, the type and severity of their child's developmental disability, and demographics. Then they were asked to input their contact information if they were interested in participating in Phase 2 of the present research. Next, they completed a short task meant to cheer them up. Lastly, they were debriefed and provided with the link to a survey in which they could input their contact information for financial compensation.

#### Phase 2

Multiple-case study designs are a useful way to collect robust information about specific, shared experiences (Stake, 2006). To deepen the quantitative data from Study 1 regarding

parental stress and COVID-19 stressors, explore participants' specific personal experiences related to the COVID-19 pandemic, and learn how these families would like to be supported in the future, some of the parents from Phase 1 were also interviewed for this multiple-case study portion of the present research.

#### **Participants**

This study used a subset of the same participants from Phase 1. In accordance with Stake's (2006) recommendation that multiple case study research include 4 to 10 cases, 8 participants were interviewed. These participants were recruited at the end of the survey in Phase 1. Out of those who indicated that they are willing to participate in Study 2 and consented to having their de-identified data re-identified, the researcher purposefully selected eight participants that represented a variety of parental stress levels. In addition to increasing the diversity of experiences portrayed here, including both parents who are experiencing high levels of stress and parents who are experiencing low levels of stress provided more insight into the risk and protective factors related to parental stress during the pandemic. The researcher also selected the same number of Asian American and non-Asian American parents. Again, these participants were offered \$15 per hour as compensation.

Therefore, the final sample of eight consisted of two Asian American and two non-Asian American parents who were experiencing among the highest levels of parental stress, and two Asian American and two non-Asian American parents who were experiencing among the lowest levels of parental stress. Of these 8 parents, participants identified as White or European American (n = 3), Taiwanese American (n = 2), Indian American (n = 1), Filipino American (n = 1), and Latinx or Latina/o American (n = 1). All participants were mothers, and their ages ranged from 33 to 51 (M = 43.50, SD = 6.37). Their children's ages ranged from 3 to 18 (M = 12.13, SD)

= 5.72). Their children's diagnoses included ASD (4, 50%), a combination of multiple developmental disabilities (3, 37.50%), and learning disability (1, 12.50%).

#### **Materials**

The interviews were conducted in a semi-structured format. As such, participants were all asked the same open-ended questions but were also able to discuss any additional information or experiences not addressed by the questions. Participants were asked seven questions about parenting stress, their experiences during the COVID-19 pandemic, and resources they would like to see in the future for families of children with developmental disabilities. The exact questions are provided in Appendix D.

#### Procedure

The interviews were conducted over Zoom. Each interview started with confirming the participants' informed consent. Then the participant was asked the questions described above and had the chance to discuss their experiences. Interviews were audio-recorded and lasted between 14 and 48 minutes. At the end of the interview, the participant was debriefed and financially compensated. Subsequently, all recorded data were transcribed.

#### **Ethics**

Several ethical considerations were addressed in the methods of Phase 1 and Phase 2. While the participants of these studies were technically not a vulnerable population, as parents of children with developmental disabilities living through a global pandemic, it was especially important to avoid adding to their stress. Though these topics could come up in a parent's normal conversation, discussing parental stress, discrimination, and COVID-19-stressors could still be an unpleasant experience for participants. Several steps were taken to address this issue and protect participants. For one, participants were required to give their informed consent to

participate in the studies. Participants were reminded during the informed consent process that participation was completely voluntary and they could leave the survey or interview at any time, still receiving financial compensation. While participants were financially compensated, this amount was minimal in order to avoid financial coercion.

Additionally, participants were given a short task meant to cheer them up at the end of the online survey in Phase 1. This task asked participants to think about and list five things they are grateful for, as research has found a connection between gratitude exercises and well-being (Wood et al., 2010). Lastly, the participants were debriefed at the end of each study. This debriefing included an overall description of the study and several resources that participants can refer to for psychological help and stress-relief, including resources that were specific to parents of children with developmental disabilities. Though this study did not involve deception, the hypotheses of the study were not revealed to the participants until the debriefing process, to avoid researcher influence on responses.

Privacy was also important to address, particularly given the cultural importance of personal privacy in the Asian American community and the almost universal stigma around developmental disabilities (Wynaden et al., 2005). The survey and interview content asked for private participant information, such as the type of developmental disability their child has, their employment status during the pandemic, and the nature of their relationship with their child. To address privacy concerns relating to the survey, participants were assured during the informed consent process that their survey data will be anonymous. Participant names and IP addresses were not collected, and a separate survey was created in which participants could give their contact information for financial compensation, so this information was not tied to any survey responses. The exception to this anonymity was the parents who indicated at the end of the

survey for Phase 1 that they were interested in being interviewed for Phase 2. These participants were informed that if they checked yes and input their email address for future contact, they were consenting to having their de-identified data re-identified by the researcher. While these participants' data went from anonymous to confidential, this was necessary in order for the researcher to purposefully sample for Phase 2 and select participants that represented a diverse range of experiences.

Private information especially played a role in the interviews, since participants were discussing personal experiences. Additionally, the interview audio was recorded, with participant consent. Data collected from the interviews was confidential rather than anonymous, since the interviewer was able to see the participant. However, the Zoom room were locked during the interview to ensure that only the interviewer and interviewee had access to the room at that time. To protect participants' privacy, recordings were stored securely and only the researcher had access to them.

Overall, while this research did include potentially unpleasant activities that asked participants to think about stress, their child's struggles, discrimination, and COVID-19, several steps were taken to minimize the negative impact on participants. Furthermore, this study had several benefits that outweigh the potential risks to participants. For one, this study added to and supplemented the knowledge about parental stress in families of children with developmental disabilities. It specifically focused on the Asian American community and the impact of a global pandemic, both relatively understudied areas in this field. Secondly, this study's findings identified and demonstrated the struggles of parents of children with developmental disabilities. The interviews included asking participants what types of resources they would like to see in the future for families of children with developmental disabilities. Therefore, the information

collected from this study can be used to identify specific areas of need and advocate for resources for this community. As parental stress can have significant effects on the whole family (Guajardo et al., 2008; Liu & Wang, 2015; McLoyd, 1990), it is important to explore and address this topic to help parents like the participants in this study, and their families.

#### **Data Analysis**

The quantitative data from Phase 1 were analyzed using SPSS. First, the internal consistencies of the parental stress scale, COVID-19 stressors scale, and experience of discrimination scale were computed. Then, a one sample t-test was used to examine whether parents thought their stress level increased or decreased since the COVID-19 pandemic happened, and several independent sample t-tests were used to examine any mean differences between the Asian American and non-Asian American participants' reported stress change during the pandemic, COVID-19 stressors, and experience of discrimination.

A multiple regression model was used to examine developmental disorder type, developmental disorder severity, COVID-19 stressors, experience of discrimination during COVID-19, child age, and ethnicity as predictors of parental stress. The data of 7 of the 110 participants were excluded from this model, as they had listed having multiple children with developmental disability and there was no way to tell which child they had responded on behalf of. To use multiple regression, dichotomous and categorical variables such as ethnicity and developmental disorder type were dummy coded. As past research has seen higher parental stress in families of children with ASD and ADHD compared to other developmental disabilities (Gupta, 2007; Holroyd & McArthur, 1976; Ngashangva & Dutt, 2015), in this model the developmental disability variable was coded into four categories: those with ASD, those with ADHD, those with both ASD and ADHD, and those with neither of these conditions. The

multiple regression model was tested with interactions of ethnicity and age as well as ethnicity and discrimination, but as none of these interactions were significant, they were left out of the final model. Along with the regression model, several Pearson correlations were analyzed to look at the associations between parental stress and some of the predictors.

The qualitative data from Phase 2 were analyzed following Creswell's (2013) recommendation that a multiple case study include narrative descriptions of each case and Stake's (2006) guidelines for conducting a multiple case study using cross-analysis. Therefore, analysis of the data began with crafting narratives that depicted each of the eight participants' specific experiences during the pandemic. Next, for each participant's interview transcript, important statements relating to the experiences of parents of children with developmental disabilities were coded into succinct units of meaning. Cross-analysis of the cases then involved grouping these units of meaning with similar units of meaning from other participants' data, leading to the identification of several common themes across the cases. Through the presentation of both specific narrative descriptions and general emergent themes, a comprehensive picture of these parents' experiences was formed.

Finally, in addition to the use of the quantitative data in selecting the participants for the secondary qualitative phase, the quantitative data from Phase 1 and the qualitative data from Phase 2 are integrated in the discussion section. The qualitative data were used to support and expand on the statistical relationships identified in the quantitative data, as well as explain some of the unexpected findings from Phase 1.

#### **Results**

#### Phase 1

#### Preliminary Analyses

As expected, all parents self-reported a significant increase in stress since the pandemic happened (M = 5.83, SD = 1.07), t(109) = 17.85, p < .001. Also as predicted, there was no significant difference between this pandemic-related stress change in the Asian American parents (M = 5.90, SD = 1.17) and non-Asian American parents (M = 5.77, SD = 1.00), t(108) = .59, p = .59.558. Additional tests compared COVID-19 stressors and experience of discrimination during COVID-19 in the Asian American and non-Asian American groups. The COVID-19 stressors scale and experience of discrimination scale both demonstrated good internal reliability (Cronbach's  $\alpha$  of .83 and .88 respectively). As expected, the Asian American parents (M =11.21, SD = 4.75) and non-Asian Americans did not experience a significantly different number of COVID-19 stressors (M = 11.97, SD = 4.90), t(108) = .82, p = .416. Though the Asian American parents (M = 9.48, SD = 3.64) were expected to have experienced more discrimination than the non-Asian American parents (M = 9.34, SD = 4.36), there was no significant difference here either, t(108) = .18, p = .858. Even when the Asian American parents were compared solely to the White or European parents (M = 8.73, SD = 3.58), there was still no significant difference, t(86) = .98, p = .332. The parental stress scale also showed good internal consistency (Cronbach's  $\alpha$  of .83).

#### Multiple Regression Model

The results of the multiple regression model featuring parental stress can be seen in Table 1, along with relevant descriptive statistics and Pearson correlation results. Overall, the multiple regression model with all eight predictors was significant,  $R^2 = .38$ , F(8, 94) = 7.15, p < .001.

Child age was not correlated with parental stress (r = .08, p = .213); neither was it significant in the multiple regression model (b = .06, p = .795). Conversely, discrimination was both correlated with parental stress (r = .39, p < .001) and significant in the multiple regression model (b = 1.01, p < .001). Therefore, on average and controlling for all other variables, a discrimination score increase of 1 point is associated with a parental stress score increase of 1.01 points. The number of COVID-19 stressors parents experience was also expected to predict parental stress, but while COVID-19 stressors were correlated with parental stress scores (r = .23, p = .010), this was nonsignificant in the regression model (b = .25, p = .283). Unexpectedly, developmental disability severity was neither correlated with parental stress (r = .01, p = .461) nor significant in the regression model (b = .69, p = .685).

However, the type of developmental disability a child had was related to parental stress, as expected. Parents of children whose diagnosis included ASD had parental stress scores that were on average 6.70 points higher than those whose children had other developmental disabilities (b = 6.70, p = .010). Having a child with ADHD was associated with a parental stress score that was 9.25 points higher than other parents (b = 9.25, p = .012), and parents of children with both ASD and ADHD were likely to report parental stress scores that were 12.61 points higher than parents of children with neither of these conditions (b = 12.61 p = .001). Finally, as predicted, there was a difference between parental stress levels in the Asian American and non-Asian American participants. On average and controlling for all the above predictors, participants who identified as Asian American were likely to report a parental stress score that was 7.80 points higher than the non-Asian American participants (b = 7.80, p = .001).

Overall, analyses confirmed the following hypotheses: (a) participants would report that their stress has increased since the COVID-19 pandemic happened, (b) Asian American parents

and non-Asian American participants would not have significantly different COVID-19 stressors, (c) experience of discrimination would be positively correlated with parental stress, (d) ADHD and ASD would more positively predict parental stress than other types of developmental disabilities, and (e) Asian American participants would show higher levels of parental stress than non-Asian American participants. On the other hand, the following hypotheses were disconfirmed: (a) Asian American participants would demonstrate more experiences of discrimination than non-Asian American parents, (b) child age would be negatively correlated with parental stress, and (c) developmental disability severity would be positively correlated with parental stress. The hypothesis that a greater exposure to COVID-19 stressors would be positively correlated with parental stress levels was partially confirmed; while COVID-19 stressors were correlated with parental stress, it did not significantly predict parental stress when controlling for all other predictors in the multiple regression model.

#### Phase 2

The interviews conducted for this multiple-case study provided rich descriptions of parents' personal experiences during the COVID-19 pandemic. Thirty-three single-spaced pages of interview transcriptions were read in their entirety to identify significant statements related to the pandemic experiences of parents of children with developmental disabilities. These significant statements were then interpreted into 224 meaning units across the eight cases. Cases were analyzed separately and then cross-analyzed, to reveal five common themes regarding parents' pandemic-related experiences and stress emerged in the parents' responses: (a) Taking on Extra Roles, (b) Uncertainty and Changes to Routine, (c) Social Isolation, (d) Marginalization and Discrimination, and (e) Reliance on Interpersonal Support. To preserve participant's privacy,

pseudonyms are used below. These pseudonyms are also presented in Table 2, along with participants' demographic information and parental stress scores from Phase 1.

# Narrative Descriptions of Cases

Case 1: Sylvia. Sylvia is a Filipino American mother of a three-year-old with ASD, and she had a parental stress score of 58 in Phase 1. She explained that the pandemic has not affected her too much, since she is used to staying at home with her son. However, she believes her stress has increased due to new parental duties, such as helping her son with his virtual sessions: "although I'm used to being with him at home, like all of this virtual thing, it adds stress to me because I'm the one who will have to facilitate, especially with ABA."

She also described how the pandemic has greatly impacted her son, as he is no longer able to receive high quality ABA or follow his pre-pandemic routine. According to Sylvia, her son struggled with the changes in routine that the pandemic caused and has demonstrated an increase in certain behaviors, such as temper tantrums, due to "being just at home." Sylvia explained that these behaviors are often a source of stress for her, and in such instances, she usually tries to take a deep breath and let him finish his tantrum before talking to him. Another source of stress for Sylvia was the rise in anti-Asian violence and hate crimes during the pandemic, which has influenced her family's behavior ("that's why we don't go out").

Case 2: Manisha. Manisha is an Indian American mother of an 8-year-old with ASD who is nonverbal. She had a parental stress score of 72 in Phase 1. Manisha discussed how the pandemic has impacted her family, explaining that her son has missed out on months of school and therapies due to COVID-19. This was very difficult for her: "I was worried about my son getting all those things which he was used to and suddenly we were at home doing nothing and he used to cry." She was also concerned about how her son missed being active in nature, which

he had loved pre-pandemic. One challenge Manisha described was her son's difficulty with following the COVID-19 safety guidelines, including wearing a mask, washing hands, and social distancing. She explained that he "has no idea about" the pandemic, and "that's why we were not taking him out as much, because we knew he won't understand all those things." For Manisha, a big source of stress was understanding what her child's needs were ("because he can't talk, I have to like judge what he wants").

Manisha described several sources of relief for her stress, including the support of her friends and family. She especially appreciated having space for herself when her husband took their son out, as this gave her time to engage in her hobby of cooking. She further explained that one of the most helpful supports she had was that her son's school has been fully in-person ever since September 2020, as well as his therapy. Though she felt the school could have done a better job preparing for the pandemic and communicating with parents, ultimately having inperson school was a big source of relief for her.

Case 3: Helen. Helen is a European American mother of a 15-year-old with a learning disability. She demonstrated a parental stress score of 51. Helen shared that, for her, the pandemic has meant less freedom and more time interacting with her kids. She explained how, with all her kids at home, there is a sense of immediacy: "I feel like now just being at home all the time everyone expects you to just be available all the time. Cause what else would you be doing?" Conversely, she also found herself "nagging" her children more.

Helen expressed concern about how the pandemic has impacted her son. She explained that he had to start high school during the pandemic, which was especially challenging as he was transitioning from a private school specifically for children with dyslexia to a mainstream school. She also felt that her children were not learning much during the pandemic, and worried that they

would struggle when they eventually returned to in-person schooling, as this could be a sort of "culture shock" for them. However, though she was "crazy stressed" at the beginning of the pandemic, she feels more hopeful now. She deals with her stress through yoga, support from friends and parent groups, and keeping busy; in fact, she used her time during the pandemic to reinstate a professional license. One of the biggest sources of support she described was a local support group where parents can "bounce ideas of each other and help each other out."

Case 4: Angela. Angela is a European American mother of a 17-year-old with ASD, with a parental stress score of 51. She described how she experienced "bad, bad days" earlier on in the pandemic, but overall, her stress has improved with time. Although she did not consider parenting during the pandemic to be too distinct from parenting pre-pandemic, she mentioned that the key difference is that she is "present for a lot more of it."

Angela expressed several concerns related to her son's well-being during the pandemic. One of the most challenging issues she encountered during the pandemic was the decline in mental health that her son experienced. "When he couldn't go to school anymore, just a few months into it, he started showing signs of really bad anxiety." In addition to this anxiety, Angela also explained how her son developed an eating disorder during the pandemic. Though he was able to overcome this eating disorder after school started again and he received help from a therapist, getting help for him was not easy for her. This was exacerbated by the lack of mental health resources for children with disabilities; Angela explained that people often think mental health resources are for "normies," so she had to "fight to get the insurance to cover him going to a therapist." Therefore, in the future, she would like to see "more emphasis on mental health for children with developmental disabilities."

Case 5: Claire. Claire is a Taiwanese American parent who had demonstrated a parental stress score of 87 in Phase 1. She discussed her well-being and parenting experiences during the COVID-19 pandemic as a mother of a three-year-old with ASD. She recounted how her family had to make many adjustments to work from home, explaining that it "never felt like we had a very stable and organized environment." She also mentioned that the pandemic kept her out of the workforce, as she now has to take care of her child full-time: "I think women left the workforce in droves, and for someone who's looking for employment even before the pandemic, it just put that at a really bottom priority for me." To deal with her stress, Claire turns to several sources of support, including faith, therapy, and a massager. She also mentioned that during the pandemic she has allowed her son to have more screen time than usual, to give herself more free time to destress.

Claire further described how the pandemic specifically impacted her son. For example, he missed his graduation from preschool and faced challenges with remote learning, especially as the schools were not prepared for this. Claire lamented the lack of active outdoor time as well, noting that she bought her son an indoor jungle gym to "get his jumpies out." She was also concerned about her son being socially isolated; though she tried to "pod-up with another family," this didn't work out. One of the biggest sources of stress for Claire was the loss of ABA therapy during the pandemic due to a conflict where the company wanted to "come in-house sooner than we were comfortable with and...let us go all of a sudden." To help make up for this loss, she was able to get her son a therapist, whose services she considered very beneficial. She also explained that she does art with her child, which improves his mood and "repairs [our] relationship." Though her son had tried a few virtual support resources during the pandemic, Claire stresses the importance of in-person interactions and recommends that schools and

organizations try to address this need for children with special needs. She also expressed a desire for more outdoor opportunities and healthy meal kits that were targeted to families of children with special needs.

Case 6: Wen. Wen is a Taiwanese American mother of a 13-year-old with ASD and ADHD. She had a parental stress score of 81. She explained that the pandemic has significantly increased her workload and stress, as she is "on all the time." The biggest effect of the pandemic, for her, is that her "limited energy now has to spread throughout the whole day." The pandemic involves a lot of multitasking for her; for example, she described how she has to cook and sit with her son as he is in online school at the same time. She also explained that "instead of having a team of community with teachers, IAs [Instructional Assistants], and school therapists working with him, I'm the main person telling him 'oh, not to do this', 'oh you should do this'. So, there's the family dynamic of mother and son that becomes always mother telling him 'you should do this'." In addition to these issues, Wen worries that her son is now "afraid of interacting with people," especially as he did not enjoy his recent temporary return to in-person school.

Wen also discussed how the pandemic has prohibited her from seeking outlets for her stress. Although she used to receive preventative acupuncture and work on projects with friends, both supports ended when the pandemic started—she now has no "me time." She described access to support groups; however, she expressed that she is too busy to attend them.

Consequently, she suggested that services offer materials for kids so they can "do some learning on their own so the parent is not always with them."

Case 7: Sarah. Sarah is a European American mother of an 18-year-old with ASD and ADHD. In Phase 1, she reported a parental stress score of 66. For Sarah, the cancellation of her son's in-person ABA therapy and helping him manage his anxiety were big sources of stress. She

discussed the stress and anxiety her son has experienced during the pandemic, due to "uncertainty about what's open and not going to school in person and so much being on Zoom." She mentioned that she doesn't "think he understood why he couldn't be at school, and he thought he was sick at first because usually he would miss school because he was sick." According to Sarah, her son also required a lot of one-on-one help with his online curriculum, which was difficult.

Furthermore, one of the biggest challenges for Sarah was having to constantly advocate for her son's needs: "as a parent of a child with special needs we're used to always having to advocate, and I feel like the pandemic just added more things we have to advocate about." For example, she struggled with finding a COVID-19 vaccine appointment for her son. She suggested that schools and other resources try to reach out to the parents more, rather than parents having to always be the initiators. Sarah explained that, to deal with all this stress, her family goes on lots of walks and even got a dog during the pandemic. Additionally, she has been glad to see how excited her son is now that his school has resumed in-person part time.

Case 8: Eva. Eva is a Latina American mother who also demonstrated a parental stress score of 66. Her 17-year-old son has ASD and epilepsy. Though she was initially excited to be with her children all the time, Eva explained that the pandemic has been extremely stressful for her and involves a large amount of multitasking, especially as she started working part time. Furthermore, because her children are always with her, she finds it difficult to destress alone or effectively discuss issues in her virtual therapy. Eva explained that this makes it hard for her to hide her stress from her children, which can sometimes lead to a "domino effect" where her son with a disability "tends to get emotional or maybe even have a behavior or get aggressive when the energy in the house is stressful." Another challenge she encountered during the pandemic

was anxiety about health, specifically how the COVID-19 vaccine would impact her son with special needs. She also mentioned that it can be difficult to decide whether to discuss world events with her children.

Eva also discussed in detail how the pandemic has impacted her son. She explained that though he was patient, he struggled with not being able to go out to visit his favorite places. According to her, virtual school and navigating Zoom have been very difficult for her son; "he's present but he's not getting any learning done because he's in his own head or thinking about something else and verbally stimming." On top of this, she feels that schools were not prepared to educate in a pandemic situation, an issue that she noticed was much more pronounced in her son's special education class compared to her other children's classes. Eva talked about how the "individualized education plan is supposed to be super important by the law…but during COVID it's sort of gone by the wayside."

Due to these and other issues, she thinks that there should be "more awareness of what families are going through." She also thinks that the general public, as well as police officers and other first responders, should be more aware of how to interact with individuals with developmental disabilities: "we're afraid, what if a child has a behavior or doesn't answer a question and the police thinks it's a threat and does something...the pandemic really highlighted like how much we need to be more patient and not literally jump the gun and just assume that people are doing things for the wrong reasons."

# Cross-Case Analysis

Although the parent experiences presented in the cases above are all unique, several common patterns emerged across the eight cases. The cross-analysis of these cases allowed for

the identification of shared themes related to the experiences of parents of children with developmental disabilities during the COVID-19 pandemic.

Taking on Extra Roles. Across the cases, all participants discussed the extra roles they had to take on during the pandemic. Due to COVID-19 school and service closures, children with developmental disabilities were no longer able to receive in-person services. In the absence of these services, parents had to take on these additional roles. Sarah shared, "you have to be the ABA provider, the OT, the speech therapist, the aide to learn online, and so I feel like to some extent I had to take on a lot of additional roles...that I didn't necessarily want to do."

Sylvia talked about how when her child is receiving ABA virtually, she still has to be present to facilitate. Claire mentioned that she must sit with her son during his virtual lessons at school, pointing out that this can be an issue for "families with multiple kids—you [can't] really do that when everyone has a video Zoom call at the same time." Eva also discussed home schooling her child with special needs, which was particularly difficult as her days include simultaneously "managing two children at the same time while [she's] sitting in the middle of helping them to do distance learning." Helen, Manisha, and Angela mentioned that it can be difficult knowing how to support their child in these ways; Angela shared that she felt stressed because she has "two kids trying to go to school and one of them is going to a special ed school, neither of which, my husband or I, are qualified to teach." These extra roles can be especially difficult to take on as parents still have to conduct their normal duties. Wen describes this: "I have to sit with him and sometimes the work is hard for him and if we were in person, there would be an IA helping him, giving him hints and guiding him, but then that will fall onto me. And when he's out of school of course the food has to be ready so I'm trying to cook and go into school at the same time with him." Therefore, though these roles could sometimes vary for the

different parents, participants across the cases reported having to take on additional roles during the pandemic.

Uncertainty and Changes in Routine. In addition to discussing these extra roles, all eight participants mentioned how their children were affected by changes in routine during the pandemic. COVID-19 completely transformed these families' schedules, which was very challenging for the parents here. Angela said that for her son, "routines are safety and security," which is why he developed anxiety when deprived of his routine. Other parents (e.g., Eva, Sylvia) similarly described how their children were impacted by disruptions to routine. Eva discussed how her son "gets emotional if [they're] not doing some of the things he's used to doing and keeping his routine." Sylvia mentioned that "the beginning of the pandemic was difficult for [her son], like adjusting to his new routine because he's used to having all his therapists come to the house." Manisha, Wen, Claire, and Helen described how conditions were constantly changing during the pandemic, making any sort of routine difficult; as Helen said: "we were learning every day in the pandemic what we could do, how far we had to be apart, all that stuff." Sarah shared that her son experienced "a lot of stress and uncertainty, especially towards the beginning", which contributed to his anxiety.

As uncertainty and changes to routine affected their children so intensely, these changes in routine impacted these parents' stress. However, the data suggests that these changes influenced parents in different ways and to different extents. It is possible that some parents were able to handle pandemic-related changes more easily, evidenced by their lower levels of parental stress. For example, though changes in routine contributed to Angela's son's anxiety, Angela highlighted how her family has "gotten better at" dealing with the pandemic over time. Perhaps relatedly, she demonstrated one of the lowest parental stress scores in Phase 1. On the other

hand, Claire (who demonstrated one of the highest parental stress levels) emphasized how she believes her family has not been able to adapt to the pandemic in a "sustainable" way. Therefore, the specific level of stress parents experience as a result of changes in routine during COVID-19 seems to depend on a variety of factors, including how well families could adapt to such changes.

Staying at Home and Social Isolation. Social isolation during the pandemic also deeply affected these families, across all eight cases. As COVID-19 lockdowns mandated that families stay at home, many parents and children were unable to see friends or go outside much. Claire said about her son, "socially he's been isolated, I think everyone has." She talked about how her son's school "did a parade for his graduation, like a car parade, but it was really hard to see his classmates and not having to get out of the car and say bye." Helen speculated that for her kids, remote school was "more isolating", as they were just "home in the rooms doing the work." Wen noted that her son "didn't have really close friends due to autism, so he probably missed peers, and he definitely misses seeing teachers in person." She believed "social interaction is very important for him to see other people and know how to behave in the community," and expressed a desire for "a social group for the kids, so they are not feeling so isolated with their family." Manisha explained that her son also "missed out on social interactions...[they] were trying to meet with new friends, that has not been possible because of COVID." Angela said about her child: "he's very social. So just about all social activities closed down, his afterschool programs, the sports that he's involved with, all of that closed down, and his world basically became mom, dad, and brother. And no 17-year-old wants that, regardless of special needs."

Meanwhile, Sylvia saw that her son demonstrated an increase in tantrums because he was no longer able to "go out in the afternoon." Similarly, Sarah said that her son was "home a lot

more" which is why she thinks "there's stress and some of the behaviors." Eva's son also missed going out: "My child with special needs in particular, he really enjoys being outdoors and he's probably the most social of all my children. He likes going to amusement parks, movies, restaurants, and of course all those things are not available." All eight participants emphasized the importance of exercise and time outside, so it follows that a reduction in this would take its toll on these families. Evidently, having to stay at home impacted all these families, whether through increased social isolation or the loss of quality outside time.

Marginalization and Discrimination. All the participants discussed marginalization or discrimination, though the participants seemed to experience this in different ways. Claire, Sylvia, and Wen all expressed concern about the rise in anti-Asian sentiment during the COVID-19 pandemic and how this might affect their families. Though Claire, who is Taiwanese, noted that she had not experienced personally experienced any overt COVID-specific discrimination, she explained how current events worried her: "even if I didn't face [racism], hearing from my friends was disheartening enough. It has changed my behavior...sometimes I wear hats out when I'm walking the dog. My partner will come walk the dog, especially during Chinese New Year." The rise in anti-Asian sentiment also changed Sylvia's behavior. She mentioned that "little by little we're starting to go out, but we refused after all [that] Asian racism that happened."

On the other hand, Manisha discussed having to deal with strangers who did not understand that it was difficult for her son to follow the COVID-19 restrictions:

the problem is because he doesn't look autistic...people were telling him...'oh, you have to wear a mask,' so I used to be like 'oh, he's nonverbal, he doesn't understand'...I am trying to make him wear [a mask] but he can't wear it for the whole time. I have a doctor's exception letter, but I can't keep on showing it to everybody.

Eva explained that she also often worries about how her son will be perceived and the lack of understanding about developmental disabilities in the general public. Additionally, she felt that though her other children were receiving a quality virtual education, it was "a whole different story" for her child with a developmental disability. Alternatively, Helen described how her son has talked about being in "the dumb class" and feeling "looked down upon."

Sarah explained that, as a parent of a child with special needs, she often must advocate for her son. She recounted how her son possibly faced discrimination in relation to vaccine distribution: "I do feel like maybe with his disability, just accessing vaccines was tough...I also know it took a lot of advocacy at the state level to even prioritize that group." Angela also discussed having to advocate for her son, specifically when trying to access mental health resources. She described this experience: "something we come across a lot is well because...he isn't typically verbal like his brother and has a hard time putting emotions into words, I think the thought is 'you know, why bother with it; it isn't going to be helpful." Eva shared, "when I notice maybe [people with disabilities] are not being fully included I do raise my voice to say something, but as far as the pandemic and emergency, it's important for communities to be aware of who in their community has special needs and how to best help them." Though marginalization and discrimination clearly play very different roles in these participants' lives, it seems these ideas were applicable to all their experiences and were always considered stressful.

Reliance on Interpersonal Support. Lastly, across the cases, parents discussed the importance of interpersonal support in managing their stress. All eight participants mentioned receiving support from their partner. Claire explained that her "partner really had to take on some of the stress and duties of getting [her] son on his day-to-day schedule." Sylvia remarked, "if I cannot handle [my son] anymore, I have my husband deal with him." Manisha shared that she

and her husband take turns caring for their son: "my husband is very cooperative, so we take turns to take my kid out." Eva said that when she had an opportunity to work during the pandemic, "since [her] husband was home he supported [her]." Angela also expressed appreciation for having her partner at home during the pandemic: "my husband was around a lot more. So there is also more help in the house; we can take turns. So honestly that is a big silver lining."

Manisha, Helen, and Wen explained that they value the support of friends as well.

Manish shared that she has "a group of friends who understand, even if they don't have a special needs kid." Helen mentioned that she "talked to friends, socialized throughout the day" to deal with her stress. On the other hand, Wen missed the stress relief her friends provided prepandemic: "I used to be able to work on projects with my friends; I play music so I will meet up with them and we will put on concerts, but now that's all gone because of the pandemic."

Sylvia, Helen, and Sarah discussed the support they received from parent support groups. Sylvia valued "meetings with the parents,...sharing and talking with them" through her regional center's parent group. Helen appreciated talking about "real stuff" in her support group, and valued "being able to relate to other people, like parents of kids with special needs...[and] being able to bounce ideas off of each other, feel supported, or being heard or telling your story and being able to have other people listen." Therefore, whether it comes from a partner, friend, or formal group, interpersonal support seems to be an important protective factor in these parents' lives. These protective factors mitigate the stressful parenting experiences each identified.

## Discussion

The purpose of this mixed methods study was to examine parental stress in Asian

American and non-Asian American families of children with developmental disabilities during

the COVID- 19 pandemic. A sequential explanatory mixed methods design was used. The integration of quantitative data from Phase 1 and qualitative data from Phase 2 helped provide a comprehensive and detailed depiction of parental stress during the COVID-19 pandemic.

Analyses from the initial quantitative phase indicated that parents who experienced more discrimination, had a child with ASD, or had a child with ADHD were likely to report higher levels of parental stress. Further, the results demonstrated higher levels of parental stress in Asian American parents of children with developmental disorders than their non-Asian counterparts, which supports past research (DeLambo et al., 2010) and suggests that this trend remains in the specific setting of a global health crisis. Though the number of COVID-19 stressors participants experienced was positively correlated with parental stress, it was not significant in the multiple regression model; neither was child age or the severity of developmental disability. This suggests that other factors such as discrimination, type of developmental disability, and ethnicity were particularly salient and had more of an influence on the stress parents experienced during the pandemic.

The qualitative data helped support, expand on, and explain some of these findings from the quantitative phase. In Phase 1, participants self-reported a significant increase in stress since the pandemic happened. This was reflected in Phase 2, in which all the parents discussed how the pandemic forced them to "take on additional roles." The stress from having to deal with increased responsibilities was further exacerbated by the lack of "breaks," the social isolation their children encountered, the high level of uncertainty during the pandemic, and the marginalization and discrimination these families faced. Participants also described the unique ways their children with special needs were impacted by COVID-19-related school and service closures; for example, Eva mentioned that though her other children's remote educations were

"excellent," her son's virtual special education class was "substandard." Manisha, Eva, and Sarah also discussed struggling with getting their children to understand what COVID-19 was and why everyone was at home. Therefore, while Phase 1 demonstrated that many parents of children with special needs are especially stressed during the pandemic, Phase 2 allowed for the pinpointing of the specific causes of this increased stress.

The qualitative findings also suggest some factors that might protect against parental stress, besides those examined in Phase 1. Across the participants, interpersonal support was highly valued by the parents and helped them to manage with their stress. Furthermore, by purposefully sampling parents who had demonstrated among the highest and lowest parental stress levels to be interviewed in Phase 2, it was possible to see why certain parents might be more or less stressed. For example, Manisha (who had demonstrated a relatively lower parental stress score in Phase 1) talked about how she was "very happy with the school. They have consistently, continuously opened it." Some of the participants who had demonstrated higher parental stress scores expressed frustration with the way their children's schools handled the pandemic, suggesting that access to high quality in-person school might be a protective factor against parental stress during COVID-19. Additionally, Claire and Angela both expressed relief that their sons were in therapy, indicating that professional psychological support might also protect against parental stress.

Moreover, the qualitative results provided insight into why ASD and ADHD were associated with higher levels of parental stress in Phase 1 compared to other types of developmental disability. Almost all the participants in Phase 2 had a child with either ASD or ADHD, so their experiences help demonstrate why caring for children with these specific developmental disabilities might be particularly stressful during the pandemic. One of the

common themes that emerged across the cases was how the pandemic has caused changes to routines that their children have struggled to adapt to. Children with ASD tend to value routine (Lee, 2020), so it makes sense that the uncertainty of the pandemic would be especially difficult for them. Similarly, the mothers of children whose diagnoses include ADHD, Wen and Sarah, both discussed having to multitask and constantly attend to their children's needs. This is consistent with past research that has identified high distractibility and demanding behaviors in children with ADHD (Gupta, 2007). It would have been interesting to include more participants of children with other types of developmental disabilities in Phase 2, to understand what stress specifically looks like in these families.

Additionally, the qualitative data helped explain why there was no significant difference in the discrimination that Asian American and non-Asian Americans (or even solely White Americans) reported in Phase 1. In Phase 2, many participants discussed the marginalization or discrimination that they experienced as parents of children with developmental disability. For example, Eva and Manisha expressed concern about how the public perceived their children with disabilities. Sarah, Eva, and Angela shared how they often had to advocate on behalf of their children, since they were often excluded or barred from certain opportunities. Therefore, though the experience of discrimination measure had originally been included in the present study to examine whether the participants experienced discrimination based on race or ethnicity, it is possible that many of the participants in Phase 1 had experienced discrimination based on their child's developmental disability. This could explain why many of the White American participants did report moderate levels of discrimination in the quantitative phase, despite the historical lack of widespread racism against White individuals. Universally, individuals with developmental disabilities have faced marginalization (World Health Organization, 2011), so it

is likely that their families are also affected by this. Furthermore, the participants in Phase 2 described these experiences of marginalization and discrimination as taxing and stressful, which supports and strengthens the positive statistical relationship between discrimination and parental stress identified in Phase 1.

# **Implications**

Overall, the findings of this research suggest that parents of children with developmental disabilities have found the COVID-19 pandemic to be a very stressful time that has significantly impacted both themselves and their children. Therefore, the most crucial next step is to use the information collected in this research to develop effective and culturally relevant resources that address the specific needs of these families in both everyday life and in times of crisis, such as a global pandemic. This research has important implications for advocating for these families. The quantitative findings demonstrate that parental stress is a widespread issue and indicate that it is especially important to support Asian American parents of children with developmental disabilities, as they seem to experience the highest levels of parental stress. The quantitative findings also suggest that families of children with ASD and ADHD might need extra support, as parents in these families experienced higher parental stress than parents of children with other types of developmental disability.

While the quantitative data emphasizes the extent of these issues, the qualitative data then is especially helpful in determining how to support these parents. The themes that emerged in the qualitative data suggest that it would be extremely beneficial to address the marginalization that the special needs community faces, as well as help parents access respite and social support. As several parents talked about having to constantly advocate for their children, these parents would also like for services and schools to reach out to them more, instead of the other way around. The

qualitative phase also included explicitly asking parents what resources they would like to see in the future for families of children with developmental disabilities, and the parents came up with a variety of ideas. Claire, for example, wanted healthy meal kits targeted at families of children with special needs, as they often "also have special diets." She also wished there were more options for outdoor social activities for children with special needs, as well as outdoor in-person ABA therapy. Manisha wanted a reliable, easily accessible source of information about the state of the pandemic: "I know there are websites, but there are like n number of different websites and each shows the data as different as possible...I wanted to be more informed about [COVID-19]."

Sylvia and Helen expressed a desire for more support groups in which they could talk to other parents of children with special needs. On the other hand, Sarah wanted "fun things for families to do that isn't a support group or training." Wen wanted meaningful, educational activities for children with special needs, so they could "do some learning on their own so the parent is not always with them." She also wished she had access to a social group for her son. Alternatively, Eva explained that she would like to see more public education about developmental disability and increased media coverage about "how much [the pandemic] affects children with disabilities, which affects the family." Similarly, after dealing with her son's pandemic-related mental health challenges, Angela wished there was "more emphasis on mental health for children with developmental disability." Clearly, there are many ways schools and organizations for children with special needs can support these families.

## **Limitations and Future Directions**

Limitations of this research include that Phase 1 was conducted using an online survey.

Therefore, the researcher was unable to control participants' environments or ensure that

participants were responding truthfully and reading the survey instructions in their entirety. For example, seven parents had to be excluded from the multiple regression model in Phase 1 because they had included information about several of their children, and there was no way to tell which child their responses reflected. Though the survey instructions had specified that parents of multiple children with developmental disabilities should only respond on behalf of one of their children, this was only mentioned once in the beginning of the survey and therefore could have been clearer. If a similar study was conducted in the future, it would be beneficial to include a question that asks parents how many children with developmental disabilities they have.

Additionally, the participants in this study were recruited through organizations and groups for parents of children with special needs. Accordingly, many of the parents in this study were likely receiving some form of services or support and therefore might not have been experiencing parental stress as intensely as parents of children with developmental disabilities who did not have such resources. Correspondingly, this data set might have underestimated the extent of the struggles that families of children with developmental disabilities experienced during COVID-19. This might be especially relevant to the Asian American participants; most of the Asian American parents in this sample belonged to organizations or support groups for parents of children with special needs despite the stigmas around help seeking in many Asian cultures (Wynaden et al., 2005), which indicates that these parents might care less about cultural stigmas around developmental disability as well. Therefore, it is possible that the Asian American parents here had lower parental stress levels than would be demonstrated by Asian American parents who do not utilize these sorts of support resources. On the other hand, the fact

that, despite this, the Asian American parents in the present study still demonstrated higher levels of parental stress than the non-Asian Americans emphasizes the pervasiveness of this issue.

Similarly, it is also important to acknowledge when this research was conducted within the context of the COVID-19 pandemic. Data collection occurred from early March 2021 to mid-April 2021; around this time, COVID-19 cases in the U.S. were declining and anti-Asian violence and hate crimes were receiving more media coverage. Conditions during the pandemic were constantly changing, so it is possible that data collected earlier or later in the pandemic might have looked very different. For example, Angela, Manisha, and Helen all mentioned that their stress had decreased as they became accustomed to the pandemic lifestyle; Angela described this gradual decrease in stress: "it peaked probably around fall of 2020; there was just a tremendous amount of stress with school starting and with still not knowing when things were gonna get better. Basically, as we've come into the new year this stress has gone down steadily." Therefore, participants might have demonstrated higher parental stress levels if this study had been conducted in fall of 2020 or when the pandemic first began; again, the data here might underestimate levels of parental stress.

Another major limitation of this research was that it lumped all Asian American parents into one group and all non-Asian American parents into another group, rather than separating and comparing the many individual ethnic groups (e.g. Indian American versus Filipino America or Mexican American versus African American) within these broad labels. The limited sample size prevented the opportunity to examine group differences with more specificity. The non-Asian American sample included here was mostly comprised of White or European Americans, with absolutely no representation of Native Americans. Similarly, the Asian American sample was mostly comprised of East Asian and Indian Americans, with almost no Southeast Asians or

non-Indian South Asians. Therefore, the results of this study do not generalize to every "Asian American" or "non-Asian American" family. Regardless, it is notable that this research did center Asian American voices, which have often been excluded from or obscured in this sort of research.

Consequently, future research that surveys a large sample of parents from a variety of ethnic backgrounds and analyzes these cultural nuances would be extremely beneficial. Research that examines the parental stress levels of parents who do not utilize support resources for families of children with special needs could also increase generalizability. Additionally, the current research did not uncover much about how cultural attitudes toward developmental disabilities specifically influenced the Asian American participants' parental stress, perhaps because the research was conducted during a global pandemic, which was likely the most salient stressor in parents' lives at the time. Therefore, future research could address this aspect of parental stress to provide more insight into why Asian Americans experience higher levels of parental stress. Other potential future directions could include research that involves observing the interactions between Asian American children with developmental disabilities and their parents, as well as comparing these interactions with those of their non-Asian American counterparts. In a different direction, a study that explores the link between parental stress and child outcomes in Asian American families of children with developmental disabilities would also be useful. These studies could provide more insight as to what parental stress looks like in Asian American families.

## **Conclusion**

Though the body of research on families of children with developmental disabilities is growing, Asian Americans continue to be underrepresented in these endeavors. Given that the

meager existing research that does focus on this specific area suggests that Asian American parents of children with special needs face unique challenges and experience particularly high levels of stress, it is especially important to address this oversight. The quantitative data reported here show that Asian American parents of children with developmental disabilities experience significantly more parental stress than their non-Asian American counterparts. Moreover, the qualitative data unveils the specific contextual factors, like marginalization and discrimination related to race, that contributes to these parents' understandings of their own stress. To best aid and advocate for Asian American families of children with developmental disabilities, it is necessary to expand research in this area and gain a better understanding of these families' unique experiences.

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Table 1
Statistics, correlations, and results from the parental stress multiple regression analysis

Predictor	Mean	STD	Correlation with PS	b	SE	β	t	p
Child Age	9.70	4.36	08	06	.24	02	26	.795
Discrimination	9.42	4.14	.39***	1.01	.27	.35	3.77	<.001***
COVID-19 Stressors	11.55	3.79	.23*	.25	.23	.10	1.08	.283
Developmental Disability Severity	1.84	.61	.01	69	1.69	04	41	.685
ASD				6.70	2.56	.28	2.62	.010*
ADHD				9.25	3.61	.24	2.56	.012*
ASD and ADHD				12.61	3.70	.32	3.42	.001**
Asian American				7.80	2.24	.32	3.48	.001**

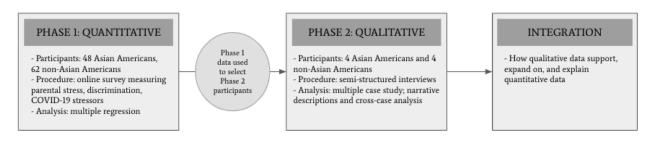
<sup>\*</sup>p < .05, \*\*p < .01, \*\*\*p < .001

 Table 2

 Pseudonyms and Demographic Information for Interview Participants

Pseudonym	Ethnicity	Parent Age	Child Age	Developmental Disability Type	Parental Stress Score (from Phase 1)
Sylvia	Filipino American	33	3	ASD	58
Manisha	Indian American	37	8	ASD	72
Helen	European American	51	15	Learning disability	51
Angela	European American	44	17	ASD	51
Claire	Taiwanese American	41	6	ASD	87
Wen	Taiwanese American	51	13	ADHD, ASD	81
Sarah	European American	44	18	ADHD, ASD	66
Eva	Mexican American	47	17	ASD, epilepsy	66

**Figure 1.**Sequential Explanatory Mixed Methods Design



#### APPENDIX A

#### **Parental Stress Measure**

This scale contains items from Berry and Jones' 1995 Parental Stress Scale and Abidin's 1995 3rd Edition Parenting Stress Index. Items with an asterisk will be reverse scored, and then all item scores will be summed to compute the parental stress score.

The following statements describe feelings about the experience of being a parent. Think of each of the items in terms of how your relationship with your child typically is. Please indicate the degree to which you agree or disagree with the following items (1- "strongly disagree", 5- "strongly agree")

- 1. The behavior of my child is often embarrassing or stressful to me.
- 2. I enjoy spending time with my child.\*
- 3. It seems my child is a little different from what I expected, which bothers me sometimes.
- 4. Having a child leaves little time and flexibility in my life.
- 5. My child does not have the ability to work as much as I had expected.
- 6. I am satisfied as a parent.\*
- 7. My child does some things that bother me very much.
- 8. I am happy in my role as a parent.\*
- 9. I think that my child does not learn quickly, unlike most children.
- 10. I sometimes worry whether I am doing enough for my child.
- 11. My child faces many difficulties in adapting to the changes that occur around them.
- 12. When I do something for my child, I feel that my efforts are not appreciated.
- 13. Having a child gives me a more certain and optimistic view for the future.\*

- 14. I feel most of the time that my child loves me and wants to be close to me.\*
- 15. My child's activity is much greater than I expected.
- 16. I feel that my child is moody and easily becomes anxious.
- 17. It is difficult to balance responsibilities because of my child.
- 18. I feel close to my children.\*
- 19. I feel overwhelmed by the responsibility of being a parent.
- 20. When my child is in a state of tension or distress, it is easy to calm them down.
- 21. Having children has meant having too few choices and too little control over my life.
- 22. It seems that care of my child is much more difficult than most children.

# **APPENDIX B**

# **Experience of Discrimination during COVID-19 Measure**

Yang et al.'s 2020 adapted version of 5-item Everyday Discrimination Scale: Please rate how often you experience the following in your everyday life (1- "never", 5- "a lot")

- 1. You are treated with less courtesy than other people are.
- 2. You receive poorer service than other people at restaurants or stores.
- 3. People act as if they are afraid of you.
- 4. People act as if you are dangerous.
- 5. You are threatened or harassed.

#### APPENDIX C

## **COVID-19 Stressors Measure**

Park et al.'s 2020 COVID-19 Stressors scale:

Which of the following stressors have you experienced in the past week?

- 1. Risk of becoming infected
- 2. Self-monitoring of symptoms
- 3. Risk of loved ones becoming infected
- 4. Risk of unintentionally infecting other people
- 5. Read or heard others talk about the severity and contagiousness of COVID-19
- 6. Stigma, shame, discrimination, or social exile related to quarantine or working in a high-risk area (e.g., others shunning you because you work in healthcare)
- 7. Stigma, shame, or discrimination related to being in a certain age group (e.g., negative statements about Millennials or Generation Z)
- 8. Uncertainty about how long quarantine and/or social distancing requirements will last
- 9. Changes to daily personal care routines (e.g., cooking, cleaning, exercise/relaxation, hobbies)
- 10. Changes to daily work routines (e.g., unable to earn money, attend full- or part-time work schedule)
- 11. Changes to daily education routines (e.g., online instruction)
- 12. Changes to social routines (e.g., spending free time with friends/loved ones)
- 13. Changed responsibilities to care for dependents (e.g., childcare, eldercare)
- 14. Cancelation of planned or scheduled celebrations, entertainment, vacations, or trips (e.g., graduations, birthdays, concerts)

- 15. Cancelation of meaningful personal or religious rituals (e.g., funerals, religious services)
- 16. Inability to travel (e.g., cancelation of vacations, weekend trips)
- 17. Increased contact with close others or loved ones (e.g., increased conflict, co-worrying)
- 18. Pressure to "make the most of" COVID-19 or "find a silver lining" while quarantining (e.g., social media fitness challenges, encouragement to increase productivity)
- 19. Loss of current job security or income (e.g., inability to earn money)
- 20. Loss of current job training opportunities or education benchmarks (e.g., certification, apprenticeship, internship, or degree completion)
- 21. Potential changes to the national or global economy (e.g., future job prospects, loss of investments)
- 22. Difficulty accessing important resources for daily life (e.g., healthcare, food, clothes, water, housing, medical supplies or prescriptions)
- Inadequate access to reliable information about COVID-19 (including your personal risk of illness)

## APPENDIX D

# **Interview Questions**

- 1. How has the COVID-19 pandemic impacted you?
- 2. How has the COVID-19 pandemic impacted your child?
- 3. How does parenting during the COVID-19 pandemic compare to parenting before the pandemic?
- 4. How do you think your stress has changed since the COVID-19 pandemic happened?
- 5. What do you usually do to deal with stress, during and before the COVID-19 pandemic?
- 6. What resources would you like to see in the future for families of children with special needs? During a pandemic/national crisis?
- 7. Have you experienced any COVID-19-related racism or discrimination during the pandemic?