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HELP SEEKING EXPERIENCES OF ASIAN AMERICAN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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ASIAN AMERICAN PARENTS HELP SEEKING EXPERIENCES

The University of San Francisco

HELP SEEKING EXPERIENCES OF ASIAN AMERICAN PARENTS OF CHILDREN WITH
AUTISM SPECTRUM DISORDER

A Clinical Dissertation Proposal Presented to the

University of San Francisco

School of Nursing and Health Professions

Department of Clinical Psychology

PsyD Program in Clinical Psychology

ASIAN AMERICAN PARENTS HELP SEEKING EXPERIENCES

In Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology in Clinical Psychology

By

Mellanie Kristelle Roxas De Guzman

University of San Francisco 2024

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Abstract

Autism Spectrum Disorder (ASD) has become more widely understood and accepted by the general and professional populations. However, self and social stigma related to ASD persist and continue to negatively impact help-seeking behaviors. This qualitative study used semi-structured interviews guided by an ecological systems model, to explore the lived experiences of 11 Asian American (AsAm) parents residing in the greater San Francisco Bay Area with a child with ASD. A thematic analysis framework was utilized. A total of six themes and six subthemes emerged from this study and included: (1) comparisons, (2) stigma, (3) resilience, (4) support for services, (5) needs for AsAm parents and their children, and (6) advice to other AsAm parents. One subtheme of cultural perceptions was generated for comparisons. The remaining five subthemes of denial, fear, language, isolation, and hopelessness were generated under stigma. Cultural perceptions of child development and behavior contributed to AsAm parents' understanding of atypical development and ASD, particularly when making comparisons of their child within their microsystem and exosystem. Social stigma endorsed in the microsystem and exosystem was often attributed to behaviors viewed as disdain within the AsAm community, increasing endorsement of self-stigma amongst AsAm parents for raising a child with ASD; thus, impacting help-seeking behaviors. A positive support system amongst nuclear family members, extended kinship, and support professionals mitigated the negative consequences of stigma and contributed to participants' engagement in help-seeking behaviors. Implications for this study include guidance for professionals in providing culturally responsive services to this hard-to-reach population.

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Dedication

“Isang bagsak” Tagalog for “One down”

When one person in our community falls, we all fall. When one person rises, we all rise.

Larry Itliong

Member of the Agricultural Workers Organizing Committee, Delano Grape Strike Organizer

This dissertation is dedicated to all the Asian American parents who shared their stories of struggles and resilience in raising a child with ASD with me for this dissertation. You are not forgotten. Your presence, your voices, your stories matter. Thank you for being a voice for your community’s experiences. Thank you for uplifting your community.

Acknowledgments

Thank you to my community for supporting me throughout the arduous journey of higher education. We did it, everyone.

To my mother, Athena Labrador Roxas, thank you for your unconditional love and endless sacrifices. Your selflessness and dedication to those you care deeply for are characteristics you possess that I hope to embody as an individual, scholar, and clinician.

To my brother, Candis, Violet, and Cecily, thank you for giving me hope for the future. There are times when this work exposes one to difficult situations and contributes to feelings of hopelessness in mankind. Your commitment to raising kind and compassionate tiny human beings makes me hopeful for the next generation of scholars, activists, and change-makers.

To my partner, Brandon, thank you for being my rock for the past eight years, but especially in the last five years. Whether it was my darkest days or joyous moments, you saw it all. To my delightful surprise, the chaos did not scare you away. Rather, you helped me stay optimistic and celebrated every milestone with me no matter how big or small. Thank you for being a part of my journey and supporting me (and our dog and bird) unconditionally the entire way.

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To LEAD Filipino, thank you for supporting my pursuit of higher education as a second-generation Filipina American and first-generation college graduate and scholar. The Lola Scholarship awarded to me exemplified to me that my presence in academia is of immense value.

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With less than 1% of Filipino Americans holding a doctoral degree, I consider my existence in this space as an act of resistance towards capitalism and white America that dictates what is considered empirical research. Thank you for uplifting Filipino Americans and encouraging the pursuit of higher education.

To the California Psychological Association (CPA), thank you for your support of Black, Indigenous, and People of Color's (BIPOC) scholarly endeavors. The Foundation Award Grant awarded to me provided the much-needed financial support to complete this important research. CPA's dedication to uplifting BIPOC researchers inspires me to continuously uplift and be in community with individuals in academia who come from underrepresented communities.

Lastly, to my dedicated dissertation committee, thank you all for believing in my work and supporting me throughout the way. To my chair and advisor, Dr. Garcia, thank you for guiding me throughout this process and ensuring that the work I do is meaningful. To Dr. Salzman, thank you for sharing your expertise surrounding ASD and being committed to advancing ASD research to be inclusive of more diverse populations through your support of my research. To Dr. Rodriguez, thank you for your check-ins and sharing your expertise in community-based research.

Signature Page

This dissertation, written under the direction of the candidate’s dissertation committee and approved by the members of the committee, has been presented to and accepted by the faculty of the PsyD Program in Clinical Psychology in partial fulfillment of the requirements for the degree of Doctor of Psychology. The content and research methodologies presented in this work represent the work of the candidate alone.

Student Signature



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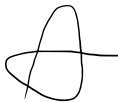
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Date



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April 30, 2024
Date

Specific Aims

The overall purpose of the proposed qualitative study is to explore access and utilization of professional services amongst Asian American (AsAm) parents for their child diagnosed with Autism Spectrum Disorder (ASD). The aim of the proposed study is threefold. First, the proposed study aims to examine cultural perceptions (e.g., stigma, typical versus atypical development) and their potential impact on accessing and utilizing professional ASD assessment and treatment services amongst AsAm parents for their child or children. Additionally, the proposed research study aims to examine how cultural factors may influence the disclosure of their child or children's diagnosis. Lastly, the study aims to offer service providers insight towards cultural considerations and factors when providing services to AsAm families. Due to the dearth of research on AsAm families seeking, accessing, and utilizing professional services for their children diagnosed with ASD, this study interviewed parents who identify as AsAm and have a child (or children) diagnosed with ASD. Specifically, the current qualitative study explored the following research questions:

1. Does perceived and/or experienced social and self stigma impact AsAm parents' perceptions of accessing assessment and treatment services for children diagnosed with ASD? If so, how?
2. Do cultural expectations of childhood development influence parents' perception of typical versus atypical development? If so, how?
3. Do cultural expectations of childhood development impact access to ASD assessment services? If so, how?
4. Do cultural perceptions influence the disclosure of ASD diagnosis to family members and other persons or systems of support? If so, in what ways?

Identification of Problem

The AsAm population is one of the most rapidly growing racial groups in the US. In California alone, the AsAm population reaches nearly 10 million, half of the US' overall AsAm population (Budiman & Ruiz, 2021). Although available state-wide and county-specific population studies have indicated high prevalence rates or risks of ASD amongst various racial and ethnic minority children, available national prevalence rates of ASD collected from particular US surveillance sites have shown the opposite –there were higher prevalence rates of ASD reported amongst non-Hispanic White children compared to children from racial and ethnic minority backgrounds (CDC, 2012; CDC, 2016; Becerra et al., 2017; CDC, 2018). An identifiable issue towards the data collected from these surveillance sites is that they gather or present limited data on reported ASD diagnoses from geographic locations containing AsAm ethnoburbs (Windham et al., 2010; Kye, 2018; Nevison, Blaxill, & Zahorodny, 2018; Nevison & Parker, 2020). Thus, the most recent recorded national prevalence rates for ASD stating that one in 44 children have a diagnosis of ASD yields limited generalizability towards the racially and ethnically diverse US population (CDC, 2021). Consequently, the limited insight towards prevalence rates of ASD amongst the AsAm population has resulted in a dearth of exploration towards the lived experiences of AsAm families with a child diagnosed with ASD. Specifically, there is a lack of qualitative research examining AsAm parents' lived experiences accessing and utilizing services for their child's prognosis and how cultural perceptions may impact parental help-seeking behaviors for their child. Therefore, interviewing AsAm parents about their lived experiences serves as a collaborative effort to better understand the various systemic, self, and social needs of this particular population. This dissertation is an effort to better inform service

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providers who seek to provide culturally-sensitive care to diverse populations and to improve these populations' access and utilization of such services.

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Alignment with Jesuit Mission of Social Justice

The proposed clinical dissertation aligns with the Jesuit Mission of social justice by examining a population historically overlooked and underrepresented by ASD research, the AsAm population. The AsAm population is considered a hard-to-reach population for research, particularly for research examining mental health related issues, due to self and social stigma, low help seeking behaviors, and language barriers with service providers. Therefore, the proposed dissertation aimed to contribute to the growing area of literature focusing on the lived experiences of AsAm parents who have a child diagnosed with ASD and explore cultural perceptions specific to working with this particular population. This dissertation aspired to uplift the voices of a historically underrepresented population by highlighting and disseminating AsAm parental reports of direct lived experiences.

Critical Literature Review

According to Nadal (2004; 2009), the label “Asian American” has been used intentionally to unify the various subgroups of Asian-identifying persons in the US for political and solidarity purposes. Nonetheless, AsAm is not an all-encompassing descriptive term as each subgroup has its own unique history and lived experiences (Nadal, 2004; Nadal, 2009). Due to the dearth of research focused on AsAms diagnosed with ASD as well as the experiences of AsAm parents accessing services for their child diagnosed with this particular Neurodevelopmental Disorder (NDD), the current research study utilizes the term “Asian American.” By utilizing the term AsAm, the current research study aims to contribute a broad and diverse perspective to the current available research on ASD which has historically underrepresented this particular racial group despite its growing population.

As part of the diverse and growing United States (US) population, the AsAm population has been reported to be the most rapidly growing racial group in the country (Budiman & Ruiz, 2021). Between 2010 and 2020, the AsAm population’s growth surpassed Hispanics, Native Hawaiians and Pacific Islanders, and Black Americans with a reported increase of 35% (CDC, 2019). Roughly 19.9 million individuals who identified as solely Asian were reported to be living in the US (CDC, 2019). Moreover, an additional four-million individuals identified as biracial Asian with an additional racial group resulting in a larger increase of the overall Asian population to 55% over the last ten years (CDC, 2019). This vast increase highlights the growing presence of the AsAm community within the US. However, this particular population has a greater presence in some geographic areas than others.

The growing population of AsAm identifying individuals are often concentrated in particular areas known as “ethnoburbs” or urban enclaves (Kye, 2018). Ethnoburbs are defined

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as neighborhoods with large populations of a particular race. More specifically, Kye (2018) defines Asian ethnoburbs as neighborhoods with “at least 20% of the population composed of Asian-identified individuals,” with twice the amount of Asian-identified individuals compared to “broader metropolitan areas” (p. 1). The state of California has a particularly large population of Asian and AsAm-identified individuals. The 2017 to 2019 American Community Survey recorded that roughly half of the AsAm population (9.8 million) lives in the West Coast of the US (Budiman & Ruiz, 2021). Furthermore, approximately a third of AsAms reside in California, making it the most heavily populated state with Asian ethnoburbs (Budiman & Ruiz, 2021). Despite the large presence of AsAms in the US and a recorded increase in national Autism Spectrum Disorder (ASD) prevalence rates, national data collected by the ADDM Network have indicated low ASD prevalence rates amongst the AsAm population compared to other non-White or ethnic minority racial groups. These discrepancies exemplify a need for further exploration to better understand the factors contributing to the gap in prevalence rates and general knowledge surrounding AsAm and ASD (CDC, 2018; CDC, 2020).

Children with Disabilities in The United States

The American Community Survey (ACS) defines disability as reported difficulty in either hearing, cognition, vision, ambulatory, independent living, or self care. When taking into consideration childhood disability, ACS looks at how “various physical, mental, or emotional conditions pose limitations to certain activities or tasks” (American Community Survey; Young, 2021, p.1; US Census Bureau, 2021). Between 2008 and 2019, it was recorded that roughly 74 million children in the US aged 0 to 17-years-old were diagnosed with a disability (US Census Bureau, 2000; 2010; 2020). Moreover, the percentage of reported households with a child diagnosed with a disability “increased from 3.9 percent to 4.3 percent between 2008 and 2019”

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(National Survey of Children's Health [NSCH] Report, 2021; Young, 2021, p.2). Thus, roughly 2.6 million American households reported having at least one child under the age of 18-years-old diagnosed with a disability (Young, 2021; US Census Bureau, 2019). Additionally, the 2009-2017 National Health Interview Survey (NHIS) indicated a "9.5 percent increase in the prevalence of developmental disabilities among children aged 3 to 17-years-old" (Zablotsky et al., 2019, p.2). Furthermore, data recorded between 2015-2018 displayed a 17.8 percent prevalence rate of developmental disabilities amongst children aged 3 to 17-year-olds (Zablotsky & Black, 2020). These statistics provide aggregated data on some of the different categories of childhood disabilities: developmental disabilities, neurodevelopmental disorders, and ASD. Despite the various ways in which ASD may be categorized, the proposed study will focus on how ASD is a type of NDD, but may be perceived by AsAm parents as a general disability.

Roughly 15% of children in the United States between the ages of 3 and 17-years-old were affected by NDDs in 2006 and 2008 (Boyle et al., 2011). NDDs are broadly defined as conditions "associated primarily with the functioning of the neurological system and brain" (United States Environmental Protection Agency, 2019, p.1) which "produce impairments of personal, social, academic, or occupational functioning" (American Psychiatric Association [APA], 2013, p. 31). The APA (2013) has grouped disorders into seven-broad categories within the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5): Intellectual Disabilities, Communication Disorders, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder, Specific Learning Disorder, Motor Disorders, and Other Neurodevelopmental Disorders. NDDs typically manifest during the early childhood developmental period unlike other disorders categorized in the DSM-5. Due to NDDs broad scope of impact on an individual's overall development and functioning, it has been recognized that early identification

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and intervention is crucial for better treatment prognosis. Studies examining the efficacy of early interventions have found that children who receive services such as naturalistic developmental behavioral interventions make greater cognitive gains and a reduction in endorsement of ASD core-symptoms (Kitzerow et al., 2019; Schreibman et al., 2015; Sandback et al., 2020). Moreover, early diagnosis and interventions have shown to positively impact not only the child's experiences, but also the experiences of their family units (Emerson, 2010).

Out of the various NDDs, there have been notable increases in ASD prevalence rates over time (Matson & Kozlowski, 2011). Recent research reports that one in 44 children are identified as having a diagnosis of ASD (CDC, 2018). Thus, an increase in ASD prevalence rates has translated into a vast exploration of various aspects related to this particular NDD including epigenetics, risk factors, and prognosis of the disorder as well as barriers to access to professional services and the impacts of raising a child with ASD on parents and family unit as a whole. The reported increase of ASD prevalence rates as well as the unique, parent-reported stress associated with raising a child diagnosed with ASD presents an area of interest this researcher aims to further investigate through this proposed study.

Diagnostic Statistical Manual of Mental Disorders-5: Autism Spectrum Disorder Criteria

As mentioned previously, ASD is categorized under the DSM-5's NDD category. The diagnostic criteria has changed over the years to better inform diagnosing individuals who present with core ASD symptoms. Compared to the previous category of pervasive developmental disorders, the DSM-5's ASD criteria is more broad to allow for better diagnosis as subtypes (e.g., pervasive developmental disorder not otherwise specified, autistic disorder, and Asperger's disorder) were identified inconsistently across clinicians and clinical settings (Lord et al., 2022; APA, 2000; Lord et al., 2018; Lord & Bishop, 2015; Lai et al., 2013). As a result, ASD

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is now characterized by two distinguishing symptomatology characteristics: “persistent deficits in social communication and social interaction across multiple contexts” and “restricted, repetitive patterns of behavior, interests, or activities” under the DSM-5 (APA, 2013, p.50). Deficits in social communication and social interaction may be due to overall challenges in socio-emotional reciprocity, use of nonverbal communication to engage in social interaction, or “developing, maintaining, and understanding relationships” (APA, 2013, p.50). Restricted, repetitive patterns however, may appear as stereotypic behaviors, inflexibility, fixated interests, or “hyper- or hypoactivity to sensory stimuli” (APA, 2013, p.50). In order for ASD to be clinically diagnosed, the described symptoms must also meet additional criteria. Firstly, symptoms must occur early in an individual’s developmental period. Moreover, symptoms must cause significant impairment to various domains of daily functioning such as social or occupational. Lastly, symptoms cannot be better explained by a diagnosis of global developmental delay or intellectual disability (APA, 2013). Due to the wide-scope impact ASD symptoms may cause, some parents of children with ASD often have greater insights into understanding the amount of support their child needs to complete daily tasks (Dovgan, Nowell, Aguilar, 2019). Attempts to identify the level of support an individual needs to navigate activities of daily living led to a shift in the DSM-5 criteria.

In order to better capture the ways in which ASD symptoms impact an individual, an additional change was made to the DSM-5. The DSM-5 ASD diagnostic criteria include the introduction of symptom severity levels. Specifically, the DSM-5 defines “severity” as the amount of support an individual requires due to their endorsed symptoms; severity levels may range from requiring some support or substantial support to requiring very substantial support (APA, 2013). Inclusion of severity levels have assisted ASD researchers in examining the impact

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of heterogeneous symptoms on individuals and the family unit. A study by Petrou et al. (2018) looked at how severity levels impacted the family unit and found that families with children who required substantial to very substantial support were more likely to be impacted physiologically, behaviorally, emotionally, and socioeconomically compared to families who had a child that required less support. Despite intentions to acknowledge the heterogeneity of ASD symptom presentations and their impact, differentiating between ASD severity levels has not been empirically supported as severity levels can be interpreted differently across clinical settings and clinicians (Weitlauf et al., 2014; Lord, 2012b). Specifically, severity levels may be attributed to ASD-specific core symptoms or associated symptoms as well as explicit or implicit environmental conditions necessary for day-to-day functioning (Weitlauf et al., 2014). Moreover, Weitlauf et al. (2014) exemplified how severity differentiation may change across the lifespan as well as potentially impact an individual's access to different services resulting in clinically significant implications for overall prognosis. Due to the lack of reliability and validity in utilizing severity levels for ASD diagnosis, there has been a recent push for clinicians to utilize “profound” ASD as it suggests the disorder's widescope impact on an individual's daily functioning (Lord et al., 2022; Weitlauf et al., 2014). Thus, emphasizing the heterogeneity of symptoms and presentations amongst this population and contributing a comprehensive perspective towards its impact.

In addition to the different kinds of ASD presentations, individuals diagnosed with ASD are more likely to experience co-occurring conditions which can lead to additional stressors and challenges for the individual and their family. For example, ASD has been linked to various medical or genetic conditions, environmental factors, and other NDDs as well as mental and behavioral disorders (APA, 2013). ASD is commonly comorbid with Fragile X Disorder, seizure,

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sleep disorders, obesity, intellectual disability, anxiety, depression, and ADHD (Bolton, 2009; Croen et al., 2015). Therefore, individuals with ASD may experience a variety of short-term and long-term complex challenges. For instance, older elementary-aged Latino children diagnosed with ASD have been found to be at high risk for social isolation (Azad et al., 2017). Moreover, challenges with social communication have been found to be a contributing factor to the high rates of depression amongst individuals diagnosed with ASD (Lever & Geurts, 2016; Pezzimenti et al., 2019). The heterogeneity of ASD symptomatology along with the high rates of co-occurring conditions presents parents with additional challenges to navigate such as attending further evaluations to appropriately identify and differentiate between co-occurring conditions and ASD symptoms, behavioral challenges, navigating additional service providers, as well as increased financial expenses or time commitments dedicated to their child's treatment and overall quality of life (De Giacomo & Fombonne, 1997; Huerta & Lord, 2012; Karst & Van Hecke, 2012; Brei, Schwarz, Kelin-Tasman, 2015; McCauley, Elias & Lord, 2020). This further depicts the impact of ASD symptomatology on the individual and collective family experience. Changes to the ASD diagnostic criteria as well as the heterogeneity of ASD are important to highlight as they present how parents' experiences may differ from one another in navigating daily life. Consequently, parents' experiences with navigating services to support their child may differ based on their child's needs.

Autism Spectrum Disorder Prevalence Rates and Statistics

The recognition of ASD's potential impact on individuals, parents, and the family has led to the further investigation of national ASD prevalence rates. Analogous to the increase of overall NDD prevalence rates within the past 10 years, rates of children diagnosed with ASD have increased from a one to 61 ratio to a one to 44 ratio (CDC, 2021; Autism Speaks, 2021).

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The US' Autism and Developmental Disabilities Monitoring (ADDM) Network has a total of 11 national surveillance sites across the US to estimate the prevalence of ASD amongst children 4 and 8-years-old (CDC, 2014; CDC, 2016; CDC, 2021). The network sites are located in Arizona, Arkansas, California, Georgia, Maryland, Minnesota, Missouri, New Jersey, Tennessee, Utah, Wisconsin (CDC, 2014; CDC, 2016; CDC, 2021). The ADDM Network included five different "bridge-race categories" in their 2012 surveillance estimates of children aged 8-years-old with a diagnosis of ASD –non-Hispanic White, non-Hispanic Black, Hispanic, American Indian/Alaska Native, and Asian/Pacific Islander (API). Out of a sample of 346,978 children, results indicated that 16,785 or 4.8% of API children were reported by their parents to have a diagnosis of ASD compared to the 61.2% of non-Hispanic Whites, 17.8% of non-Hispanic Blacks, and 19.8% of Hispanics (CDC 2018, p. 5). In contrast, the 2014 and 2016 ADDM Network's surveillance of children aged 8-years-old only included four groups --White, Black, Hispanic, and API. The 2014 estimates found that 5% of API children were reported to have a diagnosis of ASD out of the 325,483 children surveyed while reports indicated 51.3% for non-Hispanic Whites, 22.4% for non-Hispanic Blacks, and 20.6% for Hispanics (CDC, 2018). Furthermore, the 2016 estimates found a 17.9 per 1,000 prevalence rate amongst API children compared to the 18.5 prevalence rate for non-Hispanic White, 18.3 prevalence rate for non-Hispanic Black, and 15.4 prevalence rate for Hispanics (CDC, 2020). The 2016 estimates for children aged 4-years-old solely provided prevalence estimates for non-Hispanic Whites, non-Hispanic Blacks, and Hispanics due to "small numbers in other race and ethnicity categories (CDC, 2020, p. 3). Although the ADDM Network aims to provide national prevalence rates of ASD, collected data for AsAm children with ASD is sparse due to limited samples being collected from areas with AsAm ethnoburbs (CDC, 2012; CDC, 2016; CDC, 2018; Kye, 2018). As a result, literature surrounding ASD and

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the AsAm experience is still emerging. More specifically, there is much needed research that explores AsAm parental access to diagnostic or intervention services for their child diagnosed with ASD (Kim et al., 2021; Sakai et al., 2019).

While some studies have examined AsAm prevalence rates, a few studies continue to highlight the overall increased prevalence rates reported by the ADDM Network (CDC, 2012; CDC, 2016; CDC, 2018). The California Department of Developmental Services (CDDS) also found an overall significant increase of 5-year-old children with ASD who were born between 1931 to 2012 (Nevison, Blaxill, & Zahorodny, 2018). However, Nevison, Blaxill, and Zahorodny (2018) did not break down the prevalence rates by race or ethnicity. Data looking at national prevalence rates amongst AsAm children is sparse; however, a few studies have looked at the AsAm population diagnosed with ASD (Windham et al., 2010; Nevison, Blaxill, & Zahorodny, 2018; Nevison & Parker, 2020). For example, a study conducted by Windham et al. (2010) focusing on children within the San Francisco Bay Area reported that Black and Hispanic children in the years 1994 and 1996 had lower rates of identified ASD compared to White non-Hispanic children. In contrast, AsAm children had similar prevalence rates to White children (Windham et al., 2010). Despite the historical gap in knowledge, more recent studies are beginning to address this gap by examining prevalence rates of children from diverse racial and ethnic backgrounds living in California (Nevison & Parker, 2020).

Nevison and Parker (2020) looked at nine different California-county's ASD prevalence rates utilizing data from CDDS: "Santa Clara, Monterey to SF coast, Sonoma/Marin, San Diego/Imperial, Los Angeles, Sacramento, Riverside, South Central Valley, North San Joaquin Valley" (p. 4014). The study yielded various findings supporting that Black children had the highest prevalence rate of ASD in 2013 with 1.8% while also highlighting ASD prevalence rates

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for AsAm children with 1.7%, Whites at 1.4%, and Hispanic children at 1.2% (Nevison & Parker, 2020, p. 4013). Moreover, the study highlighted a shift in ASD prevalence rates amongst White and AsAm children living in wealthy counties within the San Francisco Bay Area, such as Santa Clara County. Specifically, White children who lived in wealthy counties in the year 2000 displayed a decrease in prevalence rates while AsAm children who lived in wealthy counties in the year 2000 plateaued in ASD prevalence rates (Nevison & Parker, 2020). In contrast, Black and Hispanic children living in lower income counties displayed an overall steady increase in ASD prevalence rates (Nevison & Parker, 2020).

Although ASD prevalence rates for AsAm children in wealthy California counties have plateaued, AsAm children living in “large metropolitan areas like Sacramento, Los Angeles, and San Diego” as well as “central valley counties” have shown vast increases in ASD prevalence rates that are similar to trends of Hispanic children and have either surpassed or caught up to ASD prevalence rates of White children (Nevison & Zahorodny, 2020, p. 4018). More specifically, AsAm ASD prevalence rates have surpassed White and Hispanic children prevalence rates statewide, making this particular racial population second to the ASD prevalence rates of Black children (Nevison & Zahorodny, 2020). In comparison to national ASD prevalence studies that provide limited data on AsAm children, statewide population studies highlight the rising shift in ASD prevalence rates amongst AsAm children. In addition, discrepancies between prevalence rates and socioeconomic statuses have been profound in the US compared to other countries such as the United Kingdom (UK). Research has shown that there are lower rates of ASD diagnoses amongst communities of lower socioeconomic status. In the UK however, there is no relationship between rates of diagnoses and income (Kelly et al., 2019). This suggests that in the US, parents’ socioeconomic status may play an important role in

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AsAm parents' daily lived experiences and help-seeking behaviors. The present study considered how the relationship between socioeconomic status and ASD prevalence rates in the US may impact access to services amongst AsAm parents for their child or children.

Screening and Diagnosing ASD Amongst Racial and Ethnic Minority Children

Recognition of ASD and the increase in prevalence rates have led to better screening efforts. Accessing professional services for ASD is dependent on various factors including provider education of typical and atypical development, awareness of the signs and symptoms of ASD, increased ASD referrals, provider bias, and lack of sensitivity towards racial and ethnic minority individuals across screening or evaluative tools (MacLachlan, 2020). Routine early childhood developmental screenings take place during wellness checks recommended as early as 12-months to 18-months and 24-months of age within primary care settings; these screenings can include the administration of validated checklists including the Modified Children's Autism Test (Wieckowski et al., 2021; M-CHAT; Robins, Fein, & Barton, 2009), Developmental Behavioral Checklist-Parent (DBC-P; Einfeld & Tonge, 1995, 2002), Autism Screening Questionnaire (ASQ; Berument et al., 1999), or Autism Behavior Checklist (ABC; Krug et al., 1980a, 1980b, 1993 via Brentani et al., 2013). Greater recognition of core features and symptoms of ASD amongst parents and providers have contributed to accessing diagnostic evaluations as early as 18-months-old compared to three-years-old (Landa, Holman, & Garret-Mayer, 2007; Riva et al., 2021). When concerns arise regarding a child's development and achievement of developmental milestones, a child's pediatrician or the family physician is often the parents' first point of contact; therefore, pediatricians and physicians play an important role in early identification of ASD (Di Renzo et al., 2021).

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In spite of the crucial role pediatricians and physicians play in accessing evaluation services for ASD, concerns amongst racial and ethnic minority parents for their children are often dismissed. An additional noted barrier to screen for ASD is how providers typically screen for general developmental delays rather than ASD (Dosreis & Weiner, 2006). Historically, pediatricians were also not familiar with ASD-specific screening tools and reported lack of time to conduct screenings; however, there has been recent improvement in screening for ASD through electronic screening methods which are then reviewed by pediatricians who follow-up if scores indicate concern for general developmental delays (Dosreis & Weiner, 2006; Guthrie, 2019). Despite the requirements for developmental screening, research has also indicated that provider bias and structural racism play a crucial role in referring racial and ethnic minority children to ASD diagnostic evaluations (Rea et al., 2019; Wallis et al., 2020; Broder-Fingert, 2020).

Provider bias and structural racism have contributed to the disparities in early detection of ASD amongst African American children compared to White children. Mandell et al. (2002) study also found that providers are less likely to screen racial and ethnic minority children for ASD compared to their White counterparts. Exploration of African American parents' perceptions of ASD and accessing services for their children found that some parents indicated that their children's pediatricians were not familiar with the signs and symptoms of ASD (Pearson & Meadan, 2018; Zheng et al., 2021). As a result, parental concerns were dismissed and were not followed up with additional screenings (Pearson & Meadon, 2018). Additional studies by Constantino et al. (2020) and Illand, Weiner, and Murawski (2008) found that Black and Latinx children received a delay in diagnosis more than other children. Moreover, children and families who are not native-English speakers are not screened properly due to barriers in regular

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and follow up communication with their physicians as well as interpreting or responding to questionnaires (Malik-Soni et al., 2021; Fox et al., 2017; Kairys et al., 2016; Khanlou et al., 2017). Screening disparities in non-dominant racial and ethnic groups is not only a challenge in the US but also found in other countries. An international study conducted in the Netherlands found that pediatricians exposed to clinical vignettes for European cases compared to non-European cases were more likely to refer European cases for further ASD evaluation (Beeger et al., 2009). Furthermore, families in the US from lower socioeconomic backgrounds who were English-speaking AsAms were less likely to receive ASD evaluation referrals compared to White children (Wallis et al., 2020). These findings exemplify how personal physician and systemic biases rooted in the healthcare system may impede racial and ethnic minority groups from timely access and utilization of ASD professional services (May et al., 2021; Dababnah et al., 2018; Trent et al., 2019).

Similar to systemic biases impacting the initial screening for ASD amongst racial and minority children, research has also noted biases in clinicians responsible for providing ASD specific diagnostic evaluations (Beeger et al., 2009; Mandell et al., 2002; Mandell et al., 2007; Maye et al., 2021). Good ASD evaluations utilize a comprehensive, systematic, and structured approach that includes the administration of semi-structured assessments, behavioral observations, caregiver interviews, and other standardized psychodiagnostic measures. Often the diagnostic clinicians consist of a multidisciplinary team composed of pediatricians, psychologists, speech and language therapists, and occupational therapists. This multidisciplinary approach is designed to “safeguard against potential forms of clinician bias that could impact behavioral diagnostics combining multiple clinical perspectives to address the many variables impacting early development and behavioral dysregulation” (Brinster et al.,

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2022, p.4). Despite these attempts to reduce bias within the assessment process, racial and ethnic minority children may receive a different initial diagnosis (Brentani et al., 2013; Huerta & Lord, 2012). For instance, Mandell et al., (2007) found that Medicaid-eligible African American children were more likely to receive a diagnosis of Attention-deficit/hyperactivity disorder than ASD during their first ASD evaluation; additionally, African American children were more likely to receive either diagnoses of adjustment disorder and conduct disorder. Moreover, it has been noted that there are some differences in the manifestations of early ASD symptoms in racial and ethnic minority children that may further complicate the clinician's perspective and result in a lack of ASD diagnosis (Emerson, Morrell, & Neece, 2016).

In addition to the endorsed biases and discrimination of racial and ethnic minority children throughout the initial screening and comprehensive evaluation for ASD, research has also shown that the tools and instruments used to diagnose and rule out ASD lack sensitivity towards norms amongst non-White children (Stoll, Bergamo, & Rossetti, 2021). Despite attempts to create equity and cultural sensitivity by translating these assessment tools into different languages, many of the instruments are created and validated in countries rooted in Eurocentric ideals such as the US and Europe (Øien & Nordahl-Hansen, 2018). Clinicians use a variety of assessment tools and diagnostic instruments in order to gain a comprehensive picture of the child's adaptive skills, social abilities, and maladaptive behaviors that highlight presenting concerns and observable symptomology (Brentani et al., 2013). Assessment tools may include the Social Responsiveness Scale (SRS-2; Constantino & Gruber, 2012), Vineland Adaptive Behavior Scales (Vineland-III; Sparrow & Cicchetti, 1989), Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1986), or Behavior Assessment System for Children (BASC-3; Reynolds & Kamphaus, 1992). The use of these assessment tools in conjunction with

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the administration of the diagnostic instrument, the Autism Diagnostic Observation Schedule (ADOS-2; Gotham et al., 2006) and Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouteur & Lord, 2003), help to inform clinicians' formulation of an appropriate diagnosis.

Despite being the gold-standard diagnostic instrument for ASD, there are many limitations of the ADOS-2. Firstly, Kamp-Becker et al. (2018) suggests that becoming adequately trained in the administration and coding of the ADOS-2 is a lengthy process that requires extensive "experience in the use of the ADOS-2" (p. 1203). Additionally, there is limited available clinical workshop training for the ADOS-2 (Akshoomoff, Corsello & Schmidt, 2006). Lorde et al. (2012) shed light on how the ADOS-2 has a disproportionately normed sample with a significantly larger sample of White individuals compared to those from Black, AsAm, or other racial backgrounds. This has raised concerns on the tool's validity and reliability to assess individuals from racial and ethnic minority backgrounds (Stoll, Bergamo, & Rossetti, 2021). More specifically, the ADOS-2 was found to have "significant item level bias according to race and/or ethnicity for" observed and rated behaviors such as immediate echolalia, unusual eye contact, and stereotyped/idiosyncratic use of words or phrases (Harrison et al., 2017, p. 2778; Gotham et al., 2006). AsAm children may be observed to have unusual use of eye contact during the evaluation. However, this could be due to the family embracing traditional Asian social norms as Asian culture often implicitly teaches children to avoid eye contact as a way of communicating respect to their elders (Lian, 1996; Sue & Sue, 2008; Bernier, Mao, & Yen, 2010). Additionally, Black and Hispanic children have been found to endorse greater severity levels of ASD (Harrison et al., 2017). Furthermore, individuals who endorse more behavioral and emotional challenges are more likely to have inflated ADOS-2 scores; thus further complicating clinicians' differential diagnosis (Havdahl et. al., 2016; Christopher et al., 2021).

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The culmination of these factors can prevent early diagnosis of ASD which further inhibits access and utilization of early intervention amongst racial and ethnic minority children, including AsAm children, diagnosed with ASD. Therefore, presenting an additional domain to explore in order to better understand what impacts AsAm parents' access to services for their children diagnosed with ASD.

Early Intervention and Treatment Prognosis

Providing a child and their family with a thorough, comprehensive evaluation paves the way for tailored intervention planning to enhance treatment prognosis. A previous study found that children who receive early interventions before the age of 3-years-old have better improved developmental outcomes compared to those who began interventions after 5-years-old (Zwaigenbaum et al., 2015). Despite potential parent or service provider hesitancy surrounding an early diagnosis, as well as many evidence-based practices (EBP) being tested by White-identifying researchers and clinicians amongst predominantly White, wealthy, and highly educated communities, past and current literature exemplify the importance of early diagnosis and intervention in quality of life prognosis amongst children diagnosed with ASD. Existing literature also highlights the impact of early diagnosis and intervention towards caregivers' overall quality of life (Elder et al., 2017; Landa et al., 2007; Riva et al., 2021; Shi et al., 2021; Steinbrenner et al., 2022). Dawson et al. (2009) conducted a randomized controlled trial looking at children aged between 18 and 30-months-old diagnosed with ASD and found that comprehensive developmental behavioral interventions, specifically the Early Start Denver Model, resulted in a reduction of the required support needed due to improved adaptive and cognitive behavior. Another study highlighted that children who required less support and received an earlier diagnosis and treatment were found to lose their ASD diagnosis due to

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improved adaptive, social, and cognitive skills (Helt et al., 2008). Furthermore, a recent meta-analysis reviewed studies that explored early comprehensive treatment models (CTM) and evaluated the treatment outcomes amongst children with ASD. The meta-analysis revealed that most children who received CTM displayed overall improvements in various domains of functioning such as core symptomology, intelligence, language development, as well as communication and social skills (Shi, et al., 2021). Although there is emerging evidence in the effectiveness of early interventions for better prognosis amongst children with ASD, many of the findings have not been generalized towards racial and ethnic minority children.

For instance, a study that looked at children aged 3 to 5-years-old diagnosed with ASD found greater risks of impaired expressive language and externalizing or challenging behaviors/emotional outbursts in US-born Hispanic and Black children as well as children of foreign-born Central/South American compared to Caucasian children (Becerra et al., 2014). Additionally, children with foreign-born mothers who were Filipino, Vietnamese, Black, and Central/South American as well as US-born Hispanic and African American children had an increased likelihood of cognitive impairments by 5 years of age (Becerra et al., 2014). Becerra et al. (2014) highlights that the discrepancy of language, behavior, and cognitive impairment between racial and ethnic minority children compared to their White-peers is due to lack of early intervention. Although both minority and white-children may present similarly during times of first diagnosis, cognitive impairment may be more apparent amongst minority children as a result from delayed or lack of intervention (Becerra et al., 2014).

The available research on early ASD intervention sheds light on the utility and efficacy of early CTM implemented amongst children with ASD and those at high-risk for ASD due to sibling diagnosis of ASD. Due to the known challenges that are associated with the core deficits

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of ASD, early CTM can improve the ways in which individuals communicate and interact with their surroundings. By targeting joint attention, language, and socio-emotional reciprocity, individuals may be more likely to create and maintain friendships with similar-aged peers as well as increase emotional stability through emotion regulation skills which has shown to be associated with socio-emotional reciprocity (Nader-Grosbois & Mazzone, 2014). Not only have CTMs been found efficacious in increasing skills amongst those diagnosed with ASD, early interventions have also been associated with better parental stress outcomes (Estes et al., 2014; Estes, Swain & MacDuffie, 2019; Shine & Perry, 2010). Despite research highlighting the benefits of early interventions, there is little understood about AsAms utilizing such services suggesting another gap of research. Thus, this study aimed to fill the gap in research by exploring AsAm parents' help-seeking behaviors for accessing services for their children and how parents perceive such utilized services.

Parental Perceptions of ASD: Causes and Concerns

An additional area of research crucial to further explore is AsAm parental perceptions of ASD. Variability in social behavior norms across cultural, ethnic, racial, regional, and socioeconomic contexts can result in differences in how ASD is perceived, conceptualized, and diagnosed, thus impacting early diagnosis and intervention (Schriber et al., 2014). The universality of ASD symptomatology may be better understood within the context of social norms within a particular culture (Perepa, 2014). Moreover, perceptions about ASD can vary across and within racial minority groups (Zelege, Hughes, Drozda, 2019). For example, a study that reviewed both racial minority and White-parents' perceptions of ASD symptoms found that compared to Asian, Pacific Islander, Latino, and African American parents, White parents are more likely to "view symptoms as related to a health condition" (p. 112; Mandell & Novak,

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2005). Moreover, European American families from upper to middle socioeconomic backgrounds were found to attribute ASD to genetics (Sage & Jegatheesan, 2010). In contrast, Ponde and Rousseau (2013) found that mothers living in Montreal who immigrated from Latin America, Asia, and the Caribbean compared to mothers from “the Arab world and North America” attributed their child’s presenting concerns to communication problems or developmental delays rather than ASD (p. 137). Some immigrant mothers also reported that their children did not have any problems (Ponde & Rousseau, 2013). Similarly, parents from racial minority backgrounds in the US were more likely to attribute their children’s challenges in social skills or language delays to their shy personality or overall temperament rather than a disorder (Mandell & Novak, 2005). Although there are some differences in how ASD is perceived across various family demographics, a qualitative study conducted by Locke et al. (2020) found that both racial minority and White parents who spoke either English or Spanish experienced denial, skepticism, fear, and overwhelmedness after receiving concerns from others about their child, claiming that their child’s behavior was attributed to uniqueness rather than ASD. The literature surrounding parental perception of ASD symptomatology presents a unique area to further investigate amongst AsAms as many of the findings suggest that acculturation, stigma, and other sociocultural behavioral norms may influence access to timely ASD diagnosis and early interventions.

AsAm Parental Perceptions of ASD

Few studies have explored AsAm parental perceptions of their child’s ASD diagnosis. However, the available research has explored some of the potential differences between subgroup Asian ethnicities (Kim et al., 2020). Growing literature has highlighted common themes amongst this population’s perception of ASD, raising a child with ASD, and how these

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perceptions may impact access and utilization to services amongst AsAm children (Sage & Jegatheesan, 2010; Bilaver, Sobotka, & Mandell, 2020; Seung, 2013; Bernier, Mao, & Yen, 2010). Although researchers and clinicians have emphasized the importance of multicultural understanding and sensitivity towards ASD, much of the available literature on AsAms focuses on the East AsAm population and does not offer insight towards other ethnic subgroups. For example, a review conducted by Kim et al. (2020) found that both Korean American and Chinese American parents with a newly diagnosed child with ASD had limited knowledge surrounding “the nature of their child’s” ASD (p. 316). The review also highlighted within-group differences of perceptions towards ASD based on religion or differences in faith. Korean American parents more often attributed an ASD diagnosis to their Christian faith as it was a part of “God’s plan” whereas Chinese Americans who believed in Confucianism, Buddhism, or Taoism explained their child’s ASD diagnosis to superstitions and self-blame (Kim et al., 2020, p. 318; Cho et al., 2000; Wang & Casillas, 2013). By conducting semi-structured interviews, Wang and Casillas (2012) explored Chinese Mandarin-speaking immigrant parents’ beliefs surrounding the etiology of ASD and found that parents believed their child’s ASD was caused by technology, environmental factors, genetics, or failure to participate in traditional healthcare practices and taboos during pregnancy. Another study conducted by Sage and Jegatheesan (2010) found that AsAm parents, specifically those from lower socioeconomic backgrounds, experienced shame and felt their child’s ASD diagnosis was a punishment for past wrongdoings.

In contrast, a quantitative study conducted in Macau found that the majority of participants believed their child’s ASD was caused by “neglectful and emotionally cold parenting” compared to biological factors (Qi, Zaroff, & Bernardo, 2016, p. 679). Furthermore, a study looking at Thai parental perception of ASD found that parents more frequently believed

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that ASD was caused by chemical exposure and stress during pregnancy compared to genetics (Chirdkiatgumchaia et al., 2010). Parental perception of the causes of ASD strongly influenced the types of treatments parents sought out for their children with ASD. For example, mothers who believed in environmental causes were more likely to utilize complementary and alternative medicine services (Chaidez et al., 2018). Additionally, having a child with ASD was perceived by Mandarin-speaking parents to be personally “unfair” as it requires various personal, social, and financial sacrifices which results in lessening expectations for their child (Wang & Casillas, 2012, p. 600). Despite the perceived unfairness, Wang and Casillas (2012) found that Mandarin-speaking parents also believed that ASD would be “cured” by utilizing therapy to their child’s overall improvement (p. 601). Moreover, parental devotion or the value of family goals over personal goals and endeavors, were perceived to be vital to improving their child’s condition (Wang & Casillas, 2012). These limited yet informative findings exemplify how parental perceptions towards the cause of ASD in their child may result in accessing different kinds of treatment, or no treatment at all. Thus, the growing yet narrow scope of research amongst the AsAm community presents an area to further explore and expand.

Overview of Parental Experiences: First Concerns and Factors

Parental perceptions and experiences of developmental milestones also play a crucial role to early screenings for ASD (Coelho & da Conceição, 2021). Although primary care providers may not always recognize the signs and symptoms of ASD dependent on acquired training or attend to familial concerns due to personal biases, ASD symptomatology may also not be recognized as atypical development by family members; thus, further contributing to a delayed diagnosis and access to early interventions (Pitten, 2008; Ennis-Cole, Durodoye, & Harris, 2013; Sakai et al., 2019; Crais et al., 2020). For example, a recent qualitative study by Locke et al.

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(2020) looked at English and Spanish-speaking focus groups from racial minority and White backgrounds to explore parental concerns of early childhood development and perceptions about ASD. The researchers found that parents from both groups reported concerns of their child's limited social engagement, eye contact, delays in language, and behavioral issues roughly around 17.1 months of age (Locke et al., 2020). Locke et al. (2020) also exemplified how first-time parents were less likely to access intervention services for their children due to their lack of knowledge of what constitutes developmental deviance. In contrast, having at least one older child with atypical development resulted in earlier parental concerns towards a younger child with presentations of ASD symptomatology (Chawarska et al., 2007; Ozonoff et al., 2009). These findings were further supported by a more recent study conducted by Coelho and da Conceição (2021) in Portugal in which they found that "early parental concerns may help predict ASD prognosis" (p. 1). In sum, understanding the sociocultural contexts surrounding developmental milestones are crucial to better recognizing ASD symptomatology in order to access and utilize intervention services. Therefore, it is important to also highlight the cultural differences that may impact first concerns amongst AsAm.

Cultural Differences that Might Impact Parental Experiences

Cultural differences surrounding the perception of developmental milestones may impact AsAm parental help-seeking behaviors. According to Western standards of developmental milestones, children are expected to engage in social reciprocity and nonverbal communication before the age of 24 months (Kang-Yi et al., 2018). In order to better disseminate information about developmental milestones (e.g., social/emotional, language/communication, cognitive, movement), the CDC (2022) created a checklist for parents, families, and providers to reference. For example, children at 6-months should be able to laugh, engage in back-and-forth sounds with

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another individual, mouths items, and rolls onto their back from their stomach, while children at 12-months should be able to play social games, use gestures (e.g., wave bye), look for items hidden under a blanket, and independently stand up (CDC, 2022). Furthermore, children at 18-months should be able to point to items of interest, have three or more words in their expressive vocabulary, use imitation skills, and walk without assistance (CDC, 2022). Similar to Western developmental milestones, research has shown that various cultures hold similar expectations of developmental milestones for children up to 3-years-old suggesting perceptions of these expected developmental milestones may influence the recognition of atypical development (de Leeuw, Happé & Hoekstra, 2020).

Despite the similarities, different sociocultural contexts and child-rearing practices may impact how behavior is perceived as behavior that may be viewed as atypical in one context may not be perceived as atypical in another; therefore, individuals from racial minority backgrounds such as AsAms, may culturally perceive developmental milestones differently (Daley, 2004; de Leeuw, Happé & Hoekstra, 2020). For instance, research has shown that engaging in eye contact or using social gestures while communicating to one's elders is disrespectful; thus, Western cultural expectations of making and maintaining eye contact do not always align with cultural expectations (Perepa, 2014; Wilder et al., 2004; Liu, 2005). Moreover, differences in child-rearing practices across cultures have been shown to also play a role in how behaviors are perceived within different sociocultural contexts. For example, Bornstein (2015) shed light on how some cultures do not speak to their babies as they view it is "nonsensical to speak to infants" prior to development of expressive language whereas parents from other cultures start speaking to their babies early on as they view their children as "interactive partners" starting at a young age (p. 5). Additionally, engaging in pretend play has been found to be more common in

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high-income sociocultural contexts such as in populations with Anglo-American children compared to South African or Korean American children (de Leeuw, Happé & Hoekstra, 2020).

The ways in which behavior can be perceived differently from one sociocultural context to another is an additional area this proposed study aims to explore as these perceptions may further contribute to AsAm parents' experiences in accessing services for their child. Therefore, it is also pivotal to better understand AsAm parental perceptions of available services.

Parental Perception of ASD Services

Emerging research has also explored racial and ethnic minority parents' access and perception of intervention services for their children (Benevides et al., 2016; DuBay et al., 2018; Hussein et al., 2019; Luong et al., 2009; Grinker, 2007; Lovelace et al., 2018). Although researchers and clinicians alike recognize the benefits of early interventions, available research has highlighted parental concerns regarding the cultural sensitivity of evidence-based interventions and the providers they are required to interact with for their children's treatment. For example, African American mothers reported feeling discriminated against during interactions with their children's providers (Lovelace et al., 2018). DuBay et al. (2018) found that Latino parents did not feel as if their children's providers met their needs due to lack of open communication between parents; moreover, parents expressed confusion about the effectiveness of multiple intervention plans from various providers such as speech and language pathologists, occupational therapists, or board certified behavior analysts as well as an overall desire to include extended family members in intervention services. The concern towards lack of communication between a child's different providers was commonly expressed amongst Latino parents as well as Korean American, Southeast Asian, South Asian Muslim, and Somali parents living in the US and United Kingdom (Hussein et al., 2019; Luong et al., 2009; Fox et al., 2017;

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Jegatheesan et al., 2010a; You & Rosenkoetter, 2014). South Asian Muslim immigrant parents have expressed concerns about treatments lacking a strength based approach which seems to have contributed to a lack of confidence in intervention (Jegatheesan et al., 2010b).

In addition to experienced discrimination and lack of communication between providers, as well as between providers and parents, research has found that long referral waitlists, poor outreach, and cultural sensitivity impacts timely evaluation, diagnosis, and initiation of services (MacLachlan, 2021). Additionally, the tendency for minority families to place more emphasis or weight on family members and friends' opinions compared to professionals and reliance on traditional medical treatments have contributed to lower rates of access and utilization of intervention amongst racial and ethnic minority children diagnosed with ASD (Bernier et al., 2010; Lau et al., 2004; Schnittker, 2003; Terhune et al., 2005). The available literature suggests that there is a need for better dissemination surrounding early signs of ASD, parents and providers attending to early developmental and behavioral concerns, the comprehensive evaluation of ASD, and a need for providers to address parental concerns with empathy and trust, and cultural awareness. By diversifying and enhancing literature to be inclusive of AsAm experience, researchers and clinicians may have greater insight towards the perceptions that impact the access and utilization of professional services as well as the type and quality of socioemotional support AsAm parents receive when navigating concerns about their child's behavior or development. Along with better understanding these perceptions, it is also pivotal to explore the internal and external barriers to AsAm parents' help-seeking behaviors.

Systemic, Self, and Social Barriers to AsAm Parental Help Seeking Behaviors

Positive health seeking behaviors have been associated with increased access to mental health services (Umubyeyi, 2015). Umubyeyi (2015) defines help seeking behavior as “any

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action of energetically seeking help from the health care services or from trusted people in the community and includes understanding, guidance, treatment and general support when feeling in trouble or encountering stressful circumstances” (p. 83). AsAms have been reported to underutilize mental health services for themselves due to generational effects, level of acculturation, cultural reticence, and low help-seeking behaviors for disability or mental health concerns compared to White Americans (Hasnain et al., 2020; Holland & Palaniappan, 2012; Spencer et al., 2010; Kim & Lee, 2021; Kim & Zane, 2016; Ghosh & Magana, 2009). Subsequently, under-reported concerns and limited research surrounding the AsAm population results in a limited understanding towards this broad populations’ experiences with developmental disabilities and mental health which prevent increased access to services, the creation and implementation of culturally-sensitive services, and improvement in overall quality of life (Hasnain et al., 2020). In order to better understand the experiences of AsAm parents with a child diagnosed with ASD, various barriers and facilitators to help seeking behaviors amongst this population must be explored.

Systemic Barriers

Despite the advantages of accessing and utilizing early interventions, several barriers may prevent parents from obtaining such services for their children. Systemic barriers that have been identified in literature include financial costs and insurance coverage, lengthy local and federal financial support wait times, shortage of services and access to service providers who speak various languages (Zheng et al., 2021; Taylor & Henninger, 2014; Malik-Soni et al., 2021; Zuckerman et al., 2017). According to Buescher, Cidav, and Knapp (2014), the societal cost of raising a child with ASD is roughly \$60,000 due to the high-cost of services. Moreover, parents with children or adolescents diagnosed with ASD experience increased medical expenses due to

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co-occurring health conditions from four to six times more than their typically developing peers (Buescher, Cidav & Knapp, 2014; Rogge & Janssen, 2019). High costs related to ASD support and the inability to take time off work puts AsAm families from low socioeconomic households at a significant disadvantage in engaging in help seeking behaviors and accessing intervention (Aylward et al., 2021; Kim & Lee, 2021). Furthermore, Becerra et al. (2017) explored access and utilization of services amongst five racial groups within a private healthcare system and found that 55% of white identifying individuals, 6% Black, 5% Asian, 9% multiracial, and 24% Hispanic identifying individuals utilized Department of Developmental services; thus, exemplifying how access and utilization of services differ amongst racial groups potentially due to treatment fears, perception that mental health services would not be helpful, fear self-disclosure, and cultural discrimination (Becerra et al., 2017, p. 1; Kim & Lee, 2021; Kim & Zane, 2016). Language has also been found to serve as an additional barrier in accessing ASD services amongst Latino and AsAm families as well as other families whose primary language was not English (Zuckerman et al., 2017; Fox et al., 2017; Luong et al., 2009; Malik-Soni et al., 2021). It is evident that systemic barriers play a crucial role in preventing racial and ethnic minority parents from engaging in help-seeking behaviors to access services for their child. However, further exploration of these systemic barriers can provide a more rich description of the lived experiences of AsAm parents accessing services for their children. In addition to systemic barriers, stigma related to ASD and mental health concerns poses another significant barrier in accessing timely and appropriate services for children diagnosed with ASD.

Self and Social Barriers

A noted barrier to help-seeking behaviors for accessing and utilizing mental and behavioral health services amongst racial and ethnic minority populations is stigma towards

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mental health and disabilities (Corrigan, 2004; Rao & Valencia-Garcia, 2014). Goffman (1963) defined stigma as a social process embedded within a culture that results in a discrediting, inferior attribute and is not culturally accepted. Corrigan (2004) described stigma as “four social-cognitive processes: cues, stereotypes, prejudice, and discrimination” (p. 615). Although stigmas are present universally, they are culture-bound reflecting the ways in which cultures create knowledge, share meaning, and attitudes; thus, stigmas across cultures can vary in severity (Rao & Garcia, 2014). Stigmas related to disability and disease in particular are associated with specific cultural behavioral norms (Rao & Valencia-Garcia, 2014). Moreover, self or internalized stigma as well as social stigma play a crucial role towards how racial and ethnic minority populations perceive mental health and access treatment (Corrigan, 2004). Individuals who identify as ethnic minorities within a White-Eurocentric dominant society may then experience multiple layers of oppression due to their intersecting identities (Crenshaw, 1994). Furthermore, individuals who experience various stigmas may also experience an intersection of negative effects towards health outcomes due to microaggressions related to their race, ethnicity, or disability (Sue, 2007; Berger, 2006; Reidpath & Chan, 2005). Although there is some research exploring how stigmas may impact health outcomes amongst the AsAm population, the proposed study aims to explore how this impacts AsAm parents accessing ASD services for their children.

Some studies have begun to fill in this gap of research but still leaves much to explore. Specifically, AsAm parents navigating the healthcare system for their child diagnosed with ASD may experience systemic anti-Asian racism and discrimination. Similar to other racial and ethnic minority populations, research has found an inverse relationship between self and social stigma amongst the AsAm community with help seeking behaviors and utilization of mental health services (Wang & Casillas, 2012; Seung, 2013). Self stigma can often be manifested by

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attributing their child's endorsed symptoms to other characteristics such as personality or language delays, prompting hesitation to seek out services (Ponde & Rousseau, 2013; Mandell & Novak, 2005). This hesitation or fear of seeking out services for their child may be rooted in collectivistic AsAm values as a child's accomplishments and success in life represents the collective family's success. Unlike individualistic culture where individual goals tend to outweigh the interest of the family unit, the collectivistic nature of AsAm culture presents a unique, dynamic relationship to explore and its potential impact on parental access to services for their AsAm children.

Similar to the negative impact self stigma may play a role in AsAm parental help-seeking behaviors, social stigma is also endorsed by AsAm communities and may also result in denial and shame as the sense of disability presents challenges to not only one's life achievements but also the family as a whole (Wang & Casillas, 2012; Sage & Jegatheesan, 2010). When translated from Chinese to English, the term disability roughly translates to "incomplete" and "useless" (Wangyun, 2017, p. 313). As a result, families who have a family member with a mental health condition may result in isolating themselves from the larger communities, relying solely on their nuclear family rather than extended family or close friend support group, as well as hiding (Kim et al., 2020). An additional impact of social stigma was highlighted by Korean parents who intentionally delayed access to ASD evaluations as a diagnosis would bring shame to the family's reputation (Hughes, 2011). These findings were supported by a study examining community-level cultural beliefs amongst Korean American parents of Christian faith in which there were high levels of parental shame, denial, and discomfort. These forms of self-stigma appeared to result from lack of awareness of ASD and limited knowledge of ASD services which often prevented parents from accessing services for their child. Church leaders reported that

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parents often cope with their child's disability by socially isolating or engaging in silence and inaction due to the reported competitiveness endorsed within the Korean community (Kang-Yi et al., 2018). Furthermore, stigma towards disabilities within Chinese culture was found to discourage parents from seeking out specialty ASD evaluations. Stigma in these cultures also prevented parents from reporting a diagnosis of ASD to community environments such as a child's school (McCabe, 2007). In contrast, a study looking at self-stigma amongst Malaysian parents with a child diagnosed with ASD found that parents did not endorse stigmatization due to their child's condition and therefore, seek out different kinds of services for their disabled child (Chu et al., 2020). These findings highlight the significance of self and social stigma amongst AsAm parents in preventing help seeking behaviors for their children. Despite some literature, more in depth exploration to how this impacts AsAm parental access to ASD services for their children is still warranted.

As previously stated, social stigma towards ASD and disabilities amongst the AsAm population is a barrier to AsAm parental help-seeking behaviors for behavioral health services due to feelings of shame and preference in isolation (Hughes, 2011; Km et al., 2020). According to Wang and Casillas (2012), "the underlying social construction of stigma" is the cultural idiom of "predestination or fatalism" (p. 603). Fatalism is the concept that events are predetermined and therefore, inevitable (Flores et al., 1999). In some sense, fatalism may allow parents to engage in health coping strategies as there is a belief that a condition or diagnosis serves a purpose in one's family; however, fatalism may also bring about a deep sense of remorse and anger as one may believe having a loved one with a mental or behavioral health condition is unfair (Luong et al., 2009; Kim et al., 2020). Moreover, additional cultural idioms such as "saving face," resiliency, and the importance of collectivism have been found to contribute to the

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social stigma against mental health (Seung, 2013). Saving face and shame are associated in that family members who have a loved one with a disability or mental health condition may dishonor a family's name or reputation (Kim et al., 2020). Resiliency and collectivism may lead a family member to navigate stressful situations alone in order to prevent a sense of burdening others (Luong et al., 2009). Alternatively, collectivism may instill a sense of hope and support with familial and community members, preventing access or utilization of professional services (Seung, 2013; Luong et al., 2009). In sum, cultural idioms appear to contribute to the creation of knowledge, sharing meaning, and attitudes towards mental health and professional services amongst AsAms, thus impacting help-seeking behaviors. Although literature highlights how cultural idioms may impact AsAm help-seeking behaviors, the present study aspired to further explore the cultural perceptions contributing to social stigma and how they may impact AsAm parental help-seeking behaviors for their children with ASD.

Facilitators of AsAm Parental Help Seeking Behaviors for Access and Utilization of Professional Services

Along with the emerging knowledge of systemic, self, and social barriers to help seeking behaviors, there is also some emerging research towards the facilitators to help seeking behaviors (Hebert & Koulouglioti, 2010). Similar to other ethnic minority groups, AsAm parents have expressed motivations for accessing ASD services due to their concerns for their child or children's future outlook (Wang & Casillas, 2012; Lovelace et al., 2018). Wang and Casillas (2012) revealed that many Mandarin-speaking parents were motivated to utilize services for their children in order for their children to accomplish "independence, normal life, education, contribution to society, and social relationship" (p. 601). Furthermore, parents were motivated to improve their parent-child relationship, thus serving as a facilitator to help-seeking behavior

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(Wang & Casillas, 2012). Despite the significant role shame and stigma play, Korean American parents recognized that children may experience improvements if appropriate interventions are implemented (Wang & Casillas, 2012). In a study of Korean American mothers, Seung (2013) displayed that they were more motivated to access professional services for their child diagnosed with ASD in order to improve academic skills and were less focused on improvement of social skills. An additional facilitator for help seeking behaviors amongst Korean American parents for their children was the social acceptance of disability and satisfaction of special education services in the US compared to Korea (Wang & Casillas, 2012; Parette et al., 2004). Moreover, the collaboration of creating treatment goals that align with AsAm parental values such as academics or language acquisition as well as supportive relationships between AsAm parents and their child's service provider encourages ongoing utilization of such services (Seund, 2013; Parette et al., 2004). Therefore, less impact of social stigma towards ASD and disabilities facilitated greater optimism amongst AsAm parents in seeking help for their children's challenging behaviors (Parette et al., 2004). Although internal motivation and optimism have been found to serve as facilitators for help seeking behaviors amongst AsAm parents for their children, Kim et al. (2020) highlight the ongoing need to explore "AsAm families' experiences specific to the diagnostic process, community service use, or professional relationships" (p. 318). Thus, the current research study explored AsAm parents' help-seeking experiences to add to the existing literature regarding AsAm parents' motivations for accessing services for their children diagnosed with ASD.

Parental Experiences of Having a Child Diagnosed with ASD

Along with better understanding how various barriers and facilitators may contribute to help-seeking behaviors amongst AsAm parents, it is also crucial to understand how AsAm

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parents' lived experiences raising a child diagnosed with ASD may impact their help-seeking behaviors for their child. Parental lived experiences for those caring for a child diagnosed with ASD may include navigating the US healthcare system, accessing specialists in NDDs for ASD diagnostic evaluations, nuclear family and collective community meaning-making of their child's ASD diagnosis, and utilizing EBP as a first-line of intervention (Elder et al., 2017; Kim et al., 2020; Voliovitch et al., 2021). Thus, research has heavily explored parental stress amongst parents of children diagnosed with ASD. Deater-Deckard (2004) describes parental stress as the result of adapting to parental demands which may lead to unhelpful physiological or psychological experiences. Available literature has demonstrated that parents with a child diagnosed with ASD experience higher levels of stress compared to parents who have typically developing children and parents may be more likely to develop challenges with their social cognition, mood disorders, as well as internalizing and externalizing behaviors (Elder et al., 2017; Fletcher et al., 2012; Brei et al., 2015; Voliovitch et al., 2021). Additionally, research has found that many of the associated adverse outcomes of caregiving for a child with ASD may be due to their child's core ASD symptomatology such as behavioral issues, social skills, emotional dysregulation, withdrawal, or attention problems (Brei, 2015; Voliovitch et al., 2021). Although there is research surrounding general parental stress, this study aimed to contribute to the literature surrounding stress amongst AsAm parents by exploring how parenting stress may impact their help-seeking behaviors towards accessing services for their child.

In addition to the types of stress parents may experience, research has also explored what impacts various stressors may lead to. Negative outcomes that have been identified for parents of children with ASD include marriage challenges, poor parental physical health, depression and anxiety amongst parents, family cohesiveness, and financial challenges (Brei, 2015). Moreover,

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Fletcher et al. (2012) found that mothers typically work-from-home to attend to their child's daily living and treatment needs; whereas, fathers may experience increased stress by being the sole-income earner. Literature surrounding racial and ethnic minority parents have found similar findings surrounding parental stress; however, these particular parents can experience heightened stress due to the discussed systemic, internal, and external barriers to accessing services (DuBay et al., 2018; Hussein et al., 2019; Luong et al., 2009; Kim et al., 2020; You & Rosenkoetter, 2014). In regards to AsAm parents, immigration status was also found to prevent AsAm parents from accessing additional support systems such as extended family separated by geographic location who lived in their home country (Canham, 2009). Some argue that the stress that is universally experienced by parents of children with ASD might itself lead to increased parental isolation rather than social stigma (Wang & Casillas, 2012). The literature surrounding parental stress and its impact sheds light on the importance of better understanding these experiences and how they may negatively impact parents' access to services for their child. Due to the various experiences and barriers parents may experience, this study aimed to gain a more holistic perspective of what impacts AsAm parents' help-seeking behaviors for their child.

AsAm Parent Stress Reduction Strategies

Coping skills are imperative for parents to embrace and practice when facing the day-to-day stressors related to parenting a child diagnosed with ASD. Emerging literature has highlighted parents' coping mechanisms surrounding parental stress. Compared to White parents, AsAm parents were found to engage in more cognitive reframing as a coping mechanism for everyday challenges (Troy et al., 2007). Additional coping strategies that have been found amongst AsAm parents include positive thinking, emotion-focused coping, rational coping, confronting, spiritual support, mental recharging, and passive appraisal (Troy et al., 2007; Wang

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& Casillas, 2013; Wang & West, 2016). Despite social stigma impacting help-seeking behaviors amongst AsAm parents for their children, literature on parental stress found that some parents heavily relied on families and friends for support (Gray, 2003). The emerging literature on coping strategies utilized by AsAm parents' who have a child with ASD may support service providers in fostering supportive relationships to assist AsAm parents accessing early interventions and other treatments for their children. Therefore, the study aimed to further investigate and highlight the systemic, self, and social supports AsAm parents access and utilize to reduce experienced parental stress and improve their child's prognosis.

Due to the wide-scope of factors that may impact AsAm parents' help-seeking behaviors for their child's access to care, the present study will examine the lived experiences of AsAm parents with a child diagnosed with ASD. More specifically, it will examine the experience of AsAm parents accessing services for their child as well as various barriers and facilitators to utilization of such services. Within the past decade, ASD prevalence rates have increased. Greater recognition of ASD as well as greater awareness towards the wide-scope impact ASD has on a child and their parents have prompted researchers to expand their knowledge of ASD to include those from diverse racial and ethnic backgrounds. The limited yet growing area of literature surrounding AsAm parents who have a child diagnosed with ASD presents a unique contribution of this present study. Exploration into AsAm parents' experiences navigating self, social, and systemic factors will provide insight towards appropriate service utilization amongst AsAm children.

Method

The current qualitative research study explored the lived experiences of AsAm parents with a child diagnosed with ASD in order to better understand parents' access to services for their child. In addition, this research study aimed to better understand the cultural perceptions of seeking and accessing those services. Cultural perceptions that were explored included cultural expectations of child development as well as parental help-seeking behaviors and the impact of stigma (e.g., self and social) on access to services (Corrigan, 2004). Moreover, the current study aimed to diversify and enhance the field's current understanding of the experiences of parenting a child with ASD among AsAm parents, specifically towards navigating access to services for their child to utilize. Due to the exploratory nature of the current study examining AsAm parents' access to services for their child (or children), semi-structured interviews were conducted to gather a detailed description of the lived experiences of AsAm parents who have a child with ASD. These experiences were described in-depth in order to shed light on the cultural perceptions that influenced access and utilization of professional services for their child.

Study Design

Thematic analysis (TA) framework by Braun and Clarke (2006) was used to explore cultural perceptions that potentially impacted the access and utilization of professional services amongst AsAm parents for their children with ASD. As part of the qualitative research study, an in-depth semi-structured interview guided by Bronfenbrenner's ecological systems model was conducted to explore sensitive topics and provide rich, meaningful data (Dempsey et al., 2016; Bronfenbrenner, 1977). TA recognizes the significance of sociocultural and structural conditions such that "meaning and experience are socially produced and reproduced" (Braun & Clarke, 2006, p. 85). Therefore, TA allowed the researcher to highlight the potential cultural perceptions

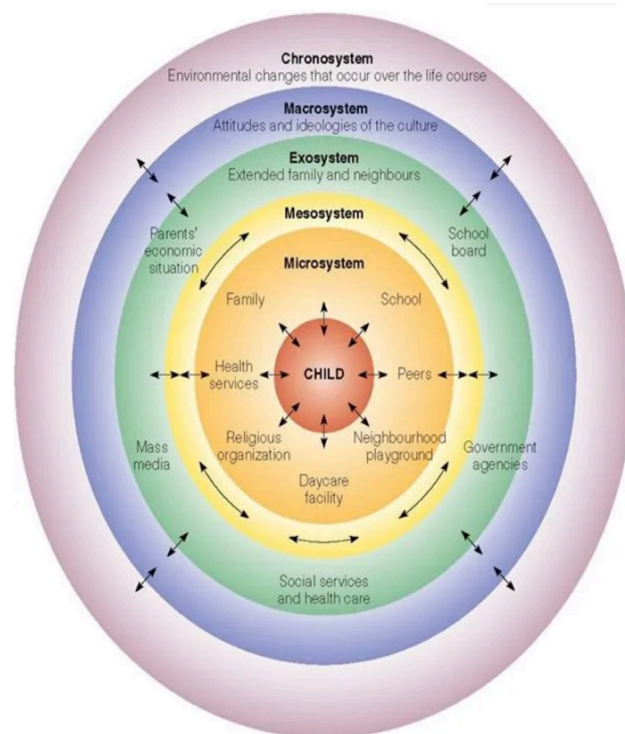
impacting access to services and dynamic lived experiences within an overarching model rooted in ecological systems theory (Bronfenbrenner, 1977).

Theoretical Framework

Bronfenbrenner’s ecological systems model was used to situate the various domains impacting AsAm parents’ help-seeking behaviors in accessing services for their child diagnosed with ASD. An ecological systems model, as seen in Figure 1, recognizes four different environments –microsystem, mesosystem, exosystem, and macrosystem –that can directly or indirectly impact one’s dynamic human development process (Bronfenbrenner, 1977; Ettekal & Mahoney, 2017). Thus, this model served two purposes for the current research study. First, Bronfenbrenner’s ecological systems model offered a way of organizing the interview guide (Bronfenbrenner, 1977). Secondly, the model aided the current study during data analysis to describe the ways in which various internal and external factors within the various ecological systems impacted AsAm parents’ access to services for their child diagnosed with ASD.

Figure 1

Bronfenbrenner’s ecological model (Bronfenbrenner, 1977; Guy-Evans, 2020)



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The first level, the microsystem, is composed of a myriad of settings that AsAm parents directly interact with such as peers, the family unit, community organizations, and health services. Due to the collectivistic qualities of AsAm culture, the current study also included and considered extended family members as part of the microsystem rather than the exosystem. In the microsystem, self and social stigma surrounding raising a child diagnosed with ASD may be internalized by AsAm parents due to influences from the macrosystem coloring their worldview, which in turn, may impact their help-seeking behaviors. The macrosystem can be described “as the set of overarching beliefs, values, and norms, as reflected in the cultural, religious, and socioeconomic organization of society” (Ettetal & Mahoney, 2017, p. 5). Although Bronfenbrenner situated the macrosystem as the final layer within his original ecological model, the reviewed literature on AsAm parents and ASD suggests that AsAm parents’ macrosystem is deeply intertwined with how AsAm parents may interact within their microsystem. More specifically, cultural beliefs, norms, and values towards ASD or having a child with a disability in general can influence AsAm parents’ worldview by endorsing shame or fatalism as well as isolating oneself from extended family or community. Additionally, the macrosystem can influence the ways in which atypical versus typical behavior and developmental milestones may be perceived. Thus, the current study’s use of Bronfenbrenner’s ecological systems model assisted in exemplifying how these individual and collective perceptions situated within the micro and macro system may serve either as a facilitator or barrier to AsAm parental help-seeking behaviors in accessing services for their child.

In addition to the microsystem and macrosystem, Bronfenbrenner’s ecological system model also takes into consideration the various external systems that may impact an individual as well as how the interactions across various systems influence an individual. The third ecological

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level, the exosystem, entails factors that indirectly influence an individual's development such as socioeconomic status as well as utilization of healthcare or government agencies such as Supplemental Security Income (SSI) or housing assistance. Some of the reviewed available literature suggests that external factors such as socioeconomic status and systemic racism embedded into healthcare may also influence AsAm parents' access to services for their children highlighting a need to further explore the role of factors in AsAm parents' exosystem.

Additionally, the emerging literature focused on AsAm parents raising a child diagnosed with ASD has not yet explored how different factors within each system interact with one another to serve as a barrier or facilitator to help-seeking behaviors in accessing services for their child. This interaction across the micro, macro, and exo systems is defined by Bronfenbrenner (1977) as the mesosystem. For AsAm parents, the mesosystem may entail coordinating their child's care across different service providers and teachers or the interaction between systemic racism and stigma. Despite some emerging literature, the current study aimed to gather rich data on how the interaction of different factors across various system levels impact AsAm parents' help-seeking behaviors in accessing professional services for their child diagnosed with ASD.

Due to the described wide-scope impact of having a child with ASD and the various factors that may hinder AsAm parents' help-seeking behaviors in accessing care for their child, Bronfenbrenner's ecological systems model served as a theoretical framework for better understanding the cultural perceptions embedded within a dynamic, multi-layered environment that influences AsAm parental help-seeking behaviors (Yamashiro & Matsuoka, 1997; Takayama, 2010). More importantly, utilizing an ecological systems framework to inform this qualitative study's semi-structured interview guide helped to understand the potential roles that internal (e.g., stigma, perceptions of atypical and typical development) and external factors (e.g.,

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socioeconomic status, systemic racism) may have on AsAm parents' help-seeking behaviors for their children diagnosed with ASD. Therefore, this qualitative study's use of TA aided by an ecological systems framework allowed for a holistic approach of creating a priori and post hoc themes that elicited a meaningful, culturally sensitive presentation of research (Theise, et al., 2015).

Participants

Participants were English-speaking, AsAm parents who identified as a child's mother or father and were 18-years-old or older, resided in the greater San Francisco Bay Area, lived with their child diagnosed with ASD, and identified as a primary caretaker involved in the coordination of their child's treatment (e.g., attends provider-parent meetings, participates in parent trainings, etc.). In the current research study, AsAm "parents" included individuals either in mother-father dyads or who are single-mothers.

Recruitment

A convenience sample and snowball sampling were utilized to recruit participants for the interviews. Convenience sampling is a simple and affordable method that recruits potential participants who meet baseline inclusion criteria (e.g., identifies as AsAm, is a mother or father to a child diagnosed with ASD) and are relatively easy to access (Etikan, Musa, & Alkassim, 2015). In addition to utilizing convenience sampling, a snowball sampling method was utilized as an additional recruitment method to ensure data saturation. Snowball sampling was used by inquiring the study's recruited participants on whether or not they know of others who have experienced similar lived experiences and can participate in the study (Naderifar, Goli, & Ghaljaie, 2017). Participants were asked to recruit others by word-of-mouth and sent the

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proposed research study's recruitment flyer to people they know of who fall into this hard-to-study population (Renjith et al., 2021).

Flyers (Appendix A) were circulated on various social media platforms (e.g., Facebook and Instagram), at targeted community settings (e.g., community health clinics, Asian focused community centers, local businesses, local churches, schools, and aftercare programs). In addition, flyers were shared electronically to colleagues and professional listservs (e.g., AsAm Psychological Association) and service agencies around the San Francisco Bay Area (e.g., Pacific Clinics, Regional Centers, First Five Programs, Resource Navigators), who were asked to post and circulate the flyer. Each potential participant was given the option to either contact the researcher either via email or phone call through Google Voice in order to share their interest in participating in the proposed study. Once potential participants were collected from a convenience sampling method, the researcher conducted a brief screening questionnaire (see Appendix B) to determine his or her eligibility to participate in the research study. Potential participants responded to screening questions conducted in a brief interview format over the phone or a password-secured Zoom video to ensure particular qualities and experiences met participant inclusion criteria (Etikan, Musa, & Alkassim, 2015). In addition, demographic information was collected using the screener (see Appendix B).

Procedure

After eligibility was determined, all participants received an informed consent form approved by the University of San Francisco's Institutional Review Board (IRB) to review, sign, and complete. The consent form provided an explanation of the study's purpose and indicated that all participants may withdraw from the study at any time without penalty. Additionally, the form included information about the length of the confidential individual interviews (i.e.,

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approximately 60 to 90 minutes) as well as the interview being audio recorded, transcribed, and protected with a password encryption. A completed and signed consent form initiated the semi-structured interview; participants who did not provide a signed consent form were not permitted to move onto the interview. Individual interviews were held remotely through a password protected Zoom meeting room. Telehealth interviews were conducted in a setting free of distractions and with stable internet connection. Two participants felt comfortable to complete the interview in its entirety with the video featured on; nine participants expressed discomfort in enabling the video feature on Zoom. In order to ensure participants' comfort level throughout the interview, the researcher and participants disabled the video feature of the Zoom meeting.

The semi-structured interview (see Appendix C) consisted of open-ended questions informed by Bronfenbrenner's (1977) ecological systems model. As a result, the semi-structured interview aimed to understand the participants' lived experiences of an AsAm parent with a child with ASD within multi-level environmental contexts. An example question that was asked of parents included *"What word or phrase do you use to describe your child's diagnosis to others?"* Additionally, the researcher specifically elicited AsAm parents' experiences with access to care and utilizing services such as *"What was most difficult about this process? What motivated you to seek out these different services for your child?"* Concluding the interview, participants were given an opportunity to ask the researcher questions and provide clarification if needed. Additionally, each participant was given a resource list (Appendix D) of different community-based resources dedicated to parenting a child with ASD (e.g., parent-support groups, parent-training groups). Participants were offered a \$20 Amazon gift card after completing the interview in order to compensate them for their time and sharing their unique lived experiences. After the interviews ended and the participant left, field notes were

documented which recorded observations and potential themes that arose during the interview in order to supplement data analysis findings. Due to confidentiality, all protected health information from each participant was de-identified. All data is presented without identifying information.

Data Analysis

The current research study utilized a thematic analysis (TA) framework to organize and provide a detailed description of the data set (Braun & Clarke, 2006). Identification of themes were generated at a latent level rather than a semantic level by utilizing TA to “theorize the sociocultural contexts, and structural conditions, that enable the individual accounts that are provided” (Braun & Clarke, 2006, p. 85). Themes identified at a latent level examine participants’ underlying assumptions that shape the surface level of data content (Braun & Clarke, 2006). The researcher utilized Braun and Clarke’s (2006) six steps of TA for the proposed qualitative study data analysis plan.

1. All interviews were audio recorded through Zoom and transcribed verbatim by Otter AI, a transcription software, to maintain the integrity and accuracy of the data. The researcher then familiarized herself with the data by reading through each transcript.
2. Each transcript was reviewed for a second time in order to generate initial codes that were relevant to the study’s research questions.
3. Initial codes were then organized into potential themes that reflect the cultural perceptions pertinent to parenting an AsAm child with ASD. This researcher coded for both *a priori* themes that were generated before data collection and *post hoc* themes that emerged during data collection utilizing qualitative coding software, Atlas.ti (Theise, et al., 2015). The categorization of themes were organized to reflect experiences accessing

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services for their child to utilize, aided by Bronfenbrenner's ecological systems model (Bronfenbrenner, 1977).

4. Themes were reviewed and compared to the collected data to determine whether or not a relationship existed.
5. Additional analysis helped the researcher define and name themes in order to refine, separate, combine, or remove themes. Through an iterative process, the researcher finalized themes and sub-themes to produce a narrative from the data.
6. Lastly, the researcher provided a story and background of the collected data based on the analysis conducted. Explicit examples were incorporated to reflect the posed research questions and literature review from the analysis.

The researcher utilized field notes to supplement the iterative process of reviewing transcripts, generating initial codes, developing themes, and creating an overarching narrative using clear examples from the collected data (Braun & Clarke, 2006). Consequently, the researcher highlighted descriptions and experiences of AsAm parents' help-seeking behaviors for their child diagnosed with ASD.

Researchers' Positionality and Trustworthiness

The researcher completed initial coding and engaged in the iterative process of data analysis informed by Braun and Clarke's Thematic Analysis (TA;2006) approach. Similar to all participants interviewed for this qualitative research study, I identify as Asian American and have a family history of immigration to the United States. Specifically, I identify as a second-generation Filipina American who has obtained post-secondary education in the form of completion of an undergraduate degree as well as a masters degree. All participants also identified as having completed some form of post-secondary education. In contrast, all

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participants identified as either a mother or father to a child diagnosed with ASD. While I lack personal experiences in raising a child, more so parenting a child with ASD, I have a family history of neurodiversity. Moreover, I have seven years of professional experience and training in how to ethically support individuals across the lifespan who have been identified as neurodiverse (e.g., ADHD, ASD, down syndrome). Thus, my intersectional identities and experiences have contributed to my dedication to serving this community.

My intersecting identities, lived experiences, and positionality may have also contributed to potential biases when looking at the data through a cultural perspective informed by Bronfenbrenner's (1977) ecological systems model. As such, this researcher incorporated reflexivity throughout the various stages of the research process. I have debriefed and collaborated with my trusted chair to ensure the interview guide was developed in a culturally responsive manner. For instance, I debriefed with my chair to delineate how to ethically and morally explore self and social stigma surrounding ASD as well as ways to explore the strengths of participants' children. In addition, I received mentorship in how to ethically conduct qualitative research by my chair who has formal TA training. Frequent check-ins ensured themes and codes were generated to be reflective of the collected data. Capturing the data from a thematic analysis methodology informed by an ecological systems framework allowed me to explore AsAm parental experiences in raising a child diagnosed with ASD from a holistic perspective. Moreover, engaging in reflexivity practices while utilizing TA assisted me in identifying themes that demonstrated to be most impactful for this particular community.

Results

A total of 11 AsAm parents who have a child diagnosed with ASD completed an interview. The semi-structured interview (see Appendix C) utilized to explore these topics were formulated to examine how access to evaluation and support services were impacted by cultural perceptions. The voices of AsAm parents were highlighted to identify how cultural perceptions impacted the disclosure of their child's atypical child development, awareness of ASD diagnosis, and initiation of professional services. Specifically, the current qualitative research study shed light on the lived experiences of AsAm parents with a child diagnosed with ASD in order to better understand parents' access to services for their child, better understand the cultural perceptions of seeking and accessing those services, and aimed to diversify and enhance the field's current understanding of the experiences of parenting a child with ASD among AsAm parents, specifically towards navigating access to services for their child to utilize. This study incorporated quotes from participants to further exemplify emerged themes from the findings. Six themes emerged from this study and included: (1) comparisons, (2) stigma, (3) resilience, (4) support for services, (5) needs for AsAm parents and their children, and (6) advice to other AsAm parents (refer to Appendix E for themes, subthemes, definitions, and proof quotes). One subtheme was generated for comparisons, which included cultural perceptions. The remaining five subthemes were generated under stigma. This included denial, fear, language, isolation, and hopelessness.

Participants

A total of 11 participants met eligibility and completed the interview process in a password protected Zoom meeting room provided by the University of San Francisco. Screenings and interviews were conducted from January 2023 to September 2023. A total of 439

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people contacted the researcher via email and phone-call expressing initial interest in completing a brief screening to determine eligibility following dispersion of the study's recruitment flyer. Out of the 439 individuals who expressed interest, 67 individuals responded back to the researcher's attempts to schedule a brief screening for determining eligibility. A total of 27 individuals did not reply to this researcher's attempts to schedule the screening. A total of 40 people completed the eligibility screener. Participants were English-speaking, AsAm parents who identified as a child's mother or father and were 18-years-old or older, resided in the greater San Francisco Bay Area, lived with their child diagnosed with ASD, and identified as a primary caretaker involved in the coordination of their child's treatment (e.g., attends provider-parent meetings, participates in parent trainings, etc.). In the current research study, AsAm "parents" included individuals either in mother-father dyads or who are single-mothers. After screening potential participants, a total of 29 participants were excluded from the study. Those not eligible to participate in the study included those who did not identify as an AsAm with Asian ancestry, lived beyond counties within the greater California Bay Area region, or the researcher had significant difficulty understanding the individual due to limited English-language fluency. Participants who did not meet eligibility were offered and received a list of community resources.

Participants resided throughout the San Francisco Bay Area and surrounding communities. Nine participants lived in the Peninsula, one lived in the South Bay, and one lived in the greater Stockton area (see Table 1 below for participant demographics). All participants either completed a Bachelors ($n = 8$; 72%), Masters ($n = 2$; 18%), or Vocational ($n = 1$; 9%) level of education. Marital status of participants included six fathers (55%) co-parenting with their wives, three mothers co-parenting with their husbands/partners (27%), and two parents who were

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single mothers (18%). All participants were employed. Participants identified their gross family income between \$35,000-49,999 ($n = 1$; 9%), \$50,000-74,999 ($n = 3$; 27%), \$75,000-99,999 ($n = 3$; 27%), \$150,000-199,999 ($n = 2$; 18%), and over \$200,000 ($n = 2$; 18%). All participants self-identified as AsAms. Ethnic backgrounds of participants included Chinese ($n = 3$; 27%), Filipino ($n = 4$; 36%), bi-ethnic Filipino and Indian ($n = 1$; 9%), bi-ethnic Chinese and Vietnamese ($n = 1$; 9%), Indian ($n = 1$; 9%), and Indonesian ($n = 1$; 9%). Four participants indicated that they had 1 child (36%), four parents reported 2 children (36%), and three parents shared they had four children (27%). All 11 participants reported having sons with ASD. Nine out of the eleven (81%) participants' children were currently elementary school-aged. Two participants' children were pre-school aged (18%). In terms of birth order, four of the participants' children (36%) diagnosed with ASD were the youngest amongst siblings. One participant's child was identified as the eldest (1%). Lastly, four participants (36%) expressed their child did not have siblings.

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Participant Demographics

Table 1

Participant Demographics (n= 11)

Participant Pseudonym	Ethnic Background	Identity of Participant & Participant's Parenting Partner	Highest Level of Education	Occupation	Annual Household Income
Jenny	Indian	Mother (w/ father)	Bachelors	Receptionist	150k
Giada	Filipino	Single mother	Bachelors	Teacher	150k
Elizabeth	Filipino	Mother (w/ father)	Bachelors	Associate Director of Nonprofit	75-99k
Logan	Filipino-Indian	Father (w/ mother)	Masters	Pharmacist	50k
Grant	Indonesian	Father (w/ mother)	Bachelors	Self Employed	50-80k
Marcus	Chinese	Father (w/ mother)	Bachelors	Digital Data Analyst	75-80k
Neil	Chinese	Father (w/ mother)	Bachelors	IT Technician	200k+
Colin	Filipino	Father (w/ mother)	Bachelors	Cashier	40k
Jason	Filipino	Father (w/ mother)	Masters	Receptionist	80k
Nelly	Chinese	Single mother	Bachelors	Waitress, Restaurant Manager	60-70k
Margo	Chinese, Vietnamese	Mother (w/ partner)	Vocational	Licensed Vocational Nurse	200k+

Table 2

Participant's Children's Demographics

Participant Pseudonym	Child's Pseudonym & Gender	Child's Age at Evaluation, Age at Diagnosis, & Current Age	Child's Additional Medical Conditions & Presenting Concerns
Jenny	Kent, son	1.5-years old 1.8-years-old 4-years-old	Difficulties eating; Minimally verbal, lack of eye contact, difficulty responding to name, social isolation, behavioral dysregulation ("anger issues," crying), restricted interest, inflexibility
Giada	Andrew, son	3.5-years-old 4-years-old 5-years-old	Gross motor delays (walking), academically behind; Challenges with verbal communication, difficulty responding to name, lack of eye contact, social isolation
Elizabeth	Lucas, son	1.9-years-old 2-years-old 4-years-old	Global cognitive delay, hyperlexic; Minimally verbal, nonverbal communication, lack of eye contact, difficulty responding to name, behavioral dysregulation, restricted interest, inflexibility, repetitive behaviors ("flap his arms"), social isolation
Logan	Jenry, son	3-years-old 4-years-old 6-years-old	Speech delay, Gross motor difficulties; Minimally verbal, lack of eye contact, challenges in understanding emotions, social isolation, repetitive behaviors, restricted interests, sensitivity to sensory stimuli

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Grant	Jordan, son	4-years-old 4-years-old 8-years-old	Intellectual disability, academic difficulties, gross motor challenges; minimally verbal, difficulty responding to name
Marcus	Arturo, son	5-years-old 5-years-old 8-years-old	Fine motor difficulties, sadness; Challenges with verbal communication, difficulty responding to name, lack of eye contact, flat affect, socially withdrawn and isolated, repetitive behavior (clapping hands, stomping feet)
Neil	Daniel, son	5-years-old 5-years-old 8-years-old	Gross motor difficulties; Minimally verbal, difficulty responding to name, lack of eye contact, flat affect, behavioral dysregulation (“gets upset easily”), repetitive behavior (line up or dangle toys), restricted interests
Colin	Jack, son	5-years-old 5-years-old 6-years-old	Minimally verbal (some words, pulling to show), social isolation, difficulty responding to name, lack of eye contact, repetitive behaviors, restricted interest (food, drawing)
Jason	Paul, son	6-years-old 6-years-old 7-years-old	Academic challenges, fine motor difficulties; Challenges with verbal communication, difficulty responding to name, lack of eye contact, difficulties with social interactions, flat affect
Nelly	Barry, son	4-years-old 5-years-old 9-years-old	Difficulties eating; Minimally verbal, social isolation and withdrawal, lack of eye contact, restricted interests, repetitive behaviors
Margo	Mason, son	1.5-years-old 2-years-old 8-years old	Behavioral challenges (“a lot of tantrums”), lack of eye contact, repetitive behaviors, challenges with sensory stimuli

Themes

In total, there were six themes and six sub-themes that emerged from the interviews. Bronfenbrenner’s (1977) ecological systems model aided in framing the data analysis. The ecological systems model, as seen in Figure 2, assisted in illustrating the help-seeking experiences of AsAm parents across various ecological systems (Bronfenbrenner, 1977). The six themes of this study included: (1) comparisons, (2) stigma, (3) resilience, (4) support for services, (5) needs for AsAm parents and their children, and (6) advice to other AsAm parents (refer to Appendix D for Themes, Codes, and Definitions). One subtheme of cultural perceptions was generated for the theme of comparisons. The remaining five subthemes were generated under stigma. This included denial, fear, language, isolation, and hopelessness.

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in her child's social communication and reciprocity, which was a commonly endorsed theme across all participants:

“... My sister's children would come at home and visit us, and then Andrew would go and hide into his room. He did not want to talk to them... That's when it had dawned to me that something was wrong.”

Another participant, Jenny, shared how she struggled to breastfeed her child; a difference she noticed in comparison to other infants. Across participants, each expressed similar challenges endorsed by their children either at the time of the study or when their child was younger in age. Specifically, all participants' children did not respond to their name when called. In addition, all participants expressed how their children experienced difficulties in making and maintaining eye contact. Most participants also expressed challenges with either expressive or verbal language. Regarding restricted and repetitive behaviors such as flapping of arms and hands and spinning in circles, some participants shared that their child engaged in these behaviors along with having sensitivities to sensory stimuli. For instance, Nelly indicated how their son “doesn't like the crowd and the noise. He hates parties.” Similarly, Elizabeth shared how her son, Lucas, had an aversive reaction to taking showers because it “freaked him out.” Moreover, some participants reported learning difficulties which led to enrollment in special education or having a one-on-one instructional aide in school. However, some participants indicated that their children were at grade level and did not require academic accommodations.

Comparisons of child behavior within the microsystem and exosystem contributed to the initial awareness of atypical child development which highlighted mixed findings regarding how participants became familiar with expected milestones and when they first expressed concerns to professionals. The ages varied across participants' children. Most participants became aware of their child's difficulties between 12 to 24-months. The participants recognized these difficulties

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independently due to knowledge of general developmental milestones as well as having extended family who received ASD diagnoses. Jenny demonstrated a general sense of developmental milestones by comparing her child's behavior to others:

When I compare how a normal child can develop the stages and all that compared to how Kent was responding to his growth. That is when I realized... His first to second year... You know, by that time he should have been responding to uh such things. But he was not responding completely.

Similarly, Elizabeth shared a general sense of what developmental milestones a child should meet around the first 12-months:

It was a little past his first birthday, because he wasn't making eye contact, and then he would be pretty stoic in his face. Except for extreme emotion, so extremely you know, very, very happy or very, very sad, but not much in between the nuances. . . And that was kind of like the thing that was making me more concerned. You know, because I was holding him and I'm like, trying to get him to like, look at my gaze.

In contrast, some participants noticed delays in achieving milestones by the time their child was between three to six-years old. For example, Colin, a Filipino father, denied noticing any developmental delays between 18 to 24-months. Rather, he shared that his son “was barely five. He was going to five like a month before his birthday... it was difficult in communication... Jack can be like a few distance away from you and you call his name, but you see he is not responding to you.” Participants who recognized developmental delays later in their child's life shared how they were prompted about their child's developmental delays by individuals within the child's microsystem including teachers or family members. For instance, Nelly indicated how “teachers were complaining that he was always on his own in class. Sometimes he hardly ate his lunch.”

Comparisons of participants' children's developmental milestones also contributed to the start of the evaluation process and age at which their child received an ASD diagnosis. Notably,

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participants' timelines varied for when they first had their child evaluated. Some participants emphasized how early recognition of developmental delays resulted in early conversations with a medical provider. In contrast to participants whose children were evaluated and diagnosed by 24-months due to early recognition of atypical development, some participants experienced delays in seeking support for various reasons despite some awareness of delayed milestones. Reasons included anticipation of developmental milestones being met, minimal endorsement of concern until participants began to notice or received notification how delays interfered with their child's academic or social well-being within the school setting, and lack of concern expressed by physicians concerning developmental delays. Jason, whose child was roughly five to six-years-old when concerns arose, shared:

... when I first noticed this problem, I just feel maybe it's a minor issue to me. So I was finding it difficult. . . like communicating to Paul. It was very, very difficult as well, my my wife noticed that she was very worried. . . I would just say the time when we noticed this, it was kind of late too late.

Elizabeth shared how she felt “some type of way about that doctor” when expressing her concerns about her son, so much so that she requested the pediatrician to send an ASD evaluation referral despite the pediatrician's lack of concern:

. . . [pediatrician] was just kind of like, Lucas seemed, he seemed fine. . . I mean, I don't think that that doctor necessarily had any concerns. But at least he was willing to follow up with my concerns. And so at that doctor's appointment, yeah, he was just like, he seems fine. You know, like, like, you know, he kind of doesn't do so much eye contact, but he was like, you know, but for a small child, like, that's not necessarily concerning, you know, it might just be a shy child.

Some participants reported how their medical provider normalized how children can reach developmental milestones at varied ages which contributed to less concerns. For example, Giada, a single, Filipino mother, did not endorse too much concern initially. Giada shared how

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her son's medical professional indicated that "some kids will take some time to start walking and others can start earlier... it was something that is normal to every kid and kids have different stages of growing." These factors (e.g., lack of participants and health professional's concerns, waiting for participants' children to meet developmental milestones) contributed to a delay in diagnosis for some children. Giada shared "how "at first I felt like, just because the doctor told me that it was something normal, I just took it lightly. And I just thought that it was going to, it was something that was going to end. But after some time, that's when I realized that the doctor was ignorant about it, and did not take it serious, and I felt frustrated. I did not feel supported." As such, participants reported that delays in diagnosis contributed to strong emotions such as frustration as well as delay in starting interventions starting in later childhood compared to early interventions. While Giada's son began receiving support at age 4, Margo's son began early interventions before 2-years-old. In sum, participants' comparisons of their child's development to other children in conjunction with a health professional's perception of developmental milestones contributed to when a child was evaluated and when help-seeking behaviors were initiated for further support services.

Subtheme: Cultural Perceptions

Most participants expressed cultural perceptions of celebrated behaviors within the AsAm community. Cultural perceptions of behavior included social participation within the microsystem and exosystem such as engaging in conversations with family members, participating in class with peers, achieving good grades, and contributing to society through obtaining a successful job or gaining leadership opportunities. While most participants recognized how closeness in familial and extended family relationships are often celebrated in AsAm culture due to values of collectivism, they also acknowledged how their child's challenges

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with social communication and reciprocity contrasted these celebrated behaviors. For instance, Giada shared how her son “did not even want to socialize with like other kids, so I know I noticed it then but then it became clear to me when he joined school.” Jenny further described how her son has difficulty “interacting with other people.” Therefore, Kent “really fights so much every morning” when he goes to daycare because “he does not like to go to the childcare.” Elizabeth shared similarities in terms of her son’s difficulties with socioemotional reciprocity, even with her son’s older brother:

I feel like all children that was raised in the pandemic, all have like, aversion to like people, because they were raised in shelter in place, but that was totally him. . . Even an aversion to like his brother, which was devastating for his older brother. . . his older brother would just want to like hug him or like, would call his name and he wouldn't respond. He had no interest in socializing, really. And it was more to get his needs met.

Elizabeth further highlighted how having a lack of interest in socializing is looked down upon in Filipino culture because “we’re all very affectionate.” Participation in social activities such as performing a song, dancing, or playing a team sport were all expressed as activities participants’ children actively did not engage in. For instance, Elizabeth eloquently captured:

I mean, I think being obedient like following directions. . . like performative behaviors. Like why don't you know, sing and dance? I definitely think our, our families ...not that they placed a high value on it, but they definitely value it. . . And my child is just like, oh, hell, no, he's not going to do that. He won't even be in the same room.

Additionally, participants expressed how academic accomplishment is valued within the AsAm community. Neil, a Chinese father, emphasized how he provides his son with positive reinforcement to encourage more engagement in celebrated behaviors amongst the AsAm community:

Yeah, like academic accomplishment of course and then excelling in sports because there's some kids that do sports very well with the sports and all. . . They actually have talents, some talents of singing, talents of good music and playing games and doing well

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academically. So I believe all these kind of things should be actually celebrated and appreciated from this kid. Of course, they need encouragement. . . But you should actually applaud the child very well. And then encourage the child, tell the child so that the child will be able to actually pursue his or her dream in a particular career. . .

All participants emphasized the importance of respecting one's elders within the community. However, participants reported challenges related to ASD characteristics such as difficulty maintaining eye contact, not responding to their name, or behavioral impulsivity (e.g., speaking out of turn); all of which reportedly interfered in their child's engagement with this celebrated behavior. When discussing the importance of respecting elders, Grant shared how lack of communication or unsolicited, random communication can be looked down upon:

“Yeah. That behavior. . . maybe not communicating frequently with each other. Yeah, you know, speaking out or maybe things you didn't really expect to be, you know, coming out . . . might feel kind of negative or viewed negatively.”

Similarly, Colin shared “Jack can be like a few distance away from you and you call his name, but you see he is not responding to you.” Moreso, Colin highlighted how lack of engagement with “public displays of affection” are behaviors that contrast “respecting” elders within the community. Some participants further highlighted the contrast between the value of respecting elders amongst the Asian American community compared to White-identifying individuals. For Nelly, addressing elders by “ma'am or mister” was pertinent for her to teach her child despite difficulties with socioemotional communication:

. . . I've seen most white kids call their elders by their names without any respectful prefix but we Asians don't do that. We always put a sir or ma'am or Mister. We can't just go and call a person or an adult, an adult, by their name, by their name. Asian parents frown, frown upon that.

In addition, some participants shared how their child's ASD symptoms are often better aligned with behaviors that are viewed negatively than positively within the AsAm community.

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For example, some participants reported how their child's tendencies of acting out of control do not align with family expectations and are often looked down upon within the AsAm community.

Colin stated:

“I'm saying seeing children that are disrespectful in nature, some students, some children are disrespectful. Some children not being taught the ethics and tradition of the Asian community. And some of them are not keeping to the different rules and regulations that regulate the community.”

Furthermore, participants such as Elizabeth shared how engaging in “non-compliance,” a term commonly used in applied behavioral analysis, aligned with AsAm beliefs and cultural norms viewing disobedience or not following directions as a negative characteristic. Elizabeth noted how non-compliance translated into “*matigas ang ulo*” in Filipino Tagalog or “hard-headed” in American English. She further described how in Filipino culture, being hard-headed can be “misconstrued” as being “rude or disrespectful” which connects to the ways in which stigma (cultural and self) are intertwined with cultural perceptions of behavior that participants identified. Specifically, stigma towards ASD characteristics can be attributed to behaviors perceived as disdain within the AsAm community, and will further be explored in the next section.

Stigma

All participants reported negative beliefs towards their child's atypical development along with their child having an ASD diagnosis. Stigma was endorsed by the participants themselves (self-stigma) by highlighting feelings of denial, isolation, fear, disappointment, shame, or embarrassment. Jason indicated, “Yeah, at first it was difficult.” In addition, participants reported that their child's local neighborhood and school (microsystem) and society at large (exosystem) through popular media and research embodied social stigma by ignoring

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participants and their children in school or the neighborhood park. For instance, Logan, a Filipino-Indian father, shared how “kids don't really like. . . they don't think a kid with autism can play so they just talk a lot. And now, I found out some, there are some parents who not allowing their kid to play with Jenry. So it has been a difficult journey.” All participants from varying ethnic backgrounds expressed how once their child received an ASD diagnosis, rumination of negative beliefs were frequent occurrences. One participant, Jenny, an Indian mother, expressed how she felt like “an odd one out sometimes.” She described how she recognized that her child was different from those in their local neighborhood. As a result, Jenny shared how she “would even feel like I should hide Kent, like he should not associate with the other children.” Jenny further commented how she “was not comfortable going out with her child,” including their place of worship.

In conjunction with self-stigma, all participants reported how social stigma was endorsed by their communities at large. Nelly highlighted how stigma towards ASD commonly generalizes a picture of “children that have like more severe forms of autism,” which contributes to “people chattering or pointing, laughing” who are situated within the microsystem and exosystem. A Chinese father, Marcus, highlighted how his 8-year-old child, Arturo, has been “mocked and abused by his mates, around the home and also in school.” Experiences of being bullied were reportedly due to described challenges surrounding socioemotional reciprocity (e.g., making eye contact, not responding to the child’s name) as well as repetitive gross motor movements (e.g., sudden clapping hands or stomping of his feet). Marcus indicated how challenges with socioemotional and repetitive behaviors contributed to “emotional trauma that some of these children face” from “a lot of nasty things said to them.” Colin further exemplified how his son was rejected due to observed characteristics of ASD:

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Jack stopped relating with most of his friends and you, you know their families. . . our people, they can read, they can give meaning to things. So, Jack, he was kind of not free with his friends again, and he was kind of rejected amongst people.

Similarly, Margo shared how the development of tics or repetitive gross motor movements may contribute to her son, Mason, being bullied by others as she observed happen with her cousin with ASD. She further explained how families may be more understanding of uncontrollable or self-soothing repetitive movements compared to those within the exosystem such as individuals in the greater neighborhood. She further shared how, “other people are, there’s bullies.” Marcus also exemplified how community-endorsed social stigma within the microsystem (school) and exosystem impacted his son’s emotional well-being and self-esteem. Specifically, Marcus noted:

“... I can see my child is feeling depressed or something. He is majorly sad. A lot of times he feels very unhappy... like someone was really lost... someone who isn’t seeing himself as a normal person...”

Overall, self stigma and social stigma were endorsed by all participants. Social stigma towards ASD contributed to participants’ endorsement of self stigma, resulting in hesitancy in being in public spaces due to experiences of negative treatment within the microsystem and exosystem that impacted their child’s emotional well-being.

Subtheme: Denial

All participants endorsed difficulty accepting their child’s diagnosis, regardless of how much or little support their child required based upon their described challenges. Margo, a Vietnamese-Chinese mother, expressed how she cried after learning about her eldest son’s diagnosis despite receiving reassurance from evaluators that her son’s difficulties fell in the “gray zone” for meeting ASD criteria.

I cried. When she told me it was hard even knowing that. Even knowing that my family had it, and I already knew because I'm a nurse, too. So it's kind of like a high chance of

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him having it. But the hopeful thing, the good thing was that she was saying like, he really was in the gray area where he could be but he's borderline, but it's up to me, I want to stamp him essentially, with the autism diagnosis. And I said, you know what, like, it's hard for me to hear, but I rather you. He has a diagnosis, and he gets all the resources and all the help he can get, versus me just trying to pretend like, oh, no, he's just, you know, on this low end.

Jenny, another participant who identified as a mother highlighted:

. . . for every mom, every, it is every mom's wish to have a normal child, a normal life, and all that. So, it was not something that I could just wake up one day and make peace with the fact that my child is autistic, and uh I will forever live with that, you know.

Similarly, Logan expressed how difficult it was to accept his son's diagnosis. His endorsement of denial was due to not experiencing similar difficulties with his first-born child. Logan shared how "it was very hard. Yeah. Because it was my first, our first experience." Logan also indicated "I talked to my therapist" for outside support to process and learn more about his son's diagnosis as well as directions on "how I can handle the situation." More importantly, to learn how to better support his son's overall well-being by taking "it slow. And just learn more, learn more about him."

Across all participants, endorsement of denial was intertwined with how their child was different compared to other children their age. Furthermore, associated stigma related to ASD and atypical development exacerbated feelings of denial. Although each participant expressed varying levels of support their child required, participants' initially expressed denial over the child's eventually confirmed diagnosis. As self and social stigma were associated with denial, fear was another identifiable associated emotion related to their children being different from peers their age which will be further explored in the next section.

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Subtheme: Fear

All participants endorsed fear. Fear was expressed in three ways within the microsystem and exosystem. First, most participants reported fear related to their child receiving negative treatment from health professionals. This expressed fear was the result of participants' observed or personal experiences of discrimination within the healthcare system. Due to recognition of the systemic racism embedded within healthcare, some participants applied this fear when seeking ASD evaluation services for their child. Specifically, some participants feared how racial discrimination may impact their child's care. Marcus shared how fear manifested after noticing his son's evaluation setting lacked racially diverse providers:

The majority of the specialists at this private hospitals are Whites. So and I've been chance to see the way some people were treated. Like someone badly injured and someone having just minor injuries. And because of race and something like that the person having minor injuries was treated first, leaving the person with bad severe injuries in a critical conditions before he was attended to.

In addition to fear of negative treatment from health professionals, all participants reported fear of the negative experiences or challenges their child or family members may face within the microsystem due to their child's ASD diagnosis and condition. Most participants shared fears for their child's future and how without support, prognosis may not improve. Margo highlighted how the anticipation of her son developing repetitive behaviors contributed to her fear as the mother of a child diagnosed with ASD:

. . . I didn't know later down the road, he might develop tics or you know, because my other cousin does have some behaviors. So that was, of course, because I don't mind it. But then you know, other people are, there's bullies. So that was one thing I worried about a lot.

Another participant, Giada, shared how she worried about telling her neighbors and her child's teacher about her child's diagnosis. Specifically, Giada noted that she was "afraid that they were

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going to spread rumors and tell everyone” and that her son would be “judged by everyone.”

Lastly, some participants indicated fear in their ability to parent a child diagnosed with ASD across the lifespan. Elizabeth shared how undergoing a traumatic childbirth experience contributed to fear such that she does not have the capacity to meet her son's needs.

I spent two years... trying to rebuild myself to be, you know, closer to the person that I used to be, before I had my medical conditions. . . And at the time, I was like, not sure, if doing that, if that's even the kind of person I can or need to be for my child. So it was more so like, the fears of not knowing how to be for him and for our family, and anticipating, like, what big changes in our lives would we have to do?

Subtheme: Language

When disclosing their child’s ASD diagnosis to family or other members within the microsystem, some participants shared how they intentionally used descriptive language to explain their child’s condition without directly using the word “autism.” For example, participants utilized “special behaviors,” “behavioral disorder,” “hard for [child] to focus,” or “superhero.” Jenny shared that she prefers to not use ASD when describing her child in order to “make him feel loved” and “not discriminated.” Moreover, Jenny noted how she does not want to “make a big deal out of this situation,” referring to her son receiving an ASD diagnosis.

In contrast, some participants preferred to directly use the word “autism” or “autistic” when disclosing their child’s condition. For these participants, such as Giada, autism or autistic was described as the “easiest word” for others to understand. This reportedly helped reduce the associated emotional exhaustion some participants experienced from having to answer constant questions about their child’s behaviors. In addition to preventing burnout, some participants indicated that the increased recognition of ASD in modern society (macrosystem) empowered them to be more direct when describing their child’s condition. For instance, Colin, a Filipino father, described the toll it takes when he is asked about his son’s condition repeatedly:

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The reason I chose that specific term is so that they won't ask much questions. I can just tell them and they move away because autism it's kind of well like getting well known today. So when you just tell them your child is autistic, they won't try to question his behavior, they'll just understand and won't ask much questions again.

Subtheme: Isolation

The subtheme isolation was endorsed by all participants when describing the journey of obtaining and accepting their child's diagnosis. Most participants, regardless of marital status, expressed how initially accessing the ASD evaluation itself was an isolating experience. In terms of feeling connected with others within the community (microsystem, exosystem), some participants described experiences of emotional isolation. Elizabeth exemplified the isolation she faced as a Filipino mother navigating her child's ASD diagnosis:

But at some point, you know, it would be great to have particular groups that are for Asian families, Filipino families. And that was really one of the first things that I was seeking out for. And in the beginning of his diagnosis, maybe the first like eight months, the first thing I, one of the first things I did was like to try to reach out and talk to as many Filipino and Asian parents of autistic children as I could. Just because I wanted advice on what to navigate, how to navigate, and I wanted their lessons

Participants also shared how isolation was experienced by their children as well. Nelly, a Chinese, single-mother described how negative social stigma contributed to her child's experience of isolation within the microsystem:

. . . Some parents don't like their kids visit anymore because they feel my kid. . . Some parents do not understand that autism is, it's not really like harmful diagnosis. Some friends just think like, some friends just feel like the kid is psycho.

Similarly to how stigma was impactful towards the ways in which participants initially denied their child's ASD diagnosis, social stigma surrounding ASD also evidently contributed to feelings and experiences of isolation participants felt. In particular, social stigma in that assumptions or perceptions of ASD are typically presented within the "severe" context presents

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itself as a “harmful diagnosis” as mentioned by Nelly. Social stigma in turn exacerbates the experiences of isolation by participants and their children which may also contribute to feelings of hopelessness discussed in the next section.

Subtheme: Hopelessness

Hopelessness was endorsed by all participants when comparing their child’s behaviors and developmental milestones with other children within their microsystem. While most participants described a close bond with their child and being able to understand their child’s needs through gestures, participants described feeling hopeless towards others’ ability to understand their child. This was particularly emphasized in that most participants reported how their child faced difficulties with verbal communication. For instance, when Jenny was asked about behaviors frowned upon in AsAm culture, she shared how challenges with communication led to her child’s engagement in these types of behaviors:

If he wants to drink water, he might point to the cup. You know, if you are new, you might not uh understand what he means, and if you uh do not respond, he might uh try to get somehow violent, he’ll take the cup, and throw the cup, and cry, and uh something like that.

Most participants felt hopelessness in their children’s ability to advocate for themselves across various settings. Settings included the home with extended family, school, and extracurricular activities. Jenny further shared how difficulties in her son’s ability to self-advocate results to his engagement in crying and others not knowing how to support her son when she is not present:

It becomes hard because I have to drop him to his daycare every day in the morning, and I also have to pick him every day in the evening after work. He does not respond well if someone else is dropping him or uh picking him, and I think I am the one who understands him the most. When other people are supposed to maybe drop him or pick him and he’s so emotional crying and all that, then they do not really understand that he requires some special attention. They get bored with him.

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All participants also endorsed hopelessness once their child received an ASD diagnosis. Specifically, when learning about the potential for their child to experience lifelong challenges despite access and utilization to professional services. Nelly shared how she “wasn't really happy with it, because I knew it would pose as an issue to basically his, um, social interaction in the future. Like, it might not mean much now, though. But as he grows older when he like gets to other places. Yeah, it might pose an issue. And also in his day to day activities. Also, it would be more stress for me, and like, family members having to cope with him and all that.” Furthermore, hopelessness was endorsed in relation to the social stigma associated with ASD. Jenny shared how her child’s diagnosis was “something that really used to break me down. I did not know who to talk to, What's the community or uh other friends and the family going to think about me and my Kent. How is my spouse going to change after this situation? How are we going to handle it as a family, you know.” Jenny’s endorsement of hopelessness experienced by herself, and family was also expressed across other participants including Elizabeth.

What I was devastated about it was just the perception that I had, that it would be an uphill battle for him at times and for us as a family at times... depending on what he might, might need in the future, or the fears of like, how he's going to be treated differently, or, you know, just like the additional challenges that he'll have to face in life because of his diagnosis.

The subtheme of hopelessness was perceived to impact the entire family unit, particularly when participants became aware or were informed of the various challenges that come with raising a child with ASD within the microsystem, exosystem, and macrosystem.

Resilience

Despite levels of stigma participants reported and experienced, resiliency also stood out. Resilience was exemplified by participants’ integration of their child’s ASD diagnosis into their family’s worldview and everyday life by framing their child’s diagnosis from a strengths-based

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approach, which contributed to seeking and accessing support for services. Elizabeth shared how she engaged in personal research to learn how to best define ASD for her family beyond a deficit-based medical model:

So much of how autism is described or defined is by, by what's missing, or what's delayed, or what's atypical, and I didn't find that very helpful in terms of understanding how my child exists in the world, versus like, just explain, you know, just just describing what he does or doesn't do. So I have done a lot of my own research to try to understand... how my child interacts with the world.

Similarly, Margo demonstrated resilience as soon as she received the feedback from her son's ASD evaluation that encouraged her to look at her son from a holistic perspective:

“You had to sit down and then they just kind of assessed what his strengths were, weaknesses, or what he needed to work on or what they should work on.”

Lastly, some participants took solace in the fact that with their child's diagnosis of ASD, their child qualified for ASD-specific professional services. Logan shared how ruminating on hopelessness did not benefit his child. As such, getting his son evaluated for ASD and learning about his child's diagnosis allowed him to “take action” as he “wanted my kid to improve, especially safety, psychologically, mentally, and also to grow as other kids.” Having positive relationships with their child's professional support services within the microsystem, such as Occupational Therapy (OT) as well as some pediatricians or family physicians, assisted participants in overcoming denial and hopelessness due to self and social stigma endorsed by the microsystem and exosystem. More importantly, a supportive team of providers supported participants' development of resilience in viewing their child as an individual with strengths as well as areas of growth.

Support for Services

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Across the varied levels of support participants' children needed, all participants expressed how difficulties with socioemotional reciprocity and communication were the primary areas of concern towards their child's development and overall well-being. Once participants' children received a medical diagnosis of ASD, their children were able to access ASD-specific professional support services. Specific services included applied behavior analysis therapy, OT, speech language pathology services, and joint-attention therapy. Through these professional services, all participants reported improvement in their children's symptomatology. In fact, all participants shared that professional support services have been beneficial towards supporting their child's development and overall well-being. Jenny expressed "I do not think there is anything that has not been helpful." Neil similarly shared that all services have been helpful and stated:

I just think that everything in the process is actually helpful. Just time for everything to perfect itself and for him to get used to the whole thing, you know... It actually helps him like the behavior of therapy, and trying to make him understand the differences between these and these, how you don't get lost in these and this and stuff like that.

All participants described receiving support in accessing and utilizing the described services for their child. Specifically, interactions and resources within the microsystem, exosystem, and macrosystem facilitated diagnostic evaluation and treatment services for participants' children. Firstly, most participants' awareness of atypical development led to recognition that their child required additional support beyond what the nuclear family could provide alone. As such, participant recognition facilitated access to the family's practitioner or child's pediatrician followed by an ASD specialist. Most participants shared how their provider's validation towards concerns surrounding child development contributed to an overall trusting relationship; participants began to view their healthcare providers as extended kinship. For

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example, Jason identified the psychologist who evaluated his son as a “family friend.” Another participant, Neil, shared how he put his trust in his family doctor who “took charge of it,” referring to the initiation of the referral process for his son’s assessment. This contrasted other participants’ experiences, who shared they had to request their physicians to submit the ASD assessment referral. Other participants, such as Marcus, shared experiences of connecting to family friends who then referred them to trusted professional colleagues who conducted the ASD evaluation for participants’ children.

Yes, definitely. I felt supported because he was a close friend of the family doctor who is a real friend of mine. So the friend of the family doctor was the one who referred us to him. They also do cases like that, in in the past, and he's had at least 60% success of helping them get better.

Additional facilitators to utilizing support included access to telehealth diagnostic evaluations, little to no intervention waitlists due to COVID-19’s shelter-in-place mandate, coordinated care amongst professional support services, and access to financial resources for timely referral turnaround times. Most participants described receiving financial support from extended family such as parents or siblings. Those with a higher annual household income were able to access evaluation and treatment services more quickly due the type of health insurance they could afford. For instance, Marcus shared:

Yes. There was a time when the medication, actually costed me a lot and financial constraints really made me reduce some of those medications just to cover up some of that price. So luckily, we got support from other family members, I was back into the normal routine. So our financial constraint has caused got to make a call to sometimes to family members.

In addition to facilitators, all participants described how interactions and resources within various ecological systems served as barriers to obtaining professional services for their child. Some participants shared how their health providers did not submit referrals in a timely manner

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due to the lack of shared concern surrounding developmental delays. This barrier also contributed to sentiments of distrust towards various support professionals. Socioeconomic status was also noted as a barrier for most participants in accessing evaluation services for their child. Lack of financial resources was a barrier regardless of the setting participants' children were evaluated in (e.g., private hospitals, private practices, community mental health clinics). In terms of accessing treatment services, Nelly described how she had to move to be closer to her son's school and access familial support:

The first school was too far. Because I moved from where I was staying, initially, I moved to be closer with my parents, so that they could like take care of Barry when I wasn't around. So I moved closer to them. And I also had to change place of work and also change the school so like, change and all that, that required money. Like financially and all that.

Moreover, participants whose annual household income was lower contributed to their delay in starting support services for their child due to the need of evaluating between benefits and anticipated additional costs. Jenny shared:

As a family, this is not something that you can just wake up and decide, and then he will just start the therapy and all that. It is something that we had to uh sit down, identify there is need for these services and all that. And after identifying the service, we have to consider, where we can get the service. And how beneficial is it going to be? How is it going to affect the family financially? And then all other factors? So we really had to take time to make sure that we made the right decision and at the right time.

In addition, some participants described how financial strain also impacted physically accessing services. Most participants noted that intervention services are typically located at various locations as it is rare for children to receive all services at one location. As such, some participants indicated how driving their child to different providers several times throughout the week contributed additional financial stress for their family. For some participants such as Collin, "mobility in terms of borrowing a taxi or a car" due to not having a car made access to

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care difficult. Lastly, some participants criticized the effectiveness of online ABA services during the COVID-19 shelter-in-place mandate. Prior to the pandemic, participants' children were receiving in-person support for toilet training, speech, and social reciprocity. Once the intervention modality shifted to telehealth out of necessity, some participants described that the services were no longer observably beneficial. Rather, they questioned the utility and effectiveness of telehealth behavioral intervention services. Margo shared:

It was a pretty big change. I mean, as far as I think a lot of it was like, they'll do like one little task or whatever task they want him to do. And then so and then they'll play a game. So a lot of it was I think, just so he doesn't lose his attention. But yeah, definitely the in person, I feel like the therapy sessions are a little bit longer. I think they're all supposed to be like an hour or 45 minutes to an hour or whatever. But like the in person ones, I'd have to sign off on it every time. The one on the online virtual ones I didn't have to sign off on so I wouldn't know.

Needs For Asian American Parents and Their Children

While participants expressed gratitude towards their child participating in the ASD evaluation process and receiving professional services, participants also expressed a wide-scope of needs they hope all providers will consider and incorporate into their practice. Specifically, all participants described needs across the micro, exo, and macrosystems in order to better support their child's psychological, behavioral, and emotional well-being. Some participants expressed the need for improved coordination of care across outside professional support services as well as professional support services within the school setting. Elizabeth indicated the struggle of working with various professionals for her son's interventions:

This is the part I don't, I still don't super understand. Because he's evaluated by like so many different people. There was like, Kaiser. And then there's the ABA people. And then there's the regional center, and their doctors. And then the school district. So all of them had evaluations. But you know, they're not all like shared necessarily with each other.

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While all participants were English speakers, some participants who spoke multiple languages expressed the need for more multicultural language services to ensure parental understanding of what an ASD diagnosis entails and what support services are available. Moreover, some participants shared the need for providers to speak to parents without professional jargon.

Elizabeth exemplified how the language utilized during the evaluation and intervention processes are “. . . not in a language that is accessible to, to families. Hell, I mean, you know, we are a college educated, English speaking family. And that shit is hard to understand.”

In addition, some participants shared that it is important for providers to respect parents’ time and attend appointments promptly. Regarding medical and behavioral health practices, some participants emphasized the importance of providers considering AsAm cultural approaches to health and wellness. For instance, visiting a hospital may not be the first option when seeking care. Rather, participants may first seek support through religious and faith-based practices. For example, Giada shared how accessing religious or spiritual leaders may take priority over visiting hospitals and providers should take this into consideration when engaging in the evaluation and treatment process to better support AsAm families:

They are supposed to know about the religious beliefs of the people they are working with like, there are some there are some religious taboo, like there are some religious taboos in the Asian communities, which are not allowed. . . They have some, some religions, where their members are not allowed to go to the hospital, and they are supposed to invite their religious leader to come and pray for them and they are not supposed to access any type of medications.

Another consideration participants shared included providers’ consideration of AsAm families’ socioeconomic status when recommending different types of support for their children. Moreover, to consider the impact of participants’ immigration status and systemic racism towards immigrants of color on securing jobs for financial security. Marcus described:

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Well, they should know that these people have gone out of country and are going through a lot. It's really hard to survive this kind of community, see where we don't get all the good jobs, we don't get all the good things. . . So yeah, companies and society should see from this point of view and should try to also treat everyone as equal without any racial discrimination or things like that. So on in everything they do, it should also be incorporated.

While some participants shared that cultural perspectives should not be incorporated into the evaluation or intervention process to discourage discriminatory practices by service providers, some participants expressed the need for the opposite. For example, participants exemplified the need for diverse social stories that are representative of their children's ethnic and racial backgrounds. In addition, children with ASD should also have the option to participate in extracurricular activities that are adapted to their needs. One activity in particular includes language classes in order for children with ASD to learn their native tongue. Elizabeth highlighted how she "haven't come across" services or resources that would help the "development of Lucas' cultural identity." Lastly, some participants stressed the importance of learning and incorporating cultural practices when working with the participant's child and family. One example shared by Margo included removing one's shoes during in-home intervention services.

Advice to Other AsAm Parents

All participants shared how they learned a lot about their child, ASD, and the various processes involved in accessing and utilizing professional support services for their child after experiencing the process themselves. Moreover, all participants described how their endorsed negative beliefs about ASD impacted the ways in which they addressed concerns surrounding their child's developmental delays. Thus, all participants provided insightful information when asked what advice they would provide to other AsAm parents who have a child diagnosed with

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ASD. Specifically, participants provided advice surrounding seeking out advice, engaging in personal research, having patience, being attentive towards their child's development, and holding onto hope. In regards to getting connected to support, whether that be professional or personal support. Grant shared:

Firstly, I'll say you'll also sometimes find maybe sometimes difficulties in seeking support. I think they might just have to, you know, sometimes make some research about, you know, what you're actually facing... So if they find, maybe, difficulties in what they're doing, they should, you know, try, seek support, and make some research.

Elizabeth also exemplified the importance of community:

. . . You're not alone. You just have to fight like hell to find other people like you. And so when you do find, you have to find your tribe. And that's, I mean, I got that from like a white mommy autism mom kind of group, which made me feel really uncomfortable, but I kind of understand, right? Like, yeah, you have to have your own net... your own support network. And sometimes it's with people who did not live with autism, that's okay. But if they can support you in, you know, develop, developing your family's ability and capacity to be able to navigate all that needs to be navigated. I think that's better than nothing.

Additional advice included the importance of having patience raising a child with ASD so their child can also develop positive experiences to combat experiences of hardship and bullying.

Nelly indicated:

I have to have a lot of patience and tolerance, to be able to deal with him, especially when it comes to his assignments. Because if I rush, I won't really get anywhere, I'll just waste more time. So I have to have enough patience to let him do his thing. And cause basically, his brain is different from ours, or that the way his brain works is different from ours. So we need to have patience to understand the child so the child can feel loved and accepted.

Moreover, most participants advised to be attuned to their child and their needs. In particular, most participants shared how without their attentiveness, presence, and engagement in personal research surrounding their child's development, they would not have brought up their concerns

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regarding observed developmental delays to their medical providers. Furthermore, all participants described how societal negative beliefs towards ASD contributed to how participants approached navigating daily life and access to care. Therefore, all participants urged other AsAm parents to prioritize their children's needs over feelings of denial and to communicate concerns with their healthcare providers as early as possible for their child to access and utilize support services earlier than later. Margo shared:

“I would say don't believe the stigma. Because it may be hard to hear, but it's better to start early than later. Because the later you start, it might not be as effective.”

Lastly, all participants endorsed the importance of loving their child for who they are, holding onto hope, and supporting their child. Marcus shared how the clinician who evaluated his son helped instill hope for the family as a whole through their rapport established throughout the evaluation process:

So the reception was a really warm call, he made us see hope. He made us believe that it's possible that with all these things, people could actually survive it. He gives the child a lot of hope, gave us parents a lot of hope.

The advice shared by participants may offer useful tools other AsAm parents with a child with ASD can incorporate to instill a greater sense of hope and combat the impact of self and social stigma when navigating the evaluation and intervention process for their child.

Discussion

This qualitative study explored the ways in which AsAm parents ($n=11$) seek, access, and utilize support services for their children diagnosed with ASD. The study aimed to investigate how stigma (i.e., self and social), cultural expectations surrounding typical and atypical development, and cultural perceptions surrounding ASD may impact AsAm parents' utilization and access to persons or systems of support. The participant sample of 11 ethnically diverse (i.e., South Asian, South East Asian, East Asian) AsAm parents living across the greater San Francisco Bay Area region. Participants' ethnic backgrounds were broadly representative of the greater San Francisco Bay Area population with the greatest ethnic group as Chinese (29.8%), second as Indian (16.4%), third as Filipino (15.9%), fourth as Vietnamese (8.4%), and a smaller population of Indonesian (0.2%) individuals (Ruggles et al., 2019). Participants were provided the opportunity to share what they have identified as additional needs to better serve this population. In addition, the participants were given a platform to share considerations for providers to incorporate or think about when providing a professional support service. Moreover, AsAm participants were provided a space to share advice and words of wisdom to other AsAm parents who have a child with ASD (see Appendix C). The incorporation of Bronfenbrenner's ecological system model (Bronfenbrenner, 1977) across various stages of the present research study (i.e., creation of the culturally responsive interview guide, creation of a priori themes) facilitated this exploration across multiple ecological systems that AsAm parents and their children interact with and are a part of.

In total, six themes were identified and included: (1) comparisons, (2) stigma, (3) resilience, (4) support for services, (5) needs for AsAm parents and their children, and (6) advice to other AsAm parents (refer to Appendix E for themes, subthemes, definitions, codes, and proof

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quotes). One subtheme was generated for comparisons, which included cultural perceptions. The remaining five subthemes were generated under stigma. This included denial, fear, language, isolation, and hopelessness.

Theme: Comparisons

The first finding (i.e., comparisons) suggests that AsAm parents recognized their child's atypical development without formal awareness of the "developmental milestone checklist" created by the CDC (2022). As part of the semi-structured interview, the researcher asked probing questions related to major milestones according to the CDC milestone checklist (see Appendix C). However, engagement in comparing their child's behavior with other children within their microsystem (e.g., their child's older siblings, cousins, neighborhood children) contributed to parental suspicion that their child was not developing in the same way as their typically developing peers. As such, making comparisons contributed to some participants feeling worried and scared while other participants did not think much of the observed developmental delays. This finding was consistent and contributed to studies conducted by Chawarska et al. (2007) and Ozonoff et al. (2009) which highlighted how having at least an older sibling allowed for recognition of atypical development amongst their child diagnosed with ASD. Moreover, participants in the present study with an only child indicated that having extended family or observing other children in their community (e.g., playground, church) also allowed for recognition of their child's developmental delay, highlighting the significance of parents making comparisons towards the recognition of atypical development and ASD. In contrast to existing literature that indicated AsAm held limited knowledge towards ASD (Chao et. al., 2018), participants in the current study recognized ASD as a diagnosis due to increased awareness amongst lay populations. In addition, while some existing literature

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indicated that developmental milestones may contrast cultural Asian norms, such as making eye contact with elders as a form of disrespect (Perepa, 2014; Wilder et al., 2004; Liu, 2005), findings from the present study contrasted existing literature and instead, described feelings of worry that their children would not respond to their name when called including engaging in eye contact. Comparisons also contributed to the ways in which participants identified celebrated and disdain behaviors across childhood, and how these culturally perceived behavioral norms compared with the behaviors their children displayed. Most participants reported how celebrated behaviors (e.g., participation in social activities) within the AsAm community were often not demonstrated by their child with ASD. Rather, participants conveyed that disdain behaviors (e.g., noncompliance towards social activities, noncompliance in following instructions related to chores, or noncompliance with engaging in safe behaviors such as staying close to family out in public) endorsed within the AsAm community were the behaviors most likely endorsed by their child with ASD. Therefore, comparisons of cultural perceptions towards celebrated and disdain behaviors added to participants' awareness towards their children's atypical development as well as the endorsement of stigma.

Theme: Stigma

The second finding (i.e., stigma) indicated that social and self-stigma within the micro and exosystems (Bronfenbrenner, 1977) interplay with one another and contribute to participants' cultural perceptions of ASD, disclosure of child's ASD diagnosis, and access to ASD professional support services including evaluation and interventions. Participants' experiences of denial, fear, isolation, hopelessness, and the ways in which they use language to describe their child's diagnosis were influenced by the social stigma towards ASD endorsed within the discussed ecological layers. Negative social interactions (e.g., bullying, intentional

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social isolation from their child's peers as well as peers' families) captured the existence and pervasiveness of community endorsed stigma towards ASD. Social stigma along with participants' engagement in making comparisons contributed to overall self-stigma endorsed by participants (e.g., sadness, feelings of being an odd one out, participants not wanting their child to socialize with others). Moreover, participants noted how social and self-stigma contributed to hopes that their child's developmental delays would resolve on their own over time (e.g., a child's development would catch up to their peers). The present study's finding that social stigma towards ASD contributes to self-stigma of feeling stressed and shame amongst AsAm participants contributes to the available findings from Wang and Casillas (2012) which demonstrated how dismissal or denial of an ASD diagnosis by extended family members contributed to participants' experience of sadness, stress, and shame towards having a child with ASD. The negative emotions associated with internalized self-stigma experienced by this study's participants may be explained by findings from Kim et al. (2020), which highlighted how shame is associated with the possibility of dishonoring a family's name or reputation due to family members who have a loved one with a disability or mental health condition. This study demonstrates how AsAm parental endorsement of internalized self-stigma may be further exacerbated based on the severity of a child's ASD impairment. Despite the reported severity of impairment of some participants' children's symptoms, more than half of the participants did not receive a diagnosis for their child until after 3-years-old. This contrasts the existing literature which has demonstrated how more severe ASD impairment along with an intellectual disability typically results in earlier diagnoses across racial and ethnic groups such as Chinese citizens (Wiggins et al., 2006; Lord et al., 2018; Leng et al., 2024). As such, self-stigma endorsed by

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AsAm parents in this study may have contributed to the delay of parental help-seeking behaviors by some participants to address their children's mental and behavioral health concerns.

Lastly, participants highlighted how social stigma contributed to them intentionally deciding who they would disclose their child's diagnosis to. This aligns with research conducted by The Asian American with Disabilities Resource Guide (2016) which emphasized the endorsement of isolation and exclusion when AsAm-identifying individuals feel as if they did not meet familial or cultural expectations. While Shea and Yeh (2008) indicated that self-stigma served as a barrier to expressing emotions and concerns to avoid social embarrassment, participants in the present study exemplified how they would share their child's diagnosis to individuals and organizations within the microsystem whom participants identified as safe, suggesting that positive social support may combat the negative consequences of stigma on help-seeking behaviors amongst AsAm parents. Moreover, participants' disclosure of their child's ASD diagnosis to particular individuals within their microsystem (e.g., child's grandparents, teachers, etc.) contrasted findings from Luong et al. (2009) who indicated that AsAm parents may prevent telling trusted individuals within their community to avoid a sense of placing a burden onto others. Rather, participants described how disclosing their child's diagnosis to others was their act of gathering more support and not feeling isolated. This further suggests that positive social support can combat the effects of stigma and contribute to help-seeking behaviors.

Theme: Resilience

The next and third finding (i.e., resilience), highlighted the ways in which AsAm parents accepted and moved beyond the social and self-stigma endorsed within the microsystem and exosystem in regards to having a child diagnosed with ASD. Despite available research outlining

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how social stigma negatively impacts help-seeking behaviors amongst marginalized communities (Wang & Casillas, 2012; Seung, 2013; Valencia-Garcia et al., 2017), participants' in the present study captured how community acceptance of atypical development and ASD can mitigate the consequences of social and self-stigma. Moreover, experiences of positive social and professional support may off-set the impact of social stigma on self-stigma. As a result, findings demonstrate how community acceptance and a positive support system contributes to parental resilience of overcoming stigma, accepting their child's ASD diagnosis, and engaging in help-seeking behaviors to access professional support for behavioral, speech, occupational, and academic interventions and accommodations.

Participants who communicated resilience demonstrated to positively shift AsAm parents' perceptions of the ASD diagnosis which contributed to parental engagement in overall help-seeking behaviors. While participants acknowledged the difficulties in raising a child that was unique from other children within their microsystem or exosystem, participants' help-seeking behaviors were centered around the parental desire to support their child's overall well-being. This finding contributes to and is consistent with existing literature which highlighted how participants endorsed help-seeking behaviors in order to "cure" their child (Wang & Casillas, 2012, p.601). However, participants in the present study also exemplified how engagement in their child's assessment and intervention services was the result of wanting their children to experience a reduction in stress, support their children's overall well-being, and foster a meaningful connection with their child by being able to understand their needs, which is consistent with additional existing literature (Al Kandari, 2008; Wang & Casillas, 2012; Seung, 2013; Lovelace et al., 2018; Waizbard-Bartov et al., 2019). Participants' shift from curing one's child to supporting their children's socioemotional, academic, and cognitive functioning may be

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due to participants' reported recognition that ASD is a lifelong condition regardless of the severity of presenting symptoms (Seung, 2013). As such, participants also embodied parental resilience by highlighting their children's strengths and viewing them holistically as an individual before the ASD diagnosis which contrasts existing research that has focused on parents and interventions emphasizing their child's deficits (Jegatheesan et al., 2010b; Johnson et al., 2023). This finding adds to the literature by exemplifying additional ways in which AsAm parents overcome the sheer fear and anxiety surrounding their child's observed challenges and receiving a diagnosis to explain such difficulties so that their children can access appropriate intervention support services.

Theme: Support for Services

The fourth finding (i.e., support for services) indicated the wide-scope of interactions and resources participants utilized in order for their child to receive professional support. This finding adds to the literature as it highlights the ways in which participants interacted across different levels within a layered ecological system, rather than one ecological system to access wrap-around services for their child. For example, Kang-Yi et al. (2018) focused on the microsystem, particularly the ways in which AsAm participants interacted or did not interact within their church community for emotional support while coping with their child's diagnosis. Participants in the present study described feeling hesitant about turning to their church community due to ignorance towards their child's behaviors. Additional literature has focused on the microsystem such as accessing emotional support through family as well as larger community support in terms of parental support groups (Shorey et al., 2020) to instill hope and combat feelings of isolation while parenting a child with ASD. In contrast, participants in the current study exemplified the dynamic interaction between the microsystem, macrosystem, and

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exosystem, shedding light on the importance of Bronfenbrenner's macrosystem (1977). In particular, participants' household income level, socioeconomic resources, access to extended family, and type of healthcare services participants had access to based off of available finances showcased how AsAm parents may have to navigate across multiple ecological layers to gain support and access professional services for their children. The necessity of parental resilience against social and self-stigma facilitated dialogue with identified individuals across the microsystem to initiate further help-seeking behaviors. Overall, this finding adds to the literature by highlighting how caring for a child diagnosed with ASD can be emotionally, physically, and financially taxing for the child's family (Petrou et al., 2018; Lord et al., 2022).

Theme: Needs For Asian American Parents and Their Children

The fifth finding (i.e., needs) suggested that despite the availability of services for children diagnosed with ASD, more is needed to support AsAm parents who have a child with ASD. All participants engaged in advocacy work by identifying characteristics, practices, and systemic resources in which professionals across the different micro and exosystems may implement or improve to better address the needs of an ethnically diverse AsAm population within the greater Bay Area region. Participant identified needs were delineated based on what participants highlighted they did not or have not had access to within the microsystem or exosystem to better support their child's overall well-being and development. Some of the needs mentioned were consistent with previous existing literature such as providers attuning to AsAm cultural beliefs and values (e.g., respecting elders, integration of religion/faith-based practices), reducing provider bias, and focusing less on a medical-based deficit model (Fisher et al., 2023; Jegatheesan et al., 2010b; Valencia-Garcia et al., 2017). In addition, participants' expressed the need to use multicultural (e.g., services provided in different languages) and family accessible

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language (e.g., strengths-based approach) versus professional jargon (e.g., deficit-focused medical model, medical terms) when describing their child's diagnosis and treatment coordination. Participants expressed needs focused on accessible language is a consistent finding with Sakai et al. (2019) in that limited language related to describing the ASD diagnosis as well as describing how to support individuals with ASD may act as a barrier and impact access and utilization of professional support services amongst linguistically diverse parents. Participants also identified needs to better support their children's ethnic-identity development by facilitating and introducing AsAm-specific social groups, social stories, and native-tongue language classes. This finding may be the result of participants' own values in their racial and ethnic identities and wanting their child to form a cultural self-identity. To this researcher's knowledge, existing literature surrounding the need for support towards ethnic-identity development amongst AsAm children and youth with ASD has not been expressed. While some participants expressed a need for eliminating cultural considerations due to fear of racial discrimination, some participants highlighted the importance of providers acknowledging their (i.e., Asm parents and AsAm children) identities as AsAm when considering treatment approaches. The conveyed needs identified in the current study extends the available research that tends to focus on AsAm parents' needs within the microsystem such as financial support, and encourages professionals to consider needs within the exosystem and macrosystem as well (Zheng et al., 2021; Taylor & Henninger, 2014; Malik-Soni et al., 2021; Zuckerman et al., 2017; Bronfenbrenner, 1977).

Theme: Advice to Other Asian American Parents

The sixth finding (i.e., advice to other AsAm parents) exemplified the significance of Bronfenbrenner's mesosystem (1977) –the interaction across ecological systems including the micro, macro, and exosystem. When transposing social and self-stigma onto the ecological

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systems model (Bronfenbrenner, 1977), each is situated within the exosystem and microsystem, and as described previously, interact with one another and contribute to negative consequences (see Figure 2). As such, participants provided other AsAm parents advice in moving beyond social and self-stigma in order to help their child. Such advice was informed by participants' identification of how their own dynamic endorsement of social and self-stigma impacted parental help-seeking behaviors; therefore, impacted their child's age of diagnosis and age at which intervention services started which is consistent with findings of Somalian parents delaying help-seeking behaviors described by Selman et al. (2018). Furthermore, participants encouraged AsAm parents to hold onto hope despite perceived negative beliefs surrounding ASD. Lastly, participants encouraged other AsAm participants to find, build, and engage in different community support. Through their personal experiences of feeling isolated, participants stressed the importance of leaning into their nuclear and extended support systems to alleviate some parental emotional and psychological turmoil. This finding has not been incorporated into existing studies and contributes to the expanding literature on ASD focused on AsAm by sharing the words and wisdom of this study's participants who identify as AsAm parents with a child with ASD.

Limitations

There are several limitations in regards to the current study and present findings. Firstly, this study included a small sample size which impacts generalizability. However, the small sample size was methodologically indicated to analyze themes that impact an ethnically diverse population. As such, 11 participants offered an ethnically-diverse sample to gather rich qualitative data. Second, all participants in this study were mono-racial Asian-American identified parents who had a boy diagnosed with ASD. The experiences of bi-racial AsAm

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identified parents were not explored within this research study, despite the racially and ethnically diverse location of the present study. Bi-racial AsAm parents' lived experiences may be significantly different from those of mono-racial AsAm parents. Moreover, all participants' children were identified to be all boys; thus, limiting the generalizability of these findings as it omits the experiences of AsAm parents who have a daughter with ASD. Third, all participants were acculturated to American culture to some extent as each participant was able to navigate the US healthcare system. AsAms' level of acculturation, including the adoption or ignorance of cultural norms within the US, may vastly impact the ways in which they perceive atypical development, ASD, and help-seeking behaviors. Individuals who have recently immigrated to the US may hold limited awareness or a different understanding towards ASD as was indicated in a systematic review conducted by Fisher et al. (2022). Fourth, the use of Zoom to participate in the interview required access to an electronic device and a secure internet connection. Individuals who face socioeconomic barriers to the extent of not having access to electronics and/or the internet may also have varied experiences compared to those interviewed. Fifth, the researcher did not include a COVID-19 specific question as part of the interview guide. Although some participants highlighted how their child's interventions services across different areas of support within the microsystem changed due to the shelter-in-place mandate, some participants did not mention COVID-19 or its impact on parental help-seeking behaviors or their family as a whole. Recognizing the ways in which COVID-19 impacted the general population emotionally, psychologically, physiologically, and financially, asking participants directly about their personal experiences navigating help-seeking behaviors and raising a child with ASD during the pandemic may have highlighted different, unique experiences amongst the study's

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participants. Further research should attempt to highlight a more inclusive child population of both boy and girl children.

Future Research Directions

The present study highlighted the voices of an ethnically diverse sample of AsAm identifying participants. It is imperative that the help-seeking experiences of AsAm parents who have a child diagnosed with ASD continue to be explored. Exploration into this topic and community may contribute to a better understanding of how AsAm parents interact and navigate different social-determinants of health across varying ecological systems in order to best support their children. More importantly, further exploration may contribute to providers' insight on how to best support this hard-to-reach community (Ellard-Gray et al., 2015). Ongoing research is necessary as findings from the present study as well as existing research outlines how ASD may present as a lifelong condition depending on the severity of symptoms; thus, contributes to the depletion of emotional, physiological, psychological, and financial resources across AsAm parents (De Giacomo & Fombonne, 1997; Huerta & Lord, 2012; Karst & Van Hecke, 2012; Brei, Schwarz, Kelin-Tasman, 2015; McCauley, Elias & Lord, 2020). It should be emphasized that the help-seeking experiences of non-fluent English speakers were not explored in this study. While the current study identified how provider biases and inherent systemic racism contributed to the challenges experienced by AsAm parents during help-seeking behaviors, individuals whose primary language is not English are at greater risk for experiencing discrimination and unfair practices within the American healthcare and educational system (Sakai et al., 2019). Thematic analysis research conducted by researchers who are fluent in AsAm parents' native languages may collect qualitatively rich data that further identifies additional gaps in accessing and utilizing ASD support services amongst this population. Lastly, generation and immigration

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demographic (e.g., age when parents immigrated to the US) information was not explored in the current study. The 2020 US Census reported that the AsAm population is roughly 31% foreign-born; and among immigrants, 57% are proficient in English (US Census Bureau, 2020). In addition, emerging literature suggests younger generations (e.g., Generation Z, Millennials) hold greater awareness and less stigma towards behavioral health challenges compared to older generations such as Generation X globally, including in the US (Foulkes & Andrews, 2023; Baral et al., 2022). It is critical that future research also examines whether language barriers across various generations as well as generational differences alone impact AsAm parental access to behavioral healthcare for children with ASD.

Clinical Implications

Findings from the present study may assist health providers, educational professionals, and health policy advocates to facilitate individual-level and systemic-level changes across the microsystem, exosystem, mesosystem, and macrosystem. Specifically, the discussed findings may help providers mitigate the impact of various social determinants of health and stigma onto parent help-seeking behaviors for their child with ASD. First, providers may want to engage in discussions surrounding AsAm parents' comparisons of their child's developmental milestones with that of similar-aged peers. This can help provide psychoeducation surrounding expected developmental milestones and manage expectations. Additionally, discussions surrounding milestones may normalize the diversity across children's development in order to encourage thoughtful exploration rather than ignoring noticeable differences. Providers may also want to discuss with AsAm parents about their cultural perceptions of celebrated and disdain behaviors as this can offer parents comfort in contextualizing why such behaviors are observed amongst their children.

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In addition to discussions surrounding typical and atypical development, the concept of stigma and how AsAm parents define this concept or how parents understand it as an influential factor of their worldview of parenting a child with ASD should be collaboratively explored with providers. Specifically, providers are encouraged to commend AsAm parents for expressing their initial concerns to their identified support system; whether they first share their concerns to extended family or their family physician, independently expressing or accepting others' observations of their children's atypical behaviors serves as the first step to accessing ASD services. Supportive reflection surrounding how difficult it might have been for AsAm parents to first express their concerns may ameliorate the study's findings of themes of denial, fear, isolation, hopelessness, and the ways in which parents describe their child's difficulties. Furthermore, providers are encouraged to provide psychoeducation surrounding the term of "neurodiversity" (Dywer, 2022) to support how AsAm parents speak about ASD in a more positive light. The ways in which AsAm parents speak about ASD to others in their communities may empower other parents who have a child with ASD or observed developmental delays to access assessment or support services for their children.

Additional clinical implications can include discussions surrounding AsAm parents' values of supporting and caring for their child with ASD. Emphasizing parental endorsed AsAm values may result in increased confidence towards the variety of community-based and professional services available within the microsystem and exosystem to support their child. Once an ASD diagnosis has been made and intervention services begin, providers may want to consider expanding the Westernized definition of a nuclear family to also include extended family in parent-training to align more with the AsAm collectivistic backgrounds. The present study identified how dynamic and essential extended families were for AsAm parents with a

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child with ASD; thus, being active members within the microsystem rather than the exosystem. In particular, extended families can provide temporary relief to the parents of the child by offering emotional, physical (caretaking), and financial support for a child.

Lastly, the discussed implication of providing psychoeducation regarding developmental milestones should also be offered in various Asian languages to further improve the awareness and normalcy of recognizing atypical development. Use of quality interpreters, emphasis on lay-person language versus psychological jargon, and connecting families to providers and community resources should be actively incorporated as part of AsAm parents' help-seeking process.

Conclusion

In sum, advice given by the AsAm parents from the present study along with the outlined future research directions and clinical implication can be used by providers across the varied ecological systems to inform clinical, educational, or health policy work for AsAm children with ASD. Reducing the negative impact of stigma may contribute to better identification of ASD amongst the AsAm population, ameliorate social determinants of health, and increase documented prevalence rates within the greater Bay Area region as well as nation-wide. Furthermore, building a community for AsAm parents, whether that includes existing extended family within the microsystem or creating new avenues of support within the exosystem, will be pivotal to combatting the wide-scope effects of caring and parenting a child with ASD. Lastly, listening and internalizing the expressed, targeted needs expressed by this study's participants may offer beneficial insight towards how to better serve hard-to-reach communities within the general public and ASD community.

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Appendix A: Recruitment Flyer

**ASIAN
AMERICAN
AUTISM
AWARENESS**



IMPORTANT STUDY: PARTICIPANTS NEEDED

Do you identify as:

- **Asian American?**
- **A mother/father of a child who has been diagnosed with Autism Spectrum Disorder?**

WE WANT TO HEAR YOUR PERSPECTIVES!



Participants will receive a \$20 Amazon gift card.

Please contact us at asampasdresearch@gmail.com for a brief screening.



Appendix B: Screening Questionnaire

Participant Inclusion Criteria

1. Are you currently parenting a child diagnosed with ASD? (Yes/No)
 - a. If **yes**: proceed to next question
 - b. If **no**: discontinue screener
2. What is your racial and/or ethnic background/identity? (Free response question)
 - a. *Asian ethnicities according to Asian Pacific Institute on Gender-Based Violence:*
 - i. Central Asians: Afghan, Armenian, Azerbaijani, Georgians, Kazakh, Kyrgyz, Mongolian, Tajik, Turkmen, Uzbek.
 - ii. East Asians: Chinese, Japanese, Korean, Okinawan, Taiwanese, Tibetan.
 - iii. Southeast Asians: Bruneian, Burmese, Cambodian, Filipino, Hmong, Indonesian, Laotian, Malaysian, Mien, Singaporean, Timorese, Thai, Vietnamese
 - iv. South Asians: Bangladeshi, Bhutanese, Indian, Maldivians, Nepali, Pakistani, Sri Lankan.
 - v. If multiracial: Do you identify with your Asian or Asian American race? (Yes/No)
 - b. If **identifies** as Asian or Asian American: proceed to next question
 - c. If **does not** identify as Asian or Asian American: discontinue screener
3. Do you feel comfortable with an English-only interview? (Yes/No)
 - a. If **yes**: proceed to next question
 - b. If **no**: discontinue screener
4. Are you 18-years of age or older? (Yes/No)
 - a. If **yes**: proceed to next question
 - b. If **no**: discontinue screener
5. What city do you currently live/reside in? (Free response question)
 - a. If **within** San Francisco Bay Area: proceed to next question
 - i. *Counties included according to the San Francisco Foundation: Alameda, Contra Costa, Marin, Napa, San Francisco, San Mateo, Santa Clara, Solano, and Sonoma counties*
 - b. If **beyond** San Francisco Bay Area: discontinue screener
6. Do you currently live with your child diagnosed with ASD? (Yes/No)
 - a. If **yes**: proceed to next question
 - b. If **no**: discontinue screener and provide individual with resource list
7. Have you been involved in coordinating/planning your child's support services? (Yes/No)
 - a. If **yes**: proceed to next question
 - b. If **no**: discontinue screener and provide individual with resource list
8. With whom are you currently in a parenting relationship with? (Free response question)
 - a. If with **heterosexual** parenting partner: proceed to next question = **ELIGIBLE**
 - b. If with **same-sex** parenting partner: discontinue screener and provide individual with resource list = **INELIGIBLE**

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Additional Screening Questions for Additional Qualitative Data

9. What is your highest level of education?
- a. Master's degree
 - b. Bachelor's degree
 - c. Associate's degree
 - d. Postsecondary nondegree award
 - e. Some college, no degree
 - f. High school diploma or equivalent
 - g. No formal educational credential
10. What is your current occupation?
- a. Management
 - b. Business and Financial Operations
 - c. Computer and Mathematical
 - d. Architecture and Engineering
 - e. Life, Physical, and Social Science
 - f. Community and Social Service
 - g. Legal
 - h. Educational Instruction and Library
 - i. Arts, Design, Entertainment, Sports, and Media
 - j. Healthcare Practitioners and Technical
 - k. Healthcare Support
 - l. Protective Service
 - m. Food Preparation and Serving Related
 - n. Building and Grounds Cleaning and Maintenance
 - o. Personal Care and Service
 - p. Sales and Related
 - q. Office and Administrative Support
 - r. Farming, Fishing, and Forestry
 - s. Construction and Extraction
 - t. Installation, Maintenance, and Repair
 - u. Production
 - v. Transportation and Material Moving
 - w. Military Specific
 - x. If currently unemployed: What was your previous occupation/employment?
11. Annually, how much do you/your family make in terms of income?
- a. Under 15,000
 - b. 15,000 to 24,999
 - c. 25,000 to 34,999
 - d. 35,000 to 49,999
 - e. 50,000 to 74,999
 - f. 75,000 to 99,999
 - g. 100,000 to 149,999
 - h. 150,000 to 199,999
 - i. 200,000 and over

Appendix C: Interview Guide

Introduction:

Hi, my name is Mellanie De Guzman and I am a doctoral student from the University of San Francisco. I am trying to learn more about Asian American parents' experiences accessing services and caring for their children diagnosed with Autism Spectrum Disorder (ASD). I plan to ask you a series of questions over the next 60 to 90-minutes.

Informed consent:

As mentioned in the informed consent document you received, I will be audio recording our interview and will later write down our conversation. Everything will be de-identified, meaning that your true name and that of your child will not be used. You can decide to use a fake name for you and your child to further ensure confidentiality throughout this process. I'm going to be using the word Asian to refer to a very large community of which you are a part of. Is that term okay with you or do you prefer to use Asian American or another term?

Many of the questions I will be asking you are about your personal experiences parenting, caring for and obtaining/seeking services for your child diagnosed with ASD. If there is a question that you do not feel comfortable answering, please let me know and we can move on. Additionally, you may also withdraw your consent to participate and will not be punished for either decision. Do you have any questions regarding what I just shared with you?

Interview Questions:

Okay, now we can get started. First off, thank you for being here.

1. Can you tell me why you decided to participate in this study?

Thank you for sharing this with me. Now, we will shift the focus to [child's name].

1. Tell me a little about [child's name].
 - a. **Probe: How old is your child now?**
2. How does [child's name] mostly communicate their needs with you (e.g., word(s)/sentences, show/pull, American Sign Language/communication device)?
 - a. **Probe: How many children do you have? Where does [discussed child] rank in birth order out of siblings?**
3. What are some of the major childhood challenges you see with [child's name]?
 - a. **Probe: Major milestones - talking, social interactions, gross/fine motor activities (walking).**
 - b. **Probe: What additional medical conditions does your child face?**
4. Now, I want you to think back to when this/other challenges became apparent. When did you first notice [your child/child's name] was struggling with [state examples given by parents e.g., speaking, walking, eye contact]? Did you notice something else?
 - a. **Probe: How old was your child when you first noticed this?**

Now, I want to ask you questions about obtaining initial services for [child's name].

1. What prompted you to follow up with the concerns you were seeing about your child's development with a professional (e.g., pediatrician, psychologist, psychiatrist)?

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2. How do you think your concerns were received by [title of professional]? Did you feel supported? How? Why or why not?

Next, I will ask you about your experience in obtaining help for [child's name]. I will ask you specifically about evaluation and diagnosis.

1. Tell me about your experience in getting your child evaluated.
 - a. How old was your child when they got evaluated for ASD?
 - b. Where did you go for your child's evaluation (e.g., hospital, community mental health clinic, private practice)?
 - c. Who was involved in the evaluation?
 - d. What were their races/ethnicities? Gender? Of those evaluating your child.
 - e. How comfortable were you throughout the process?
 - f. How old was your child when they received an ASD diagnosis?
2. How was it for you to learn about [child's name] ASD diagnosis?
 - a. How do you think this affected your family?
 - b. Did you perceive that people would treat your family or your child differently?

Now, I want to ask you questions related to sharing [child's name] ASD diagnosis with others.

1. Who knows about your child's diagnosis?
 - a. Who did you tell?
 - b. When you told [the person that was told], did you fear that your child would be treated differently? If so, how?
2. What word or phrase do you use to describe your child's diagnosis to others?
 - a. **Probe: Tell me why you chose that specific term?**

Next, I want you to think about your experiences with the different services and supports your child receives.

1. Tell me about the types of services and support your child receives.
 - a. What types of support or accommodations does your child receive in school (e.g., school aid/IEP/504-plan)?
 - b. Does your child receive any other types of services to help them (e.g., behavioral therapy, OT, SLP)?
2. How old was your child when they began services?
 - a. **Probe: Why do you think it took that long? What assisted in getting connected to services so quickly?**
3. What motivated you to seek out these different services for your child?
 - a. What was most difficult about this process?
 - b. **Probe: Did your family's household income impact access to diagnosis, services, etc.? If so, in what ways?**
4. What was most helpful in getting/starting these services?
5. What services were/have been most helpful for your child?
6. What do you think has not been helpful for your child?
 - a. **Probe: What services are needed that your child is not obtaining?**

We are just about done. Now, I will ask you about your cultural experiences and support for Asian families.

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1. What types of childhood behaviors might a child be celebrated for in the Asian community?
2. Are there any childhood behaviors that are frowned upon or looked at negatively in your culture or community?
 - a. ***Probe (for stigma experiences or opinions) - Not following gender expectations, speaking out of turn, etc.***
3. What important traditions, cultural beliefs, and values do you think service providers need to know when working with Asian families?
4. What advice would you give other Asian families if they have concerns about their child's development but may be hesitant to have their child evaluated? Or seek services or treatment?
5. Is there anything else that you would like me to know?

Thank you!

Appendix D: Resource List

Autism Society San Francisco Bay Area

650-637-7772

info@sfautismsociety.org

Parents Helping Parents

408-727-5775

info@php.com

Stanford Medicine Early Support Program for Autism

650-723-3772

autismsupport@stanford.edu

Support For Families

Peer Groups

Parent Mentor Program

415-920-5040

info@supportforfamilies.org

The Arc San Francisco

(415) 255-7200

info@thearcSF.org

Project Awareness and Special Sports

info@projectawarenessandspecialsports.org

Yo Re Mi Children's Yoga

info@yoremikids.com

Appendix E: Identified Themes, Subthemes, Definitions, and Proof Quotes

<i>Themes and Definitions</i> <i>Subtheme and Definitions</i>	<i>Codes</i>	<i>Proof Quotes</i>
Comparisons: Parental comparison of their child’s developmental milestones to siblings, extended family (e.g., cousins, family friends’ children), and neighbors.	Comparisons	<p>“So sometimes when he just dangling those kinds of toys and sometimes when I see it I will maybe want to go and interrupt and then if I just go and then I will scatter it and then he arranged immediately. Of course he'll still be mad mad, very very mad at me. Why do you have to do that , you don't have to do that you get it. So that's when I started noticing this thing that I know that oh, this thing is actually not far not really normal but is close to normal, of course, child will play, child will get mad. Child will play, child will get mad at some kind of stuff, but it's only a hair.” -Neil</p> <p>“... I come from a large clan, like, I have like 61st cousins. Right? That's scary. When we're all together, it's kind of overwhelming. You don't have to be autistic to be overwhelmed by that. But yeah, like even tolerance for loud noises and just this big family gathering tolerance and kind of even enjoyment of those things is definitely very valued in my family.” -Elizabeth</p> <p>“Oh, I think that it's hard for him to focus. I think that's one of the main things or like, like right now. He gets excited. So once he gets excited, like, everything's out the door, like you to ask him to do something. And he'll like, the listening is a little is a big problem too still. Like, I'll be like, Can you get my phone? On the hallway as an example. And then he'll like, go in the kitchen or something. Like, what, where do you, what do you what are you doing? And he goes, Ah, I don't remember. So like, it can also be a kid thing, just not focusing too.” - Margo</p>
Cultural Perceptions: Parental cultural perceptions of behaviors.	Cultural Perceptions	<p>“... having good integrity and showing respect to individuals. Yeah, maybe public displays of affections... they should be able to know, maybe they should be able to have interest or maybe whatever things might occur in this society, maybe an individual is facing. They should just have this sympathizing heart with the individual” -Jason</p>
Stigma: Negative beliefs that parents, community, or society at large hold towards an ASD diagnosis.	Stigma- social	<p>“This is something that really used to break me down. I did not know who to talk to, What's the community or uh other friends and the family going to think about me and my Kent. How is my spouse going to change after this situation? How are we going to handle it as a family, you know.” -Jenny</p> <p>“My stigma was just like. . . you see other children that have like more severe forms of autism and, you know, the stigma, you hear people, like, like I said, like the bullies or just people chattering or pointing, laughing. It hurts me, and it would hurt them like, even if my child didn't understand, you know, like I said, his readings a little off. So someone was teasing, he might not necessarily know... But, like, I think that or, just feeling that, oh, they're stamped with that diagnosis that it's gonna hold him back from future jobs or just advancing in class or whatnot.” -Margo</p>
Denial: Parents’ endorsed difficulty accepting their child’s ASD diagnosis.	Denial	<p>“Every parent wants the best for their child... I just wanted him to be like the other kids and also to improve on. I wanted him to improve on everything.” -Giada</p> <p>“First of all, I can't lie, it was very hard. Yeah. Because it was my first, our first experience. So I was a bit scared. That's why I can't remember some things happened. So yeah, because I was very emotional. But by time by time, as I said earlier, I talked to my therapist, and was able to direct me on how I can handle the situation. I take it slow. And just learn more, learn more about him. And yeah, I think how, for now, I'm good.” - Logan</p> <p>“So yeah. I mean, it sucked. But it was something that, it was so beneficial for him that he got.”- Margo</p>
Fear: Parents’ perception of	Fear	<p>“... Depending on what he might need in the future, or the fears of like, how he's going to be treated differently, or, you know, just like the additional challenges that he'll have to face in life because of his diagnosis. So it's, I view it more as like, he was more so like, is my is my</p>

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<p>negative treatment from health professionals , or negative impact on child and/or family due to child's ASD diagnosis.</p>		<p>son going to be bullied when he grows up? You know, is he going to be targeted? Or, you know, like, yeah, like what, you know, like, is he gonna become a statistic or something? You know, like, is he gonna be depressed because of the challenges he's gonna face? It's more so like those things that I was, like, really scared of." - Elizabeth</p>
		<p>"Yeah, so he, you know, after he was born, he was a C section, baby. . . I basically got an infection in my C section site and a couple of other things. And I mean, it basically sent me into septic shock. So I mean, I almost died. . . So you know, and then had to recover from all of that I like, had to go to rehab. And like relearn how to talk, relearn how to walk, and all those things. So my parenting and like, my ability to care for my child, you know, has been kind of an uphill... struggle and challenge to like, develop my own personal kind of capacity and ability to even like, you know, carry my child and things like that... It was more so like, because I was going through my PTSD at the time." -Elizabeth</p>
<p>Language: The ways in which parents directly or indirectly describe their child's diagnosis when disclosing to others.</p>	<p>Language</p>	<p>"I just went straight to the point. Yeah. I would just say like you know, it's a trait, don't worry about it. I got to lay the whole thing for you know, I wanted to be to be clear about the whole thing like you know, like, about what is really happening to reach out, to address so and yeah, these are my child's behavior. This is what we see and this is what I've been observing... You know, I describe my son to be an autistic person." -Grant</p>
<p>Isolation: Parental endorsement of loneliness after noticing their child's atypical development and/or learning about their child's ASD diagnosis.</p>	<p>Isolation</p>	<p>"I did not have any other family members supporting me. I did it all alone." -Giada</p>
<p>Hopelessness: Parental endorsement of despair after noticing their child's atypical development and/or learning about their child's ASD diagnosis.</p>	<p>Hopelessness</p>	<p>"Yeah. I felt supported because, first of all, I was scared, and uh I did not only get the medical attention for the child. I also got uh therapy for myself as a parent, because uh you know, for every mom, every, it is every mom's wish to have a normal child, a normal life, and all that. So, it was not something that I could uh just wake up one day and make peace with the fact that my child is autistic, and uh I will forever live with that, you know." -Jenny</p> <p>" He has a lot of anger issues when uh he feels that he's not being understood, that is uh one problem that uh he has. He will uh, throw keys up, around... Sometimes I have to control. So most of the time I prefer to be around him because uh personally, I understand him well. Uh, I know when he's for example, behaving in a certain way he wants food, or maybe when uh he is behaving in a certain way, he wants uh to go out and uh play with other children, you know. I really understand uh how he communicates, but when it comes to he might interacting with other people. Then it becomes hard. Yeah." -Jenny</p>
<p>Resilience: Parental acceptance and integration of their child's ASD diagnosis into the</p>	<p>Resilience</p>	<p>"At first it was hard for me to accept the facts, but I had to get used to it, because I'm the only parent, and I had to be there for him, I had to support him. So I just attempt to deal with it the way it was. Yeah." -Giada</p> <p>"And I think a lot of our framework now, and has been, is that, you know, he's great as he as he is. And it's just trying to learn more about him, since he can't self advocate yet. So that we</p>

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<p>family's worldview and everyday life.</p>		<p>can identify how to how to adapt our lives so that we can support him growing to become the best person that he could be. That's kind of like our general framework with, you know, with his diagnosis and knowing that he's autistic and whatnot... And it's important to arm him with tools to be able to communicate, so he can self advocate, and whether that's, that's verbal words or not, you know, we that's, that's, we don't care about that. As long as we have, we have an ability to communicate, that's what's what's important.” -Elizabeth</p>
		<p>“But yeah, and then, you know, we realized he's autistic. And I think a lot of our framework now, and has been, is that, you know, he's great as he as he is. And it's just trying to learn more about him, since he can't self advocate yet. So that we can identify how to how to adapt our lives so that we can support him growing to become the best person that he could be. That's kind of like our general framework with, you know, with his diagnosis and knowing that he's autistic and whatnot... I just did my own research to understand that autism is a neurological condition and just know that even the framework of neurodiversity and I, yeah, I've just done a lot of my own research on how to define what autism is in a humane way. And that's not like centered around his perceived limitations or, you know, like, you know, non typical kind of development, developmental milestones or expectations and things like that.” - Elizabeth</p>
		<p>“Basically, at first when I heard he had autism, I wasn't really happy but I didn't let it show because I knew I would love him either way. So he knows he has autism, actually. Yeah. Yeah. So I tell him everyday that I love him that way. And I don't try to rush him. I don't force him to do things he doesn't want to do. So I don't force him to play with other kids. I don't force him to watch TV shows he doesn't want to watch. So I just basically let him do his own thing. And with the assignments, I just tried to coerce him a bit into doing this assignment because I know that's important.” -Nelly</p>
<p>Support for Services: Interactions and resources provided by others that have facilitated parents' access and utilization of their child's ASD diagnosis, treatment, and prognosis; or the opposite, personal characteristics and interactions that have served as a barrier.</p>	<p>Support for Services-facilitators</p>	<p>“... Most of the time, I was accompanied by my mom, or my sister while going with Barry to the hospital. So yeah, and if I ever needed money, my dad was always there, my brothers were there. So yeah, I think they were really really supportive.” -Nelly</p>
		<p>“Yes, I've attended seminars, workshops, classes, online meetings. Other parents having the same issues, though not of the same race, but having similar issues. Some who have overcome, some who are still struggling with it. A lot of question and answer sessions just to learn from each other and incorporates one or two things. So it has also helped me a lot.” -Marcus</p>
		<p>“Oh, so I think the only thing that we kept on with him was they put us in ABA therapy. So that's what we did for let's see from 2, 3, 4, five, when did we move here. So up until we moved here, so that was in 2020. And I think he continued. So from like, 20s, I'll say late 2016, early 2017, up until that'll be like three or four years, like three and a half to four year almost he's got therapy, that was basically the only thing we did. And they were at the house pretty frequently, I think it was like at least three times a week... And then right before with the ABA therapy, we did start going in their office, that's they had actually open it so it was awesome that he was able to do like group sessions too, and they were able to do one on one in there. So they can see how he is in the home setting versus in a controlled setting like that. But yeah, those are the those are the resources that we had. Uh, he didn't have anything else” - Margo</p>
		<p>“Yeah, it was when I noticed, you know, I believe in the medicals the medical was very well. I believe everything as a as a way of getting over it. So I was from then on, I was really advised by my physician that I should get a therapist for John. And I did, I immediately because that's my family physician. I had no other option than to do what he say.” -Colin</p>
		<p>“When shelter in place just started. And so yeah, I mean, I think the world was really scary at the time. And I was trying to understand my son. And I just wanted as much resources and services and support that I could, that we could get, you know, as a family, to help us to give us the tools to kind of understand our son at the time.” -Elizabeth</p>
	<p>Support for Services-barriers</p>	<p>“Yeah, it impacted assessment diagnosis services, because without the family income, I wouldn't have been able to handle some of the bills I had to handle.” -Colin</p>
		<p>“Yeah, definitely, I was sure that not everyone was going to correspond positively. I accepted that. You know that it is that, through difficult times that you are able to identify who your true friends are. So I was expecting that some friends uh would nickname me, give me names,</p>

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		<p>and all that. So I was ready for anything. I was not telling them to create awareness, but I have a child who needs special attention, and we can no longer maybe hang out like we used to do before, or go to parties like we used to do before, or even spend money like we used to do before, because I need to forecast in that of my finances, because definitely Kent needs a special care. I have to forecast to make sure that I spend more time with him because definitely I am the one that has a stronger bond with him compared to everyone else. - Jenny</p> <p>“ Like, and he knew to sign on what time to sign on and stuff. But I don't know what time they'd end like I just let him do his thing, because that's what he understood. So that would teach him responsibility. But yeah, I think the in person was definitely more beneficial for him versus virtual. So I'm glad it was all before COVID because I don't know how this whole situation would have been had been stuck with just virtual therapy.” - Margo</p>
Needs For Asian American Parents and Their Children: Parents’ expressed needs to better support their child’s prognosis and overall well-being.	Needs For Asian American Parents and Their Children -race specific	<p>“I think social groups and parent groups, support groups. So there are some that I've found. But it's a mix. And, you know, I mean, it's, it's just at the level where it is right now. It's, you know, anything is appreciated when there's nothing. But at some point, you know, it would be great to have particular groups that are for Asian families, Filipino families. . . So I think the development of his cultural identity and resources that are competent for Filipino families, Filipino immigrant families, especially, or monolingual families, or low English proficient families, there's, there's, I mean, I have no idea if there's any, at all. I haven't come across it.” -Elizabeth</p>
	Needs For Asian American Parents and Their Children -provider considerations	<p>“And just to make people understand that we are also humans, and we deserve better. So yeah, companies and society should see from this point of view and should try to also treat everyone as equal without any racial discrimination or things like that. So on in everything they do, it should also be incorporated.” -Marcus</p> <p>“ . . I don't really know much about the medical terms that we are asking him or a series of questions.” - Neil</p>
		<p>“Yeah, I mean, I feel like we're not well, I mean, okay, so in the Bay Area, right, we're technically low income. Because the median income here is ridiculous. But the cost of living is so ridiculous also. So even though we are technically low income, we are not at at poverty level. And you have to be at poverty level to like, actually get free ...free resources, and services. And even that the wait time to be able to get the services that you are, that you're supposed to get is ridiculous. So we do find ourselves, there's a lot of costs that are not covered and just not calculated in providing care. So we pay a lot of out of pocket costs. And and yeah, so I mean, you know, we, I think it places a lot of pressure to like, for example, like my, my husband works for FedEx, and so he places a lot of pressure, our our healthcare is under him. So it places a lot of pressure to, to withstand exploitation in the workplace, because we need this job, and we need this health care, and that sucks. Yeah, I think, I definitely think you can pay your way for better services or private services, and make it faster. But moving through the social services system is slow, it's hard. And 80% of the times, they won't call you back, you're the one who has to, you know, be persistent, to be able to talk to a real person.” -Elizabeth</p>
Advice to Other AsAm Parents: Wisdom parents would provide to other AsAm parents who have a child diagnosed with ASD.	Advice- self	<p>“I can say that the wellness of a child should come before anything else. Not think about what people might think about your family if you have an autistic child, so you have to like hide them from the public and all that. We should focus more on the results. What is your child likely to gain from this process. Is it going to be beneficial or how is it going to impact the child and the family, or something like that? Yeah.” -Jenny</p>
	Advice- community	<p>“...they should be able to maybe meet with people who could be having this heart of sympathy and be able to know maybe what that individual is facing and be able to give a quick response to it” -Jason</p>