Autism Spectrum Disorder and Postsecondary Pathways: A Descriptive Study

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The education of the Hand implies the dignity of labor, self-reliance, and service to humanity. The education of the Head implies appreciation of the wonders of nature, an understanding of the mysteries of the universe and a search for truth. The education of the Heart includes the awakening of the higher self and the seeking of true wisdom from within. (Guru Nanak) Of all elements, the most significant is the element of knowledge. (Sri Guru Granth Sahib, 152)

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Abstract

Autism Spectrum Disorder and Postsecondary Placements: A Descriptive Study

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Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder impacting social interaction and communication skills. ASD can cause restrictive or repetitive behaviors, interests, and activities, with associated challenges and co-morbidities that often carry over into adulthood. These can limit opportunities for higher education, socialization, and employment. Although much literature exists on educating children with ASD, there is less research and evidence, including parental and self-reports, on postsecondary experiences for teens with ASD, particularly of South Asian descent. This descriptive study investigated postsecondary options for teens with ASD from ethnically diverse backgrounds. An online survey collected data on the transition planning and decision-making process from high school to postsecondary from two groups: (1) US parents of ethnically diverse backgrounds excluding South Asian parents (n = 73) and, (2) South Asian American parents (n = 62). The following research questions guided the study:

(1) What are teens with ASD doing in the two years post-high school?

(2) What teen-related factors (level of functioning with ASD, ethnicity) or parent-related factors (level of education, involvement in transition planning processes, ethnicity) are related to postsecondary placements?

(3) What parent factors (e.g., awareness of programming) impact postsecondary placements?

Parent group categorical data was analyzed, and findings reveal little variation in teen and parent factors impacting postsecondary placements amongst the two groups. T-test analyses further determined that there is a statistically significant difference in the mean age of diagnosis for ASD for teens from the US group ($\mu = 8.47$ years old) and the teens from the South Asian American group ($\mu = 10.88$ years old). Other non-statistically relevant findings include parents report 64% of their teens as moderately functioning with ASD. In postsecondary, 40% of teens are involved in working part/full time or volunteering, 32% are engaged in postsecondary education and 28% of teens with ASD are unemployed or taking a gap year.

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Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impacts social interaction, communication skills and can cause restrictive or repetitive behaviors, interests, and activities (5th ed.; DSM-5; American Psychiatric Association, 2013; L. Jackson et al., 2018). The current prevalence rate of ASD in the US is one in 36 children of all ethnic backgrounds (Maenner, 2023). ASD is a spectrum disorder, and it presents heterogeneously, resulting in vast differences in skills and levels of support needed for children with ASD (Von Below et al., 2021; Widman & Lopez Reyna, 2020). Leo Kanner, one of the first people to identify ASD, emphasized the heterogeneity of the population (Kanner, 1943). Furthermore, Kanner emphasized that each child should be treated uniquely, as children with ASD do not often fit neatly into categories (Harris, 2018). For some individuals, the symptoms associated with ASD can create challenges in social referencing, the ability to respond to social cues, and to initiate and maintain social relationships; individuals may also develop unusual responses to sensory experiences (Anderson et al., 2018; S. Jackson et al., 2018; Kuder & Accardo, 2018; Lie et al., 2020; Lucas & James, 2018).

The symptoms and behaviors associated with ASD can also impact learning, language, and comprehension (Anderson et al., 2018; Sarrett, 2018). Students with ASD may experience comorbid conditions such as generalized anxiety disorder, social anxiety disorder, depression, learning disabilities/attention deficit, bipolar disorder, specific phobia, panic disorder, obsessive-compulsive disorder, and oppositional defiant disorder, all of which can complicate diagnosis, interventions, educational planning, and may impact school outcomes (Anderson et al., 2018; Elias & White, 2018; S. Jackson et al., 2018; Lie et al, 2020; Nachman et al., 2021).

Education Laws for Students with Disabilities

ASD is a lifelong disorder. Although there is a great deal of research demonstrating the efficacy of early intensive behavioral interventions for ameliorating behavioral excesses and skill deficits associated with ASD and teaching necessary skills across developmental domains (Dawson & Burner, 2011; Lovaas, 1987; Odom et al., 2012; Rogers & Vismara, 2008), challenges and co-morbidities often carry over into adulthood and can negatively impact opportunities for higher education, socialization, and employment (L. Jackson et al., 2018; Nachman et al., 2021). In part due to early intervention, the advent of programs focusing on this population, and the broadening of the diagnostic criteria, the rates of college enrollment for children with ASD has risen (Cox et al., 2020; Lucas & James, 2018; S. Jackson et al., 2018b; Sarrett, 2018; Steinbrenner & Hume, 2020).

Prior to exploring the various options of higher education and their accessibility for students with disabilities it is important to acknowledge the advent and continual growth of such programs would not have been possible without two critical education laws: 1) the Individuals with Disabilities Education Act (IDEA) (initially Public Law 94-142) and 2) the Higher Education Opportunity Act (2008) (initially Public Law 110-315). IDEA, which was initially passed in 1975, has been reauthorized several times and continues to raise the expectation for academic achievement for students with disabilities. The requirement for transition planning has set the stage for increased numbers of students considering higher education as a possible option. The rights of IDEA entitles all students with disabilities the right to free, appropriate education, and specialized instruction, supports, and services to access learning in the least restrictive environment from preschool to the completion of the 12th grade. IDEA requires transition

planning for what the student is going to do after secondary school. The IDEA protections end when children graduate from high school or turn 22, which results in students 22 or older lacking an entitlement to services, including protections related to Free Appropriate Public Education (FAPE) in postsecondary settings. With the rise of students with ASD in higher education, the importance of individualized assessments, collaboration, and person-centered planning become key components of a comprehensive plan to address each student's needs for education and services.

The Higher Education Opportunity Act (2008) (initially Public Law 110-315) was reauthorized in 2008 with two major provisions to support the increased enrollment of students with disabilities into higher education. In the first provision, the U.S. Department of Education Office of Postsecondary Education (OPE) awarded five-year grants to two - and four-year institutions of higher education and consortia to implement model demonstration projects. These projects provided the infrastructure for 27 institutions or consortia to establish or extend programs for students with disabilities in postsecondary education settings (Shanley, 2011). The purpose of these projects was to develop infrastructure within higher education programs to support students with ASD. The elements of infrastructure including developing effective teaching methods and strategies, transition practices and programs, distance learning initiatives, training for educators, education accessibility, and the circulation of research related to postsecondary students with disabilities (Madus et al., 2012). The Higher Education Opportunity Act (HEOA) specified that the teaching methods and strategies utilized in these project models across higher education institutions must be consistent with the principles of the universal design for learning (UDL) (Madus et al., 2012). The HEOA strove to improve the accessibility of course materials for students with disabilities by creating a National Center for Information and

Technical Support for Postsecondary Students with Disabilities (Madus et al., 2012). The objective of these centers was to provide postsecondary institutions with information and technical assistance to serve students with disabilities, collect and disseminate data, evaluate, and improve disability support services on campuses (Madus et al, 2012; Shanley, 2011).

The second provision of the HEOA enabled eligible students with disabilities to receive federal financial aid if they were enrolled in approved comprehensive transition and postsecondary programs, including programs that are non-degree granting (Shanley, 2011). To further support students with disabilities in college, HEOA legislation stipulated that the U.S. Department of Education operate a website called the College Navigator (www.nces.ed.gov). The College Navigator website provides detailed information on higher education institutions, tuition costs, retention numbers, and the percentage of undergraduate students who are formally registered with the office of disability services (or the equivalent) in higher education institutions (Madus et al., 2012).

College and ASD

Postsecondary academic opportunities for students with ASD include several options in addition to traditional four-year college degree granting programs, such as vocational school, technical/trade school, business school, and two–year community college programs, and non-degree granting programs designed for people with disabilities (S. Jackson et al., 2018a). As noted previously, the heterogeneity of ASD requires individualized planning for postsecondary programs as students with ASD and intellectual disability (IDD) have differing needs in college than students with ASD and without IDD. The programming for students with ASD and IDD is typically nondegree granting and designed for students with disabilities. The level of support for these programs goes beyond the standard accommodations offered in the college disability

services office. Postsecondary programs for students with ASD and IDD are relatively new but are continually expanding. The challenges, however, are that there is no centralized databank of information about programs that focus specifically on students with ASD and IDD, and often there a few programs that exist exclusively for students with ASD and IDD. Typically, general college programming exists for all students with an IDD. Information about programming is shared in the following ways: in literature, on autism advocacy websites, advocacy blogs, college websites and, college prep websites like Think College. There is much variation amongst the types of programs, level of supports, and classes. However, in line with the scope of this dissertation, this literature review has focused on factors critical for the success of students with ASD (without IDD) and four-year college degree-granting programs.

Researchers at the University of North Carolina at Chapel Hill examined the Center on Secondary Education for Students with an Autism Programming Model (Steinbrenner & Hume, 2020), an ASD intervention for teens and young adults to increase high school graduation rates and to successfully transition students to postsecondary education. Steinbrenner and Hume (2020) conducted a large-scale multi-site intervention study for families and teens with ASD in high schools (n = 547). The researchers found that 57% of teens completed standard diplomas and of this group 36% attended some type of postsecondary education. In the next decade, of the 550,000 children with ASD who will transition into adulthood, it is estimated that 45% will enroll in college, university, technical or vocational schools (S. Jackson et al., 2018b). Although it sounds promising that 45% of teens with ASD will enroll in college in the coming years, the college enrollment rate of neurotypical teens in 2022 was 74%, illustrating a large gap between these two student groups (Welding, 2023).

While college is not the best postsecondary pathway for all students with or without ASD, studies have correlated college completion for students with ASD to successful adult outcomes (e.g., employed, financially independent or stable relationships) (Anderson et al., 2018; S. Jackson et al., 2018a). It is critical to make decisions about goodness of fit for postsecondary for students with ASD by considering each student's level of functioning with ASD, both academically and socially. ASD impacts every student uniquely, which means that postsecondary placements must be individualized. This is in fact so critical that the IDEA requires transition planning for all students with ASD upon exiting high school.

Transition planning is designed to be a results-oriented process focused on improving the academic and functional achievement of a student with a disability to facilitate their movement from school to post-school activities. These activities include postsecondary education, vocational education, continuing and adult education, employment, volunteerism, taking a gap year, adult services, and independent living (http://www.ncset.org/). The transition planning process should include school, agency (e.g., DVR), community, and family members; be based on data; and influenced by and comprehensible to students with disabilities. Transition planning considers the child's strengths, preferences and interests and includes (1) instruction, (2) related services, (3) community experiences, (4) the development of employment and other post-school adult living objectives, and if appropriate, (5) acquisition of daily living skills and provision of a functional vocational evaluation. Transition services may also constitute special education (6), if provided as specifically designed instruction, or be a related service required to assist a child with a disability to benefit (National Dissemination Center for Children with Disabilities, 2018).

Although it is encouraging to note that studies have found an increased number of students with ASD enrolling in college (Anderson et al., 2018; Cox et al., 2020; S. Jackson et al.,

2018b; Lucas & James, 2018; Sarrett, 2018; Steinbrenner & Hume, 2020), it is equally disheartening to know that students with ASD have been found to have a high attrition rate. Research found that the dropout rate for students with ASD in college was 61.2% in comparison to the dropout rate of neurotypical college students, which was 47.6% (Anderson et al., 2018). In some studies, students with ASD were at a heightened risk of being marginalized in higher education and experiencing failure in postsecondary settings (Anderson et al., 2018; Lucas & James, 2018). Studies identified that the increased academic demands of college may have attributed to college attrition in a small way, but factors related to ASD had a greater impact on college dropout rates (Anderson et al., 2018; Lucas & James, 2018). Research studies identified factors like social, communication, sensory, routine adherence, executive functioning impairments, and the impact of these impairments as contributing to student marginalization and experiencing college failure (Anderson et al., 2018; Lucas & James, 2018). At the same time, it also appears that the two years following high school graduation were critical in setting up students for success (Anderson et al., 2018; Lie et al., 2020; Steinbrenner et al., 2020; Widman & Lopez Reyna, 2020). The two years post-high school are a critical period for all teens with ASD compared to teens with other disabilities as teens with ASD have been found to have lower rates of engagement in further education or employment (Shattuck et al., 2012). Studies suggest that students with ASD had much poorer outcomes educationally and vocationally compared to their peers who had speech and language disabilities, learning disabilities or intellectual disabilities (Elias & White, 2018; S. Jackson et al., 2018a; Lie et al., 2020; Lucas & James, 2018; Taylor & Seltzer, 2011). In fact, students with ASD without a comorbid intellectual disability are the most vulnerable group of students to potentially experience the worst outcomes overall. They were found to be three times more likely to have no daytime activities or postsecondary placement

compared to students with ASD and a comorbid intellectual disability (Taylor & Seltzer, 2011). College students with ASD without an intellectual disability experienced the lowest rate of college completion compared to students with other disabilities. Research findings by Welding (2023) reported that 73.7% of neurotypical peers completed college, while findings by Anderson et al. (2018) reported 40.7% of students with other disabilities completed college; however, only 38.8% of students with ASD completed college – the lowest rate of college completion of all the student groups. Although the difference in the rate of graduation is not statistically significant amongst students with disabilities and students with ASD, still less students with ASD graduate college. Research determined that college outcomes were correlated with adult outcomes. This places students with ASD who drop out of college at a much greater risk of experiencing poor occupational attainment, a difficult time forming social and romantic relationships, and living independently (Anderson et al., 2018; Jackson et al., 2018a). Inversely, the research findings suggested that successful completion of a college degree for students with ASD was a significant predictor of positive adult outcomes (Anderson et al., 2018; S. Jackson et al., 2018a).

The Impact of Mental Health on College Students with ASD

Postsecondary struggles for students with ASD have been associated with a multitude of wellness issues such as feeling overwhelmed, loneliness, anxiety, and social isolation, or mental health issues like depression (Anderson et al., 2018; Elias & White, 2018; Fletcher-Watson et al, 2021; S. Jackson et al., 2018a; Kuder & Accardo, 2018; McLeod et al., 2021). The results of two research studies of college students with ASD that investigated student experiences of academic, social, and mental health factors in postsecondary concluded students with ASD were also at risk for experiencing hardships in all three domains (Anderson et al., 2018; Kuder & Accardo, 2018). Three-quarters of the 56 adult respondents with ASD aged 18-57 reported high rates of

depression and suicidal ideation compared to their neurotypical peers in college (Jackson, et al., 2018a). Struggles of mental health impacting college outcomes were also reported by parents when describing their children with ASD in research studies by Elias and White (2018) and Viezel et al. (2020). Parents noted that despite their children with ASD being academically and intellectually prepared, they were scholastically underperforming due to issues of emotional regulation, social isolation, executive function, and personal challenges with adaptive skills (Elias & White, 2018; Viezel et al., 2020).

Parental Involvement and Postsecondary Placements

Making decisions about postsecondary options is a complicated and anxiety-provoking process for many families, particularly for ethnically diverse families of teens with ASD (Lie et al., 2020; Makin et al., 2017; Parsons et al., 2009). Parents play a vital role in helping their teens with ASD develop aspirations, plan, prepare, investigate colleges or other types of postsecondary programming to assess goodness of fit, consider costs, and succeed through postsecondary school (Hill & Wang, 2015; Sarrett, 2018). When thinking through the complexities of the decision-making process for higher education, parents must contemplate many concerns simultaneously, including but not limited to the following: 1) assessing how ASD impacts their teen, 2) teen's executive functioning skills, 3) academic level, 4) resources and supports, 5) school/disability office and professors' level of expertise with and responsiveness to students with ASD, 6) teen's desires (teen may decline services/supports), and 7) the social environment of the college (Krell & Pérusse, 2012; Nachman et al., 2021; Ruble et al., 2019; Sarrett, 2018). The social environment of college and other types of postsecondary programming have been found to be fast-paced and requiring more social skills than students with ASD often have (Krell & Pérusse, 2012). Early adulthood from 18 to 25 years old is considered the identity formation

years, when college students make social connections and join groups and clubs both in and outside of classes. For students with ASD, these make the college years an incredibly challenging time, in part as college or other types of postsecondary programming are less structured than high school (Elias & White, 2018). This requires students to make adaptations to fluctuating schedules, while challenges with social interactions and communication may make it harder to interpret the social landscape, make friends, and build a social network (Elias & White, 2018; Lie et al., 2020; Makin et al., 2017; Starr et al., 2001). Learning more about the decision-making process, the types of considerations important to parents in selecting postsecondary placements and identifying important elements for a successful transition into higher education is essential to understand as more students with ASD are pursuing higher education than ever previously recorded (Cox et al., 2020).

Diagnostic Disparities

Although the prevalence rate of ASD in the US continues to rise, a discrepancy in diagnosis still exists for children of racially and ethnically diverse backgrounds (Constantino et al., 2020; Fombonne & Zuckerman, 2021). This is important to address because early diagnosis and intervention are not only critical to success in the early years but is also impacts the later years and opportunities for postsecondary placements. However, Black, Hispanic, and Asian children are diagnosed less frequently and at later ages than white children (Constantino et al., 2020; Fombonne & Zuckerman, 2021; Jones & Mandell, 2020). In a study by Maenner et al. (2020) that utilized the Autism Developmental Disabilities Monitoring Network, 11 sites in the US (n = 3,981) were reviewed. The study found that the percentage of children evaluated by 36 months of age for ASD varied by race and ethnicity, with white children being evaluated at a slightly higher percentage than children of other ethnicities despite parents of diverse

backgrounds raising developmental concerns about their children with healthcare professionals. A recent study by Pham et al. (2022) that reviewed 1,489,594 electronic medical records of children diagnosed with ASD suggested that the racial and ethnic disparities gap in diagnosis is closing across racial and ethnic groups. One major limitation of this study, however, is that findings were based solely on a records review. Clinicians who serve disproportionate numbers of minority patients or minority patients themselves were not contacted. Minority patients were unable to share their experiences of the ASD diagnosis process including the timeliness and sensitivity of healthcare professionals addressing their concerns limiting the overall generalizability of the results (Pham et al., 2022).

The Intersectionality of Disability and Diversity in the South Asian Community

Research conducted in the Center for Immigration Studies by Camarota and Zeigler (2014) finds that South Asian Americans from India were identified as the fastest growing population in the US. This suggests that increasing numbers of the South Asian community are trying to navigate systems that exist to address ASD like systems of service utilization, schooling, and the transition-planning process from high school to postsecondary for their children. Parent perspectives often differ from traditional scientific/professional perspectives in that parents often access spiritual, moral, or personal interpretations to understand the complexities of ASD and how these might impact their child's schooling and adult outcomes (Desai et al., 2012; Jegatheesan et al., 2010). The South Asian culture is predominantly collectivistic, with interdependence and group norms highly valued (Panjrath & Misra, 2018; Shorey et al., 2020). Social interaction, social communication, and the ability to relate to others is given high importance in the South Asian culture, meaning that the threat of social devaluation from having a child with ASD looms within many members the South Asian American

Community (Desai et al., 2012; Kaur, 2011; Panjrath & Misra, 2018). Making sure children with ASD have access to postsecondary options that will create secure career opportunities are highly coveted in the South Asian American Community (Panjrath & Misra, 2018). Education and careers are highly regarded in the South Asian American Community (Kaur, 2011; Panjrath & Misra, 2018). Children with ASD who can attain an undergraduate degree or skilled trade certification and secure a well-paying job uphold family goals, aspirations, and cultural norms (Kaur, 2011; Panjrath & Misra, 2018). Well-educated and employed children with a disability have the potential to create a larger pool of marriage prospects, which in turn can potentially restore the social standing of their family within the South Asian American Community (Shorey et al., 2020). Research studies have reported that South Asian American parents of children with ASD aspire for their children to experience full inclusion into classrooms and believe that children will be able to learn skills necessary for positive academic outcomes with more exposure and practice in the company of their neurotypical peers (Ecker, 2010; Jegatheesan et al., 2010). In comparison, when non-Asian parents of children with ASD were asked about their goals in the classroom, parents hoped to see more opportunities for their children to engage, more staff trained with ASD knowledge in classrooms, and for their children to feel more a part of the school culture (Hodges et al., 2020).

Although it is natural to assume that South Asian American parents living in the US would experience less social and cultural stigma about having a child with ASD, allowing for parents engage in open conversations with educators and professionals about the impacts of ASD, data does not support this assumption. Research studies found that South Asian American parents were extremely private and reluctant to share information about their child with ASD unless they were directly asked questions by service providers (Gabel, 2004; Kaur, 2011). Being

inhibited in discussing concerns with educators and experts about their children with ASD is a disadvantage for South Asian American parents engaged in the decision-making/transition planning process for postsecondary placements.

Purpose of this Study

The rising rates of ASD, with a current prevalence of one in 36 children (Maenner et al., 2023), impact every public and most private schools in the United States. Although much has been written about educating young children with ASD, there is much less research and fewer parental reports of postsecondary experiences for students with ASD. In the past few years there has been an increase in the attention given to the range of postsecondary options available for teens with ASD, initially with the website (www.thinkcollege.net), which was the first website of its kind to disseminate information about postsecondary options for children with all types of disabilities. Although it was not specifically developed to meet the needs of children with ASD, more recently a second website (www.collegeautismspectrum.com) was launched which focuses on postsecondary placement options particularly for students with ASD, and provides information on both two- and four-year college programs across the US (Nachman et al., 2021). More and more young adults with ASD are now attending traditional college programs or non-degree granting programs on college campuses designed for people with ASD (Nachman et al., 2021).

As the number of teens with ASD pursuing college continues to increase, it is necessary to better understand the pathways accessed in postsecondary for students with ASD (Cox et al., 2020). Making choices about postsecondary is stressful for most parents but has been found to be even more so for the parents of students with ASD (Lie et al., 2020). However, currently, little research exists to help researchers understand which pathway parents of children with ASD are

accessing and how decisions for postsecondary placements are made (e.g., as a family decision, based on guidance from teen's high school support team, or through guidance by professionals). This dearth of information is even more pronounced when it comes to understanding the experiences of South Asian American parents and their decision-making process for postsecondary placements. Rooted is collectivism, the South Asian community places emphasis on the importance of acquiring scholarship in higher education to increase the individuals' prospects for marriage, strengthen the earning power of the individual to the support their family, and uphold the social status of their family within the South Asian community (Kaur, 2011; Panjrath & Misra, 2018). More research is needed to learn about parents' decision-making process of postsecondary placements for their children with ASD. It would also be advantageous to know if similarities or differences exist in the postsecondary pathways accessed, the level of parental engagement in the transition planning process, and the types of supports or accommodations considered necessary by parents from ethnically diverse backgrounds.

The purpose of this study was to investigate postsecondary placements accessed and how these decisions were informed by comparing the choices made by the two parent groups (1) American parents of South Asian descent and (2) Diverse parents excluding South Asian American. It is important to recognize the multitude of factors families must consider in this decision-making process. Prior to making decisions about postsecondary placements based on goodness of fit, it is imperative for parents to understand their child's level of functioning with ASD. The role of parents in postsecondary placement decisions is critical so it is necessary to know about the parents' level of engagement with the transition planning process, if the student had access to experiences that may strengthen college preparedness, the role of the student's

team to guide and support decisions for postsecondary placement, and finally what types of services parents access for their children to be successful in their postsecondary placements.

Research Questions

The following research questions guided the design of this study:

(1) What are teens with ASD doing in the two years post-high school?

(2) What teen-related factors (level of functioning with ASD, ethnicity) or parent-related factors (educational attainment, involvement in the transition-planning process, ethnicity) are related to postsecondary placements?

(3) What parent-related factors (awareness of programming, considerations) impact postsecondary placements?

Chapter 2: Literature Review

Predictors of Successful College Outcomes for Students with ASD

College is a time of new learning for students both academically and practically, as they gain an understanding of how they learn, how to be a student, how to manage the everyday responsibilities of college life, and how to form social connections with peers to better navigate college expectations (Jackson et al., 2018a). Research has found that predictors for success in college for all students and especially students with ASD include:

- family support
- academic preparation
- self-determination/self-advocacy skills
- independent living and executive functioning skills (Anderson et al., 2018; Daly-Cano et al., 2015; Duncan et al., 2021; Elias & White, 2018; S. Jackson et al., 2018a; Lie et al., 2020).

The following the sections review these predictors in more depth. This is followed by a section on transition planning including accommodation and autism specific programming (ASP) in colleges. The final section of this chapter focuses on gaps in the literature.

Family Support

Given the unique nature of ASD and how it impacts each student differently, both the student and parent/family stakeholder perspective are important to research. Families are often still highly involved in the education planning process while their student with ASD is in high

school and serve as the primary conduit between educators, service providers and their students (Elias & White, 2018).

The importance of the role of families during the transition planning process and their impact has been recognized in multiple studies (Jackson et al., 2018; Elias & White, 2018; Lie et al., 2020; Nachman et al., 2021; Sarrett, 2018). Families can enhance college student outcomes with their knowledge and involvement in the following ways: (1) families possess deep knowledge of their student's level of functioning, strengths, areas of needs, and can work with their student to identify colleges that would be a good fit, (2) families can work with their student and high school counselors to navigate the structure of college disability services offices, as disability services vary across colleges, (3) families can collaborate with their student and high school counselors to assess the college's levels of expertise with ASD, (4) families can investigate which supports/accommodations are available at colleges, so they can help their student advocate to receive them, and (5) families can partner with their student and advocate for individualized supports to meet social, living and academic needs of their student in college (Jackson et al., 2018; Lie et al., 2020; Nachman et al., 2021). A recent study by Elias and White (2018) discovered that family involvement was central to the planning process for the transition post-high school for all students, but even more critical for students with ASD as they are at greater risk than other students for nonengagement or college attrition. The study found that the timing of transition planning was important and recommended that families complete transition planning while their student was in postsecondary.

Academic Preparation

Academic preparation for college or college readiness is defined as grasping key concepts in the areas of mathematics, English, language arts, writing, and science in accordance with a set

of common core state standards (Lombardi & Conley, 2011; Mishkind, 2014; Moreno et al., 2023). Students are expected to have developed skills in critical thinking, problem solving and collaboration across a range of academic subjects (Lombardi & Conley, 2011; Mishkind, 2014; Moreno et al., 2023). The goal of college academic preparation is to allow students to enroll and succeed in credit-bearing general education college courses without remediation (Moreno et al., 2023).

As previously stated, the literature demonstrates a rise in college enrollment for students with ASD with the broadening of diagnostic criteria (Cox et al., 2020; Lucas & James, 2018; S. Jackson et al., 2018b; Rando et al., 2016; Sarrett, 2018; Steinbrenner & Hume, 2020). This has led to more children accessing early intervention services and Individualized Academic Planning (IEP) which in turn has created more opportunities for college (Cox et al., 2020; Lucas & James, 2018; S. Jackson et al., 2018b; Steinbrenner & Hume, 2020). For students with ASD and no comorbid learning disabilities or challenges with executive functions studies report that these students are academically capable of succeeding in college (Dipeolu et al., 2014; Rando et al., 2016; VanBergijk et al., 2008). For students with ASD and comorbid learning disabilities or executive function challenges IEP's, accommodations and tutoring are often accessed for college preparedness (Dipeolu et al., 2014; Rando et al., 2016).

Although great importance is placed on academic skills for college, studies have reaffirmed that social, communication, and daily living skills are in fact a core component of academic preparation (Elias & White, 2018; Sarrett, 2018). Studies have found that these skills are lacking for students with ASD for both those who are academically prepared and others who are struggling academically (Elias & White, 2018). This is further explored in living and executive functioning skills.

Self-Determination/Self-Advocacy

Studies investigating college for students with ASD define self-advocacy as the ability to communicate individual needs and wants, and the ability to make decisions about the supports/accommodations needed to achieve them (Daly-Cano et al., 2015; Sarret, 2018). Research findings assert that self-advocacy skills are related to academic performance and successful adaptation to college (Daly-Cano et al., 2015). Unlike schooling in the elementary and secondary years, where families work closely with schools, postsecondary educational settings require all students and especially students with disabilities to self-advocate (Sarrett, 2018).

For accommodations to be relevant and effective, students need to be involved in the process of planning for college and in the day-to-day decisions of college life. It is important for students with ASD to self-advocate for accommodations that will best support their learning style, needs, and vocalize those needs to the transition planning team, college disability services counselors and to professors (Jackson et al., 2018; S. Jackson et al., 2018a; Sarrett, 2018).

One obstacle to self-advocacy, however, is that students with ASD often need explicit instruction to understand that they need help, what type of assistance they need, and how to ask for the necessary help (Jackson et al., 2018; S. Jackson et al., 2018a). Parents have reported concerns about their student's limited self-advocacy skills both as they are preparing to transition to college and while their students are attending college (Jackson et al., 2018; S. Jackson et al., 2018a; Lie et al., 2020).

Living and Executive Functioning Skills

Daily living skills are defined as the tasks required for everyday tasks that are required for everyday independence at home, college and in the community (Anderson et al., 2018; Duncan et al., 2021; Lie et al., 2020; VanBergeik et al., 2008). Researchers Duncan et al., (2021) identified three main areas of daily living skills that included personal (e.g., brushing teeth, showering, taking medication, managing one's own health), domestic (e.g., cleaning, cooking, laundry), and community (e.g., managing time, managing personal finances, getting, and maintaining a job). While most daily living skills are acquired during child development in neurotypical children, often daily living skills must be taught with direct instruction for children with disabilities (Anderson et al., 2018; Duncan et al., 2021).

As teens make the transition from high school to college, students with ASD described how they were expected to meet daily living skills and social demands of college, which were at times exhausting (Anderson et al., 2018; S. Jackson et al., 2018a; Lie et al., 2020). Previous studies reported that nonacademic factors including living skills such as cooking, laundry management, navigating transportation options, financial management, self-care, and roommate issues were tricky to manage and impeded college outcomes for students with ASD (Anderson et al., 2018; Duncan et al., 2021; Hillier et al., 2021; Lie et al., 2020; VanBergeik et al., 2008). Changes in routine, including things like a last-minute classroom and staff change, were also difficult to manage for students with challenges in executive function (Elias & White, 2018; Jackson, et al., 2018a; Lie et al., 2020; Lucas & James, 2018; Sarrett, 2018).

Literature finds that there is a gap in the accommodations necessary for students with ASD to graduate college and what colleges consider necessary for successful college outcomes. Currently, colleges focus primarily on academic support and emotional support (Anderson et al.,

2018; Duncan et al., 2021; S. Jackson et al., 2018a; Lie et al., 2020). In the study by Elias and White (2018), parents participated in an online survey specifically examining parent-identified educational challenges and areas of service need/supports for their students with ASD. Parents were asked to rate transition services, academic tutoring, speech/language services and therapies, assistive technologies, social interaction training, emotion regulation therapy, counseling, career counseling, independent living training, study skills training and peer mentoring. Parents identified competency in social skills and behaviors in postsecondary settings as more pressing than executive functioning and academics. Many of the parents of students with ASD reported their children's need for social support, living arrangements, speech and language services, transition services, and independent living training as necessary in their child's postsecondary placement (Elias & White, 2018).

Transition Planning

In accordance with IDEA (initially Public Law 94-142), it is mandatory for all students with an IEP to have a transition plan by age 16, though it can occur earlier as determined by the IEP team or state laws. Transition planning differs from the IEP in that it is focused on preparing youth with disabilities as they enter postsecondary life. Transition planning requires a coordinated set of activities within an outcome-oriented process that relies upon active student involvement, family engagement, and cooperative implementation of transition activities, as well as coordination between the vocational rehabilitation agency, the State educational agency, and the local educational agencies (C.F.R. §300.43).

Traditionally postsecondary transition planning was focused on vocational training but now, as previously mentioned, the rates of college enrollment for students with ASD has increased considerably. This is in part due to early intervention, the advent of programs focusing

on this population, and the broadening of the diagnostic criteria (Cox et al., 2020; Lucas & James, 2018; S. Jackson et al., 2018b; Sarrett, 2018; Steinbrenner & Hume, 2020). To support the growing number of students with ASD enrolling in college, the focus of transition planning for postsecondary has also shifted to support students in the aforementioned four predictors for college success (family support, academic preparation, self-determination/self-advocacy, executive functioning and living skills).

College planning for students with ASD is different than college planning for neurotypical students because the heterogeneity of how ASD impacts students. Studies advise that families helping their students make the transition to postsecondary education should have comprehensive planning that addresses their student's individual needs, as well as help their student advocate for student-specific accommodations and assess college program options, specifically Autism Specific Programs, for goodness of fit (Anderson et al., 2018; S. Jackson et al., 2018a; Kuder & Accardo, 2018; Lie et al., 2020; Nachman et al., 2021; Sarrett, 2018).

Comprehensive transition planning is so integral to successful college outcomes (Anderson et al., 2018; S. Jackson et al., 2018a; Kuder & Accardo, 2018; Lie et al., 2020; Sarrett, 2018) that the transition guide to postsecondary education and employment from the Office of Special Education and Rehabilitative Services (OSERS) of the US Department of Education (2020) offers specific guidance pertaining to transition planning from high school to postsecondary school. The OSERS guidance (2020) requires postsecondary transition planning to be guided by the interests and goals of the child in conjunction with the child's team and family with the purpose of pursuing postsecondary education, employment, community participation and independent living. The OSERS report (2020) detailed that for students with an IEP who wish to pursue postsecondary options like college or university, the IEP Team was

responsible for course planning during high school, and ensuring specialized instruction, supports, and services needed to assist the student in preparation for college and or other postsecondary educational options were provided.

Positive transition planning requires high school counselors to coordinate closely with college disability services officers, students, and families (Jackson et al., 2018; Sarrett, 2018). The intersection between the special education transition plan and the high school counselor is the vital first step. The amount of information, resources, knowledge of student's strengths, interests, and challenge areas are all meant to be addressed in the transition planning process, affirming the need of the special education plan to coordinate with the high school counselor, student, and family.

Making a transition from a familiar high school to a new and much larger postsecondary institution is challenging for many students especially students with ASD. In a recent study by Anderson et al. (2018), study recommendations included a proposed model for students with ASD to advocate for an Individualized College Plan (ICP). The proposed ICP was a plan meant to provide detailed information on the types of supports across all domains necessary to thrive in college, thereby serving much like an Individualized Education Plan (IEP) that is used during the elementary and high school years.

The six major elements identified as key in transition planning by Kuder and Accardo (2018) and Lie et al. (2020), are as follows: (1) advise students to register at the office of disability services and consent for disability services officers to contact them, allowing disability officers to be in contact with students prior to the beginning of the academic year, (2) acclimate small groups of students to campus early (autism summer school), (3) assist students and build alliances with families, (4) select trained advisors for students, (5) predict and meet residential

needs, and (6) provide ongoing support during the first year and subsequent years if necessary. The current literature suggests that teaching students the rhythm of college and expectations of college life before they start may be helpful. As an example of fulfilling elements two and five of transition planning, this could occur through summer programs where high schoolers live on the college campus, high schoolers take college courses, and/or teaching high schoolers living skills like laundry, meal prep and balancing finances before they start college (Anderson et al., 2018; Duncan et al., 2021; S. Jackson et al., 2018a, and Lie et al., 2020). Similarly, Duncan et al. (2021) suggests teaching daily living skills through direct instruction with a life coach, living skills classes, video modeling and teaching students with ASD to utilize a daily self-care checklist increases independence and acquisition of living skills.

Researchers Lucas and James (2018) investigated the effectiveness of a specialist university mentoring program designed to address the social and emotional needs of students with ASD. The study found that the university mentoring program was effective in creating a solid support system for students with ASD, so they were less reliant on families and better able to navigate college life autonomously. The specific mentoring program investigated was a tailored partnership where students had a strong personal relationship with their mentors resulting in greater self-confidence and independence in college (Lucas & James, 2018).

Accommodations

Individualized accommodation plans, including training and support on the residential needs of college students with ASD, are recommended as part of the transition plan (Sarrett, 2018; Widman & Lopez Reyna, 2020). College students with ASD have described academic accommodations as a method of leveling the playing field rather than making course work easy for them (Sarrett, 2018).

Currently, college accommodations for students with ASD exist in most postsecondary placements; the challenge, however, is that accommodations are standardized, and often not sensitive to the individualized needs of students with ASD (Sarrett, 2018; Viezel et al., 2020; Widman & Lopez Reyna, 2020). Accommodations have been a critical part of individualized educational planning for all students with disabilities but students with ASD need more tailored accommodations than is regularly available.

Traditional disability accommodations are available at nearly every college for students with ASD to access learning and generally include academic accommodations like those offered in high school. Extended time for tests, alternative testing sites, flexible due dates, breaks during class, and the use of technology in class are often utilized as accommodations in colleges (Sarrett, 2018; Viezel et al., 2020; Widman & Lopez Reyna, 2020). While in theory these packages of accommodation seem reasonable and applicable, a key issue is that these accommodations are often recommended by practitioners without directly consulting the student with ASD for their input to describe their individual needs (Sarrett, 2018). In fact, few colleges offered specialized services such as a learning strategist, support for executive functioning, anxiety management, and accommodations for sensory needs that were commonly reported in studies by students with ASD (Kuder & Accardo, 2018; Widman & Lopez Reyna, 2020).

Academic Accommodations

Research studies for college students with ASD continue to emerge and make recommendations in various areas that must be addressed in comprehensive transition planning through accommodations. In terms of learning accommodations, a study by Sarrett (2018), suggests employing a Universal Design for Learning Framework (UDL) to make college more accessible for students with ASD. With flexibility central to this approach to meet the needs of

students, UDL is a multimodal instruction that is meant to create educational environments that are respondent and accessible to a variety of learning needs and cognitive styles. In addition to the traditional accommodations offered, UDL accommodations also include an online learning format, note-takers, clear directions, the use of visuals, optional group activities, coaching, group sessions, sessions to practice conversational skills, residential assistance, social activities, and content tutoring to support the diverse needs of college students with ASD (Sarrett, 2018).

A second study focused on the needs of college students with ASD was the subject-specific accommodation suggested by Jackson et al. (2018). The subject-specific accommodation was a writing accommodation for students with ASD who were having a difficult time writing and organizing concepts in response to an abstract prompt. Researchers recommended that support in strategy instruction for writing should be made available to students who have trouble in areas including generating relevant information while writing, taking the perspective of the reader, responding to abstract prompts, organizing, and synthesizing information from more than one source, and analyzing and interpreting an author's message (Jackson et al. (2018).

A third study focused on the needs of college students with ASD recommended a testing-specific accommodation. The goal of the testing-specific accommodation was to assist students with ASD who were experiencing anxiety around exams and proposed an alternative exam format that included deferring exams or taking them in smaller groups rather than with the entire class. The research found that taking exams in smaller groups or writing take-home tests was effective for the reduction of stress and for managing difficulties with planning and organization (Anderson et al., 2018). Some students in college reported needing extra support to manage and organize time so they could complete and turn in homework prior to deadline dates and initiate

follow-up meetings with professors to gain a clearer understanding of assignments (Elias & White, 2018; Jackson, et al., 2018a; Lie et al., 2020; Lucas & James, 2018; Sarrett, 2018).

Nonacademic Accommodations

In a fourth study focused on the executive function needs of college students with ASD, scheduling changes were recommended for students with ASD. Findings by Sarrett (2018), suggested that classes should be scheduled within a three-day block in the week so that two days could be devoted entirely to homework. This delineation of class to homework days was recommended to mitigate some of the pressures around time management and organization.

In a fifth study findings by Brown (2015) and Sarrett (2018), investigating college students with ASD addressed sensory needs that students often struggled with but were largely missing from the list of regular accommodations. Students with ASD often experience sensory over-responsivity and their experiences with smells, sounds, crowds in lecture halls, in the hallways, or in the cafeteria were found to be overwhelming (Brown, 2015; Glennon, 2016; Sarrett, 2018). Study recommendations included creating sensory spaces on campus that would allow students with ASD to take a much-needed break, encouraging the use of headphones to reduce sound, and masking to limit smells (Sarrett, 2018). Sensory coaching, support groups and organized social activities were also recommended to help with sensory needs (Brown, 2015; Sarrett, 2018).

As enrollment numbers of students with ASD continue to rise and transition planning becomes more tailored to student success, colleges and universities are faced with the competing aim to uphold rigorous academic standards while honoring and supporting the intersectionality of students and disability. Students with ASD and the accommodations they require serve as a

stimulus for a bigger discussion about what types of reasonable changes should colleges and universities make to facilitate learning and promote student belonging.

Autism Specific Programs in College

Many programs to support students with ASD on college campuses are being developed. These programs are designed to work through existing disability student service programs. Students with ASD apply with the general population for admission, and once they are admitted they can request services or admission to these special programs. The range of services vary across campuses. Some have minimal ASD specific services, while others have support programs designed for students with ASD that may require extra fees and provide individualized supports.

Autism Specific Programs range from two to four-year options in both public and private universities and colleges. The diversity of ASPs varies significantly from institution to institution but in general terms most programs are degree granting and serve as a consolidated center for support across all domains (educational, social, and mental health) for enrolled students. ASPs enroll a cohort of students each year that checks in and supports students throughout their respective programs.

Autism Specific Programs in colleges were designed to support students' success by capitalizing on strengths and providing students with support to meet students' distinctive needs. These findings further emphasized the necessity of individualized transition planning and team coordination (school team, therapists, student, and parents) to identify appropriate supports for postsecondary (Nachman et al., 2021). While there is no set of prescribed supports for successful college outcomes, nor is there information about college students with ASD receiving too much support, the literature does acknowledge that the 10 supports most beneficial to students with

ASD include: (1) testing accommodation, (2) curriculum accommodation, (3) tutoring, (4) transition services, (5) parent involvement, (6) social skills training, (7) life skills support, (8) mental health support, (9) class activities, and (10) peer mentoring (Jackson et al., 2018; Lie et al., 2020; Nachman et al., 2021). The literature affirms that students with ASD might access all, some, or none of these supports to be successful in their postsecondary placement, but it is critical that students with ASD self-advocate for their educational and social needs (Jackson et al., 2018; Lie et al., 2020; Nachman et al., 2021).

It is encouraging to know that programs are emerging and an important component of transition planning for students with ASD is locating colleges that are supportive to the needs of neurodivergent learners (Jackson et al., 2018). Having an accurate assessment of the amount and type of support that a student will need in college is essential when selecting an appropriate program. Some students will flourish with limited support, while others may need the support of a program designed to meet the needs of college students with ASD.

Gaps and Challenges in Accessing Information About ASPs

One major challenge for families seeking information about ASPs is that until recently there was no aggregated data to locate colleges with a strong support infrastructure for students with ASD or colleges that have Autism Specific Programming (ASPs). Information about programming was shared in the following ways: in literature, autism advocacy websites, advocacy blogs, college websites, and college prep websites like Think College and College Autism Spectrum.

As ASP programs are so new, having just appeared in the last six years, information continues to grow and change all the time. It can be hard for parents, teens with ASD, and high school counselors to track ASD-specific programming or be aware of new college programs

(Nachman et al., 2021). Just like many parents of teens graduating from high school, parents of teens with ASD use institutional websites to collect data on potential college choices. One of the earliest websites to consolidate and disseminate information on colleges with programming to support the needs of students with disabilities was Think College (www.college.net). Think College was valuable and necessary for program awareness at the college level (S. Jackson et al., 2018a). However, as discussed in Chapter 1, Think College serves college students with all disabilities and was not designed to serve the very specific and often divergent needs of college students with ASD (Anderson et al., 2018; Elias & White, 2018; Kuder & Accardo, 2018; Nachman et al., 2021).

A groundbreaking study emerged in 2021that aggregated information for college programming specifically for students with ASD to help streamline information for families searching for college options (Nachman et al., 2021). Nachman et al. (2021) conducted a yearlong search from August 2018 to August 2019 of all postsecondary institutions in the US to identify all the Autism-Specific College Support Programs available. Researchers discovered 74 ASP programs in 29 states. An expansive listing of all ASPs up to 2021 is available on College Autism Spectrum (www.collegeautismspectrum.com). This website also provides a brief description of the programs, direct links to institutional websites, cost of tuition, and the accommodations available at the various colleges (since publishing this article there are now 80 ASPs listed). Most ASPs appear at four-year public institutions concentrated in the Midwest (Great Lakes) and Eastern regions (Nachman et al., 2021).

College Outcomes and Their Impact on Adult Outcomes

Although many factors, both academic and nonacademic, can impede college outcomes for students with ASD, college completion has been correlated with positive adult outcomes for

students with ASD. Jackson et al. (2018a), found that young adults with ASD who dropped out of college had poor occupational attainment, a difficult time forming social and romantic relationships, and living independently. Inversely, however, the findings also indicated that successful completion of a college degree for students with ASD was a significant predictor of positive adult outcomes (Anderson et al., 2018; Jackson et al., 2018a; Widman & Lopez Reyna, 2020). Students with ASD who completed college were more likely to be gainfully employed, financially self-sufficient, and living independently (Anderson et al., 2018; S. Jackson et al., 2018a; Widman & Lopez Reyna, 2020).

Gaps in the Literature

Although previous research has demonstrated the importance of school placements for children with ASD in the elementary school years (Kurt & Mastergeorge 2012; Lauderdale-Littin & Blacher, 2013; Sansosti & Sansoti, 2012), there has been little research on what school placements students with ASD access during postsecondary and how these decisions are made by families. To better support students with ASD in postsecondary placements, it is necessary to learn more about what types of educational pathways are accessed and what informs the decision-making process for parents. While evidence-based recommendations have emerged in studies about how family involvement is advantageous in the transition planning process, to date there are no recommendations based on long-term data regarding the role of families in supporting their students in postsecondary placements, and what is the optimal way for students and families to navigate the postsecondary transition planning process.

A second gap in the autism literature is the underrepresentation of participants from racially and ethnically diverse backgrounds (Streinbrenner et al., 2020; West et al., 2016); within this, information about the South Asian American experience is largely missing. With the

changing racial and ethnic demographics of all children and youth in the U.S., and the largest growing community being South Asians Americans (Camarota and Zeigler, 2014), it will be increasingly important to enhance efforts to recruit participants from this community and conduct more focused analyses of the South Asian American Community (Steinbrenner et al., 2020). Learning about the experience of ASD in the South Asian American Community will provide information about the possible differential effects of culture (Streinbrenner et al., 2020) on the decision-making and transition planning process for postsecondary placements of children with ASD.

Chapter 3: Method

This chapter presents the study's methodology including information about participants, exclusion criteria, recruitment, background research for survey development, approvals, research design, procedure, data analysis and hypothesis. It then shares the results, implications, limitations, and conclusions.

Participants

One hundred and thirty-five parents of teens with ASD who completed high school within the last two years were recruited through non-probability sampling (Dillman, et. al, 2014). The survey respondents were US residents, able to read and write in English, and had access to a mobile device such as a laptop, cellphone, or tablet.

Two groups of parent participants were recruited for this study: Group one was comprised of 73 parents (54% of respondents) of racially and ethnically diverse backgrounds including white but excluding South Asian Americans. Group two was comprised of 62 American parents (46% of respondents) of South Asian (Indian) descent. Participant eligibility was determined through pre-screening questions to confirm the four inclusion criteria: (1) US resident, (2) Non-South Asian (Indian) descent, (3) has access to a mobile device, and (4) parent of a child with ASD who has completed high school in the last two years, as shown in Table 1. For the parents to participate in group two of this study eligibility was determined by pre-screening questions to confirm the four inclusion criteria: (1) US resident, (2) South Asian American (Indian) descent, (3) has access to a mobile device, and (4) parent of a child with ASD who has completed high school in the last two years. Participant recruitment occurred over two time periods: December 1- December 29, 2022, and January 12 – January 31, 2023.

Table 1

Parent Participant Recruitment

Respondent Groups	Data collection periods	Eligibility criteria
(1) US ethnically diverse sample, excluding South Asian parents (n =73) (2) US parents of South Asian descent (n = 62)	(1) 12/1/22 – 12/29/22 (2) 1/12/23 – 1/31/23	(1) US resident (2) English literate (3) access to mobile devices (4) parent of child with ASD who completed hs in the last two years

Ideal sample sizes were predetermined to allow for advanced statistical analysis and evaluation of statistical significance between groups. To test for statistical significance between groups, the chi square $\chi 2$, Fisher's exact test, and t-test were implemented. To better compare the two parent groups, it was necessary to test for statistical significance across categories. For this study, the Fisher Exact Probability Test with a three-rows by three columns contingency tables (Khan, 2003) were used for each of the two participant samples to compare probabilities of responses for teen characteristics and parent characteristics. More specifically, the Freeman-Halton Extension of the Fisher Exact probability test for a three-rows by two column contingency table was used and for a three-rows by three column contingency table (Khan, 2003), which is used for data sets of no greater than n = 90. In the final analysis, data was compared by responses across groups to gain a deeper insight into parents' experiences with postsecondary placement decisions and the transition planning process.

Demographics for each participant was collected and are presented in Table 2. The questions pertaining to demographics for the parents included gender, age, level of education, race/ethnicity, relationship to the child with ASD, and zip code. The questions pertaining to demographics for the child included gender, age, race/ethnicity, and level of functioning with ASD (see Appendix A).

Table 2

Parent Demographics

	US Sample		South Asian American Sample	
Characteristics	N	Percentage	N	Percentage
Gender				
Male	35	48	29	47
Female	36	49	31	50
Other				
I prefer not to answer	2	3	2	3
Ethnicity				
American Indian or Alaska Native	1	1	2	3
Asian/Asian American	5	7	41	66
Black or African American	10	14	5	8
Hispanic American	11	15	3	5
Native Hawaiian/Pacific Islander			1	2

White/Caucasian	45	62	8	13
Multiple Ethnicities	1	1		
I prefer not to answer			2	3
Age				
18-29	19	27	15	24
30-44	28	38	30	49
45-60	25	34	15	24
>60	1	1	2	3
Relationship to child				
Father	29	40	24	39
Mother	34	47	26	42
Legal Guardian	5	7	7	11
Other	1	1		
I prefer not to answer	4	5	5	8
US region currently residing in				
East North Central	14	19	6	10
East South Central	4	5		
Middle Atlantic	12	16	13	20

Mountain	2	3	2	3
New England	3	4	3	5
Pacific	8	11	22	35
South Atlantic	17	24	8	13
West North Central			1	2
West South Central	13	18	6	10
I prefer not to answer			1	2
Highest Level of Education				
Less than high school	3	4	4	6
Graduated from high school	15	21	8	13
Some college	16	22	13	22
Graduated from college	19	26	17	28
Some graduate school	7	10	4	6
Graduated from graduate school	13	17	15	25
Gender of child with ASD				
Male	50	69	38	61
Female	22	30	23	37
I prefer not to answer	1	1	1	2

Ethnicity of child with ASD				
American Indian or Alaska Native	1	1	3	5
Native Hawaiian/Pacific Islander	1	1		
Asian/Asian American	4	6	41	66
Black or African American	10	14	3	5
Hispanic American	11	15	4	6
White/Caucasian	46	63	11	18
Multiple Ethnicities				
Age of child with ASD				
17	25	34	22	35
18	10	14	8	13
19	12	16	11	18
20	16	22	7	11
21	3	4	11	18
22	2	3	1	2
23	1	1		
>24	4	5	2	3

Recruitment

Participants were recruited via Survey Monkey, an online panel survey platform considered one of the best platforms for short surveys collecting categorical data (Litman et al., 2021). The study followed the set process of survey development stipulated by Survey Monkey, which requires that each survey protocol is reviewed by Survey Monkey's administrative research review panel. For this study, the lead researcher set up a profile and submitted their survey instrument and Institutional Review Board approvals for consideration. After Survey Monkey's administration approved the survey instrument, the survey link was emailed to participants meeting the inclusion criteria. Each participant was paid approximately $15 to $20 for their completed survey. The number of individuals who received the email invitation to participate is unknown; as data tracking for this is unavailable, a corresponding response rate cannot be calculated. The online survey was open from December 10, 2022, to January 11, 2023. Recruitment and data collection was conducted until the online survey collection was closed.

Exclusion Criteria

Adults who could not complete the survey independently online, in English, or did not have a child with ASD who had recently completed high school were excluded from the study. The demographics of both parent groups are described in Table 2.

Background Research for Survey Development

To develop the survey instrument and gain a broad perspective of postsecondary placements for students with ASD and how choices were made, three ASP websites were examined. Information about the types of programming, services and accommodations was collected about California Lutheran University (CLU), California; New York University (NYU), New York; and Bellevue Community College (BCC), Washington. These three colleges were

selected to explore the range of colleges, including from public to private, two-year to four-year programs, and those located in different geographic areas of the US. Each of these colleges emphasized the importance of individualized supports, accommodations in areas beyond academics to supports the needs of college students with ASD.

In addition to a web search, the lead researcher interviewed the BCC Neurodiversity Navigators Director to gain primary data to inform this study (see Appendix B for interview questions), attended online seminars, and gathered information from the website and brochures for the Neurodiversity Navigators.

Approvals

Institutional Review Board (IRB)

This study was approved by University of Washington for IRB under exempt status as it was categorized as no greater than minimal risk. The online survey was sent to Survey Monkey, that administered the survey. The first page of the survey for every participant was a consent form (see Appendix C).

Research Design

This research study used a descriptive research design considered non-experimental. Descriptive research aims to systematically obtain information to describe a phenomenon, situation, or population (Tripodi & Bender, 2010). There was no attempt to control, interfere, or manipulate the parent or student characteristics; data was analyzed to compare responses across both parent groups. Descriptive research is like correlational research that measures and assesses the statistical relationship between two or more variables without controlling or manipulating them (Williams, 2007).

An online survey data collection method was used to answer the three research questions. The non-probability sampling method was appropriate for this study because the respondents were selected based on non-random criteria (parents of teens with ASD who completed high school in the past two years). Not every member of this parent population had a chance to be included, which limits the generalizability of the findings. However, some of the advantages of this sampling method are that respondents respond more quickly compared to randomly selecting respondents, respondents have a high motivation to participate, and online surveys can reach a larger group and can reflect actual diversity within the targeted sample (Dillman, 2009). Furthermore, non-probability sampling used in online surveys allows for geographic diversity and the opportunity to improve population validity. Geographic and ethnic diversity is important in this study to better understand the postsecondary educational opportunities available and accessed by students with ASD from diverse backgrounds and regions of the United States.

Procedure

An online survey was sent to participants via the Survey Monkey platform. The online survey consisted of 36 multiple choice questions and one open-ended question, that took approximately 12 minutes to complete. The survey consisted of four sections: 1) information and consent, 2) demographic questions, 3) high school transition planning process, and 4) postsecondary placements including higher education, work, and community involvement. The Survey Monkey platform did not allow respondents to complete the survey more than once. The online survey remained open until 135 parent responses were collected.

Data Analysis

Survey results were analyzed in several ways. To answer RQ1 (What are teens with ASD doing in the two years post high school?), postsecondary placement data was analyzed using frequency and percentages for both parent groups. Postsecondary placement data is presented in Table 3 with the following categories: taking a gap year, unemployed, volunteer work, working part/fulltime, attending tech/trade school, attending community college (2-year program), attending college with Autism Specific Programming non degree seeking, attending college with Autism Specific Programming degree seeking (BA/BS), attending college for 4-year degree (BA/BS), and other.

To answer RQ 2, (What child-related factors (teen's level of functioning with ASD, ethnicity) or parent-related factors (level of educational attainment, level of involvement in the transition planning process, ethnicity) are related to postsecondary placements?), data was collated to describe the demographic information. Data was analyzed using frequency, percentages, and means (Xμ). To illustrate different patterns of responses, teen characteristics (level of functioning with ASD, ethnicity) and parent characteristics (educational attainment, level of involvement in the transition planning process, ethnicity) are presented in Table 5, Table 6, and Table 7. For teen characteristics (level of functioning with ASD parent-reported measure), teens are stratified into three groups: low, moderate, or high functioning. For parent characteristics, participants are stratified into three groups based on educational attainment: attended some or graduated from high school, attended some college, or graduated college, and attended some graduate school or graduated from graduate school.

Initially, statistical testing was completed to test for differences in the types of postsecondary placements between the group one (Diverse Parents) and group two (South Asian

American Parents). The second test was conducted to test for differences in the teen factors (level of functioning with ASD, ethnicity) and parent factors (level of educational attainment, level of involvement in the transition planning process, ethnicity) that are related to postsecondary placement between group one (Diverse Parents) and group two (South Asian American Parents).

To answer RQ3 (What parent related factors (awareness of programming, considerations influencing final postsecondary placements) impact the decision-making process for postsecondary placements?), data is presented in Table 8 and Table 9. Awareness of specialized ASD programming was categorized as "yes" or "no" responses. Considerations impacting final postsecondary placement decisions made by parents were categorized in the following ways: family decisions, guidance from students' high school support team, guidance by professionals, student preference, or other. These categories were selected based on main sources of information on transition planning from high school to postsecondary (Anderson et al., 2018; S. Jackson et al., 2018a; Kuder & Accardo, 2018; Lie et al., 2020). Data was analyzed using frequency and percentages to illustrate different patterns of responses. The third test was conducted to test for differences in parent-related factors (awareness of programming, considerations influencing final postsecondary placements) that impacted the decision-making process for postsecondary placements between parent group one (Diverse Parents) and parent group two (South Asian American Parents).

The two parent samples were tested for statistical significance using advanced statistical analysis like the chi square $\chi 2$, the t-test, and Fisher's exact test $H0$ (null hypothesis) if the two variables were independent or $H1$(alternative hypothesis) if the two variables were not independent (Kim, 2017). Testing was completed for all three research questions.

Chapter 4: Results

This study surveyed 135 American parents from ethnically diverse backgrounds. Parents were divided into two groups, South Asian American parents and parents from other backgrounds. The study asked parents about their teens' postsecondary placements including their experiences in the decision-making and transition planning process. For students with ASD the most frequently selected postsecondary option was employment. According to parent report, 40% of the teens were engaged in working part/full time or volunteering, 32% were enrolled some type of postsecondary education (all types of programming both degree and non-degree seeking), and 28% of students in the study were uninvolved in education or work (unemployed or taking a gap year.

Mean Age of Diagnosis

The demographics of the two groups were similar, with only one statistically significant difference. The age at which children were originally diagnosed with AD was significantly different across groups. The mean age of diagnosis in group one was diagnosis of 8.47 years, and the mean age of diagnosis in group two was 10.87 years. The t-test, a test for statistical significance, was calculated for these two groups. The two-tailed t-test with two samples assuming unequal variances, found $t = -2.63$, $df = 115$, and p value is <0.01. Since the p value is <0.05 for an alpha level 0.05, you can reject the null hypothesis in favor of the alternative. The South Asian American children were diagnosed with ASD at a later age compared to the children in the Diverse group.

Postsecondary Placements

The results of RQ1 (what are teens with ASD doing in the two years post high school?) are shown below in Table 3. The types of postsecondary placements for teens in both groups followed similar trends. In group one (Diverse Parents), teens with ASD were engaged in a range of plans following high school. As far as pursuing further educational programming, (3%) of teens were nondegree seeking attending college with Autism-Specific Programming (ASP), (10%) of teens were attending a two-year community college, (5%) of teens were attending a four-year college seeking a BA/BS, (5%) of teens were attending tech and trade programming, (26%) of teens were working part/full time, (14%) were engaged in volunteer work, (11%) of teens were taking a gap year, and (21%) of teens were unemployed.

In group two (SAA Parents), teens with ASD were engaged in a range of plans following high school. In terms of pursuing further educational programming, (7%) of teens were attending college nondegree seeking in ASP, (9%) of teens were attending a two-year community college, (7%) of teens were attending a four-year college seeking a BA/BS, (7%) of teens were attending tech and trade programming, (27%) of teens were working part/full time, (13%) were engaged in volunteer work, (7%) of teens were taking a gap year, and (16%) of teens were unemployed.

Table 3

Postsecondary Placements for Students with ASD

	Diverse Students (n = 73)	SAA Students (n = 62)
Postsecondary Placement		
College w/ASP nondegree seeking	2 (3%)	4 (7%)
Community College 2yr	7 (10%)	6 (9%)
College w/ASP, BA/BS seeking	4 (5%)	3 (5%)
College 4yr BA/BS seeking	4 (5%)	4 (7%)
Tech or Trade Program	4 (5%)	4 (7%)
Working part/fulltime	19 (26%)	17 (27%)
Volunteering	10 (14%)	8 (13%)
Gap Year	8 (11%)	4 (7%)
Unemployed	15 (21%)	10 (16%)
Other	0 (0%)	1 (1%)
Prefer not to answer	0 (0%)	1 (1%)

The results describing teenagers' level of functioning with ASD as rated by their parents is shown below in Table 4. The overall most common rating of level of functioning with ASD for students in this study was moderate functioning (54%).

In group one (Diverse), parents rated their teens' level of functioning as high-functioning (27%), moderate-functioning (66%), and low-functioning (7%). In group two (SAA) parents rated their teens' level of functioning as high-functioning (35%), moderate-functioning (41%), and low-functioning (23%).

Table 4

Teens' Level of Functioning with ASD

	Diverse Teens' Level of Functioning with ASD (n = 73)	SAA Teens' Level of Functioning with ASD (n = 62)
High = 1 Moderate = 2 Low = 3	H = 20 (27%) M = 48 (66%) L = 5 (7%)	H = 22 (35%) M = 25 (41%) L = 14 (23%) Prefer not to answer = 1(1%)

The results of RQ 2, what teen-related factors impacted postsecondary placements (e.g., teen's level of functioning with ASD, ethnicity), are shown below in Table 5. There were no statistically significant differences in the postsecondary placement of teens and their level of functioning with ASD between the two groups. One interesting difference, however, was the relationship between student's level of functioning with ASD and their choices for postsecondary engagement.

In the SAA group of students there were some clear patterns. In the SAA group, it was reported that only high-functioning students attended higher education, only moderately-functioning SAA students engaged in work or volunteerism, and finally only low-functioning SAA students were taking a gap year or were unemployed. Conversely in the Diverse student group, parents reported a wide spread of postsecondary placements across all levels of

functioning with ASD. Students considered low-, moderate- and high-functioning attended higher education, engaged in work, volunteerism, took a gap year or were unemployed. When examining those students considered low-functioning in both groups, it is interesting to note that in the Diverse group no low-functioning students were unemployed whereas all the students considered low-functioning in the SAA group were unemployed or took a gap year.

Table 5

Level of Functioning with ASD and Postsecondary Placements

	Diverse Students (n = 73)			SAA Students (n = 62)		
Level of Functioning with ASD Postsecondary Placement	Low	Moderate	High	Low	Moderate	High
College w/ASP nondegree seeking		1 (1%)	1 (1%)			4 (7%)
Community College 2yr		4 (6%)	3 (5%)			6 (10%)
College w/ASP, BA/BS seeking	1 (1%)	3 (5%)				3 (5%)
College 4yr BA/BS seeking		2 (3%)	2 (2%)			4 (7%)
Tech or Trade Program		4 (6%)				4 (7%)
Working part/fulltime	1 (1%)	11 (16%)	7 (10%)		17 (28%)	
Volunteering	2 (2%)	5 (7%)	3 (5%)		8 (12%)	
Gap Year	1 (1%)	5 (7%)	2 (2%)	4 (6%)		
Unemployed		13 (17%)	2 (2%)	10 (16%)		
Other						1 (1%)
Prefer not to answer						1(1%)

The findings for RQ2 investigating parent-related factors (level of educational attainment, level of involvement in the transition planning process, ethnicity) and their relation to postsecondary placements are shown below in Table 6 and Table 7. When comparing both

groups in terms of parent educational attainment and their relation to postsecondary placements, there were no significant differences. The plurality of parents (47%) in this study attended some or graduated from college and their teens with ASD were employed post-high school.

Table 6

Parent Educational Attainment and Teen Postsecondary Placements

	Diverse Parents (n = 73)			SAA Parents (n = 62)		
Postsecondary Placement	Some HS/ HS grad	Some college/college grad	Some grad school/ GS grad	Some HS/ HS grad	Some college/college grad	Some grad school/ GS grad
Uninvolved	4 (4%)	10 (16%)	8 (11%)	3(5%)	7 (12%)	4 (6%)
Employed	11(15%)	11 (18%)	5 (5%)	4(6%)	13 (21%)	7 (12%)
Education	3 (4%)	12 (18%)	6 (6%)	4(6%)	10 (16%)	8 (13%)
Incomplete Data				2(5%)		

When examining if the parent's level of involvement in the transition planning process was related to teens' postsecondary placements, there was no significant difference between groups, as shown in Table 7. More than (80%) of parents in this study were involved in the transition planning process for their students from high school to postsecondary and students were most commonly working or seeking higher education after high school.

The categories in Table 7 and Table 8 have been collapsed. The category "unemployed" refers to students being unemployed or taking a gap year. The category "employed" refers to students working part or full time or volunteering. The category "education" refers to students engaged in all types of postsecondary programming, including degree and non-degree seeking options.

Table 7

Parents' Involvement with Transition Planning and Teens' Postsecondary Placements

	Diverse Parents (n = 73)		SAA Parents (n = 62)	
	Parent involved	Parent not involved	Parent involved	Parent not involved
Involved in TX Planning	59 (81%)	13 (19%)	51 (84%)	10 (16%)
Unemployed	17 (23%)	5 (8%)	14 (23%)	0 (0%)
Employed	24 (33%)	5 (7%)	18 (29%)	7 (11%)
Education	18 (25%)	3 (4%)	19 (32%)	3 (5%)

RQ3 examined if parent-related factors (awareness of specialized programming, considerations influencing final postsecondary placements) impacted the decision-making process for postsecondary placements. The results showed that there were no significant differences between the groups, as shown below in Table 8 and Table 9. Most of the parents (74%) in this study were aware of specialized ASD postsecondary programming in the transition planning process and, as previously mentioned, the most common postsecondary placement for teens was employment followed by education, and finally nonengagement with programming or work.

Table 8

Parent Awareness of Specialized Programming in Transition Planning and Postsecondary Placements

	Diverse Parents (n = 73)		SAA Parents (n = 62)	
	Parent aware	Parent not aware	Parent aware	Parent not aware
Awareness of programming	49 (67%)	24 (33%)	51 (84%)	10 (16%)
Unemployed	14 (19%)	9 (12%)	13 (22%)	2 (3%)
Employed	21 (29%)	8 (11%)	18 (29%)	7 (11%)
Education	13 (18%)	8 (11%)	14 (23%)	8 (12%)

Investigating the impact of parental influences on postsecondary choices revealed that, while there was no significant difference between groups, there were some variations, as shown in Table 9. Group one (Diverse Parents) relied primarily on the advice of high school teachers and high school counsellors when considering their students' postsecondary placement. Group two (SAA Parents) primarily considered recommendations from family, friends, and community important when making final decisions about their students' postsecondary placement.

Table 9

Parental Influences on Postsecondary Options

	Diverse Parents (n = 73)	SAA Parents (n = 62)
College Prep Counselor	12 (16%)	18 (29%)
HS Teacher/Counselor	25 (35%)	14 (23%)
Rec Family, Friends, Community	19 (26%)	20 (32%)
Online college search	9 (12%)	3 (5%)
Student recommendation	5 (7%)	7 (11%)
Other	2 (4%)	-

Chapter 5: Discussion

This descriptive study investigated postsecondary options for teens with ASD from ethnically diverse backgrounds. In so doing, it contributes to the large body of literature on educating young children with ASD, and a much smaller research and evidence base, including from parental- and self-reports, of postsecondary experiences for teens with ASD. The evidence gap is particularly significant for teens with ASD of South Asian descent, making even the small-scale nature of this study highly relevant for better understanding postsecondary experiences for this population.

The results indicate that teens with ASD in both groups followed similar patterns for postsecondary options. The plurality of students with ASD (40%) were engaged in working part- or full-time or volunteering post-high school. The next most accessed postsecondary option for students in both groups was higher education (32%). Most of the teens (64%) in this study were described as moderately-functioning with ASD.

Several themes emerged from the results of this survey. The first relates to the key statistical difference found in the study, which was the average age of diagnosis between the two groups. There was a significant discrepancy in the mean age of diagnosis between teens in the two groups. The South Asian American children were diagnosed with ASD at a later age (10.87 years) compared to the children in the Diverse group (8.47 years). Although the CDC now reports the racial disparities gap in ASD diagnosis is closing (Maenner et al., 2020), the findings suggest that much work still remains to be done. The later age of diagnosis suggest that the South Asian American parents may be accessing services later due to lower levels of awareness about ASD or experiencing social or emotional barriers of service utilization that are impacting the age of diagnosis. The later age of diagnosis of students in the SAA group also calls attention to the

phenomenon of moderate and high functioning students not being diagnosed until later compared to low-functioning students, as they may present differently at a younger age.

The second theme relates to what students with ASD do in the two years post-high school. One of the most surprising findings of this study was the relatively low number of teens who were reported to be unemployed (e.g., not working, not in school). Only 28% of young adults in this sample were reported to be unemployed. Although this is still an alarmingly high number, it is much lower than the 66% unemployment rate reported by the Autism Society (2023). Factors attributing to the lower unemployment rates in this sample could be attributed to the select population that was surveyed. The parents in this study were a self-selected sample who could potentially be more interested and knowledgeable about ASD, specifically regarding where and how to access support during their teen's schooling process. If this is the case, this may set their teens up for more success in postsecondary and career outcomes than teens of less involved or ASD-aware parents. In this study 47% of parents had attended or completed college themselves, making it possible that these parents were better able to understand the demands of college and access services/supports for their teens before and during college. As a result, this may have led their teens to have higher rates of college completion and employment. This study was conducted with a limited sample of 135 parents, and it is possible that with a larger sample size the rates of teen unemployment and nonengagement in higher education could be greater.

The third theme that emerged in the results was if teen-related factors (level of functioning, ethnicity) were related to postsecondary placements. One of the most interesting findings of this study was the link between level of functioning with ASD and postsecondary placements for the students in the SAA group. In this study all SAA high-functioning students attended higher education, all moderate-functioning students worked or volunteered, and all low-

functioning students were unemployed or taking a gap year. In fact, 100% of low-functioning students in the SAA group were not engaged in work or school compared to the low-functioning students in the Diverse group. In the Diverse group, students were engaged in a wide range of postsecondary placements with no association to their level of functioning with ASD. This finding is particularly relevant as higher education programming for low-functioning students not only exists but is continually expanding (S. Jackson et al., 2018a; Nachman et al., 2021; Think College).

The difference in postsecondary choices between the two groups may be associated with cultural beliefs from SAA families that higher education is practically unavailable for low-functioning students (Jameel, 2011). Historically in India, college is a well-established next step in schooling after high school, and is seen as necessary for social change, social transformation, and important to uphold family honor (Choudhary, 2008). However, higher education, including nondegree granting programming, for students with disabilities is almost nonexistent in India (Jameel, 2011) so it is possible that SAA parents of low-functioning students may not have been aware about programming or how to locate it. This finding also highlights the need for transition planning teams to engage in more thoughtful career planning with the SAA Community. Work agencies like DVR need to assist the SAA families to locate work placements that are both culturally meaningful and culturally appropriate.

The final theme that emerged from the results was the high level of engagement in the transition-planning process and the considerable parent awareness of specialized programming. These two findings were among the most encouraging findings of this study. Parent engagement in the transition-planning process was reported at 81% in this study. Another encouraging finding was that 74% of parents reported being aware of specialized postsecondary

programming. While current studies of college enrollment report that only 32% of students with ASD are pursuing college (Petcu et al., 2021; Welding 2023), it was surprising to see how well-informed and involved parent participants were in the transition-planning and how aware they were about specialized programming. As previously discussed, this difference between current study reports and the high number of students with ASD attending higher education in this small study was perhaps attributed to the limited, self-selected, and well-educated sample of parents.

Overall, the study results indicate that teen-related factors (level of functioning with ASD, ethnicity) and parent-related factors (level of education, involvement in transition planning processes, ethnicity) had little relationship to postsecondary placements. While over 70% of parents from both groups were aware of ASP, this also had little effect on postsecondary placements. In line with the hypothesis, there was a difference between the two groups, but it was unanticipated that the statistical difference would be the teen's initial age of diagnosis.

Implications

This study has several key implications for research, policy, and practice. Firstly, it begins to fill a large gap in information about how families of children with ASD from other cultures such as South Asian Americans experience the decision-making and transition planning process for postsecondary placement planning. The South Asian parent perspective often differs from mainstream Western scientific and professional perspectives as it is common for South Asian parents to access spiritual, moral, or personal interpretations to understand the complexities of ASD and how these might impact their child's schooling and adult outcomes (Desai et al., 2012; Jegatheesan et al., 2010). The South Asian American Community interprets disability as a looming threat to social devaluation where family honor is associated with the attainment of higher education and financial independence (Desai et al., 2012; Kaur, 2011;

Panjrath & Misra, 2018). The expectations in this collectivist culture can create reluctance on the part of parents to discuss or access services for ASD (Panjrath & Misra, 2018).

In line with the literature on racial disparities of ASD diagnosis (Constantino et al., 2020; Fombonne & Zuckerman, 2021; Jones & Mandell, 2020), there was a significant difference in this study amongst the two groups in the mean age of diagnosis. The teens in the South Asian American group were diagnosed with ASD at $X\mu = 10.87$ years old whereas the teens in the US group were diagnosed with ASD at $X\mu = 8.47$ years old. This suggests that the South Asian American parents may be accessing services later due to lower levels of awareness about ASD or experiencing social or emotional barriers of service utilization that is impacting the age of diagnosis. This is an area worthy of further study. Given these findings, this exploratory study highlights the value of researchers and service providers collecting more information on the South Asian American Community to help identify the social barriers that impact service utilization and find ways to connect families to more educational opportunities.

Aside from the mean age of diagnosis, the results of this exploratory study found that there were no significant differences between group one (American parents of diverse backgrounds excluding South Asian American parents) and group two (South Asian American parents) in terms of teen- or parent-related factors impacting the decision-making process for postsecondary placements. The teen's level of functioning with ASD, their ethnicity, parents' educational attainment, parents' ethnicity, parent's level of involvement in the transition-planning process, and parent's awareness of specialized Autism-Specific Programming in college were similar in both parent groups.

However, there were some small differences amongst the groups regarding students' level of functioning with ASD and their postsecondary choice, as well as whose consideration

parents took into account when making decisions about postsecondary options. It is important for service providers to understand that South Asian American parents experience postsecondary planning and decision-making differently than American parents. As the South Asian American parents relied on social networks rather than the school support team when exploring options about postsecondary, it might be advantageous for school support teams to make connections with families and build relationships earlier in their student's academic years. Schools and work agencies engaged in transition planning with families who have low-functioning teens need to provide work options that are more culturally responsive and sustainable. Reaching the South Asian American Community through community partnership programs such as having educators present to engage with the South Asian American Community in medical information sessions (e.g., ASD awareness series) could be beneficial. This is a topic worth exploring with a larger participant pool in further study to ascertain statistical significance.

More broadly, the literature review section of this study reveals a dearth of information about postsecondary placement planning for students with ASD. To better understand the postsecondary needs of these students, the options of programs, and the factors critical to college success, more studies, and particularly qualitative research, are necessary to gain a deeper understanding of this process. Further studies will also help provide insight into how students with ASD can successfully transition from high school to postsecondary. This exploratory study begins to identify the steps necessary in navigating the transition process from high school to postsecondary, including student-centered planning, parent involvement in transition planning, and parent awareness of specialized programming. However, more information on how families can best support their child and serve as an active member of the individualized planning team is necessary. Further studies should also collect information about where students with ASD are

living while attending college (at home, on campus or off campus) to better understand what type of environment students are accessing to be successful in higher education. Questions about where students were living during college and environments that they deemed supportive were not examined in this exploratory study.

This study also identifies a need to create a regularly updated aggregated database of specialized postsecondary programs for students with ASD. The literature review of the study found that there was no single source of information about higher education programming for students with ASD. Currently, information is dispersed across journals, college websites, college preparatory websites, autism advocacy blogs, and by word of mouth, which may make it particularly difficult to access for immigrant families, families with low literacy levels, families less accustomed to navigating the American college process, and families that are less accustomed to deciphering the quality of information sources. As the enrollment number of students with ASD in colleges continues to increase, it is necessary for information about programs options to be easily accessible, current, and aggregated, as students and families are often looking for specific programs or types of supports in colleges. Dedicated funding maybe useful to address the need for a centralized and maintained databank of information as programs are continually emerging and changing to meet the needs of students with ASD.

More information is needed to better understand the college outcomes of students with ASD. This is particularly important as most students attend junior or community colleges. However, most community and junior colleges do not have enough funding to track students with ASD as they exit or complete programming, despite the advantages of learning about what students go on to do after they leave (Alfred & Seybert, 2007; Roux et al., 2015). For example, it would be helpful to know which models of programming are more effective in preparing

students with ASD to go on to complete further education (e.g., tech and trade programs, public 4-year colleges, or graduate school) or which ASP programs within colleges better equip students to be successful in work/volunteer placements. This could take the form of a longitudinal study that followed up with students at six months, one year and five years after exiting or program completion. It would be advantageous to disseminate the results of the tracking data as soon as possible to inform families and students with ASD in the process of picking college options.

Limitations

This study has several methodological limitations. Participants were a self-selected group that identified as having a child with ASD. The study did not collect medical records or educational records, including formal diagnoses for ASD, to verify study participation. The limitation of self-selected participants in this study was that the parent participant pool may have been well-informed about ASD or were overly enthusiastic about participating, which could limit internal validity. It is also possible that parents offered socially desirable rather than honest responses to survey questions (Alreck & Settle, 1995; Eyal et al, 2021). Response bias may have also impacted how parents rated their child's level of functioning with as ASD.

By its nature, exploratory research does not yield conclusive results as it explores a phenomenon which is not clearly defined and has relatively little information in the literature; however, exploratory research can identify issues that can be the focus for future studies (Halskov & Hansen, 2015). While the limited sample size of this study also makes the finding less generalizable (Mehta et al., 2019), it was decided that exploratory research was the right choice for this study given the current dearth of information on postsecondary placements and the decision-making process for students with ASD.

Conclusions

This research has explored families' decision-making process for students with ASD transitioning from high school to postsecondary. It found that while many characteristics were the same between groups, the mean age of diagnosis was significantly later for South Asian American students with ASD. Among other implications, this highlights the importance of cultural awareness and sensitivity in ASD programming and postsecondary placement. Through its focus, the study also opens up a larger discussion on the purpose of postsecondary placements beyond American and South Asian American families' differences in culture, teens' level of functioning with ASD, and decision-making for higher education. While students with disabilities may decide not to attend any form of higher education, better understanding the value of completing college for students with ASD might allow students and families to make decisions that better align with student-centered goals.

Research has found that students with ASD without an Intellectual Developmental Disability are amongst the most vulnerable group to be at risk for nonengagement in education or employment and have lower indicators of wellness post-high school (Anderson et al., 2018; Lucas & James, 2018; Lie et al., 2020; S. Jackson et al., 2018a; Shattuck et al., 2012; Taylor & Seltzer, 2011). The benefits of attaining higher education and employment are identified as establishing and maintaining social relationships, self-esteem, having a strong sense of belonging and acceptance, personal-development, financial independence that can lead to an increased quality of life and satisfaction (Anderson et al., 2018; Jackson et al., 2018a; Hart et al., 2010; Tomczak et al., 2021; Widman & Lopez Reyna, 2020). With the acknowledgement of the role higher education plays in the lives of all students with and without disabilities, it is important to

continue to have choices about postsecondary placements that are both accessible and suitable for all.

Appendix A

Inclusion Criteria and Demographic Questions

Inclusion Criteria

1. Do you have a child who has been diagnosed with ASD?
2. Has your child with ASD completed high school in the last 2 years?

Demographic Questions

1. What is your age?
2. What is your gender?
3. What is your race/ethnicity?
4. What is your relationship to the child diagnosed with ASD?
5. What is your highest level of education?
6. Were you born in the US?
7. What is your zip code?
8. What is the gender of your child?
9. What us your child's race/ethnicity?
10. What is your child's age?
11. Based on your child's overall functioning at home, at school, and in the community, please indicate your child's level of functioning with ASD.

Appendix B

Interview Questions for Director Sara Sanders Gardner, Neurodiversity Navigators Program, Bellevue Community College

Interview Questions

1. Do you have an autism or neurodiverse program at your institution?
2. What is unique about this program for students with ASD?
3. Please describe the Neurodiversity Navigators Program.
4. What types of classes are students taking in the program?
5. What types of skills are emphasized in the program?
6. How many students with ASD do you estimate are on campus?
7. What percentage of these students have sought support from your office, or other direct support?
8. What is your biggest concern regarding an autism program?
9. Do students need to enroll at the Disabilities Services Office and disclose disability to access the Neurodiversity Navigators Program?
10. How do students find out about Neurodiversity Navigators Program or seek out this program?
11. Can parents apply or enroll their children into this program?
12. Do you think most students seek out this program to explore their neurodiverse identity?
13. For students with ASD that are not enrolled in Neurodiversity Navigators, does the Disabilities Services Office refer them to the program?
14. If students exit the program are they tracked?

Appendix C

Survey Questions

- For the purpose of this survey, I will use the term Autism Spectrum Disorder (ASD). This term is meant to be inclusive and incorporate people who identify as being autistic, having Asperger's syndrome, and PDD-NOS.

Part I: Demographics about your child with ASD

1. *Do you have a child who has been diagnosed with ASD?*

Yes	
No	

- ***If they say no, they will be exited from the survey and thank you.***

2. *Has your child with ASD completed high school in the last 2 years?*

Yes	
No	

If they say no, they will be exited from the survey and thank you.

3. *How old is your child with ASD?*

4. *What is your child's gender?*

Male	
Female	
Other	

5. *How old was your child when they were diagnosed with ASD?*

6. *Which race/ethnicity best describes your child? (Please choose only one.)*

American Indian or Alaska Native	
Asian/Pacific Islander	
Black or African American	
Hispanic American	
White/Caucasian	
Multiple ethnicity/Other (please specify)	

Other Children

7. *Do you have other children?*

Yes	
No	

8. *Please indicate the gender of your other children in a numerical value. (ie: 1 male and 2 females)*

Male	
Female	
Other	

IF NO, PLEASE SKIP TO QUESTION 11.

9. *Do you have other children that have been diagnosed with disabilities?*

Yes	
No	

10. *How old is/are your other child(ren) with disabilities?*

Part II: Demographics about the person completing the survey

11. What is your relationship to the child with ASD?

Father	
Mother	
Legal Guardian	
Other (please indicate)	
Prefer not to answer	

12. What is your gender?

Female	
Male	
Other	
Prefer not to answer	

13. What is your highest level of education?

Some high school	
Graduated from high school	
Some college	

Graduated from college	
Some graduate school	
Completed graduate school	
Other	

14. Which race/ethnicity best describes you? (Please choose only one.)

American Indian or Alaska Native	
Asian/Pacific Islander	
Black or African American	
Hispanic American	
White/Caucasian	
Multiple ethnicity/Other (please specify)	

15. Were you born in the US?

Yes	
No	
Prefer not to answer	

16. If you were not born in the US, how long have you lived in the United States?

	Years
	Prefer not to answer

17. What is your zip code?

Part III: Child's Educational History

18. In the last two years of high school did your child have an IEP or 504 plan?

Yes	
No	
I don't know	
Prefer not to answer	

19. How much time did your child spend in a general education classroom in the last 2 years of high school?

TIME SPENT IN GENERAL ED CLASSROOM

GRADES	Less than 50%	51-80%	81-100%
Junior (11th)			
Senior (12th)			

20. *Based on your child's overall functioning at home, at school and in the community, please indicate your child's level of functioning with ASD.*

Low functioning	
Moderate functioning	
High functioning	

21. What is your child doing now? (Check all that apply)

Taking a gap year	
Unemployed	
Volunteer work	
Working part/full time job	
Attending tech/trade school	
Attending Community College (2-year program)	
Attending College with Autism Specific Program **non** degree seeking	
Attending College with Autism Specific Program degree seeking (BA/BS)	
Attending College for 4-year degree (BA/BS)	
Other	

- ***If your child did not attend college, this is the end of the survey, thank you. If your child attends/attended college, please continue.***

Part IV: High school transition planning process.

- ***Now I would like to ask you some questions related to high school transition planning process for decisions around post-secondary schooling.***

22. Were you involved in the transition planning process from high school to college or any other post-secondary programming for your child?

Yes	
No	

23. At what age did formal transition planning begin for your child?

14	
15	
16	
17	
18	
No transition planning occurred as a part of my child's high school experience.	
Other	

24. During the transition planning process from high school to college did you know about autism specific or specialty programs that were available for your child?

Yes	
No	

25. Did your child have access to college courses on the college campus during high school?

Yes	
No	

26. Did your child have work experience (e.g., job, internship, volunteering) during high school?

Yes	
No	

27. How satisfied are you with your child's current level of education, engagement, and employment?

Not Very Satisfied	
Slightly Satisfied	
Moderately Satisfied	
Very Satisfied	
Extremely Satisfied	

28. What aspirations did you have for your child after completing high school? (Check all that apply)

Get a job (fulltime)	
Take a break	
Learn a trade or tech	
Attend an autism specific higher education program	
Attend a college (non-autism specific)	
Other (please specify)	

Part V: Decisions about college and community

29. When did you begin to believe that college was an option for your child?

Always	
In Middle School	
In High School	
Other (please explain)	

30. How did you and your child decide on a college?

Family Decision	
Recommendation from the high school counselor	
Recommendation from teen's support team	
Student's preference	
Other (please specify)	

31. How did you and your child learn about college options?

High School Counselor/Teacher	
College Preparation Counselor	
Recommendation from family, friends, community members	
Online college search	
Student recommendation	
Other (please specify)	

32. Did the presence and quality of general support programs for students with disabilities influence your decision in selecting a college?

Yes	
No	

33. Did College Autism Specific Programs for academic support, social support, behavioral support, or living skills support influence your decision in selecting a college?

Yes	
No	

34. Did the college programs' goal of exploring and empowering the neurodiversity (autistic) identity influence your decision in selecting a college?

Yes	
No	

35. Did your child register at the Office for Disability Resources for Students (or similar office at your child's school) at their college?

Yes	
No	

36. Does your child access any of the following services in college? Please mark all that apply.

	Was this service provided by the College?	Was this service arranged and paid for privately?
Peer Mentoring		
Tutoring		
Testing Accommodation		
Curriculum Accommodation		
Accommodation for class activities		
Mental Health Support/Therapy		
Social Skills Training		
Living Skills Training		
Transition Services/Specialized Orientation		
Parent Involvement		
Other (please specify)		

37. Is there anything else you like to tell me about your child's current educational experience and/or your child's preparation for college/ postsecondary transition?

Appendix D

Informed Consent Form

Purpose

The purpose of this study is to learn about post-secondary placements for students with ASD. I will be asking parents questions about how decisions were made about their child's post-secondary placements, the transition planning process and how they came to know of programs.

Consent

PARTICIPANT CONSENT FORM

Understanding parents' experiences of post-secondary placements for autism

Investigator: Narinder Dhaliwal, UW PHD Student 216-798-6523, nkd2@uw.edu

Faculty Advisor: Dr. Ilene Schwartz, 206-616-3450, ilene@uw.edu

Investigator's Statement

I am asking you to be in a research study that I am completing as part of my doctoral coursework at the University of Washington. The purpose of this consent form is to give you all the information you will need to help you decide whether or not to be in the study. Please read the form carefully, the consent information will take you about 5-10 minutes to read. The survey may take 15-20 minutes to complete. You may ask questions about the purpose of the research, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." If you understand the statements and freely consent to participate in the study click the "I Agree" button at the bottom at the end of this consent form.

PURPOSE OF THE STUDY

The purpose of this study is to learn more about parent's perspectives and how decisions were made around post-secondary schooling. I would like to know about the transition planning process, how parents came to know about post-secondary programs and how were made about the selection of programs for the children with ASD.

PROCEDURES

If you choose to be in this study, I will ask you to please fill out the email survey attached to the best of your ability.

RISKS, STRESS, OR DISCOMFORT

Some people feel that providing information for research is an invasion of privacy. I have addressed concerns for your privacy in the section below. Some people feel self-conscious when disclosing information about themselves in a survey.

BENEFITS OF THE STUDY

You may not directly benefit from taking part in this research study. One benefit of this study is to add to the current knowledge base about parent's experiences with ASD during the transition planning process and learning about how decisions were made around post-secondary schooling. Participants will be paid $15.00 for their completed surveys. Payments will be mailed out to participants as surveys are completed and submitted (mailed payments may take up to 1-2 weeks after submitting the completed survey.)

OTHER INFORMATION

Taking part in this study is voluntary. You may refuse to participate, and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. Information about you is confidential. I will not have access to any personally identifying information, those records are kept with the Survey Monkey platform, and I will not be able to access or link to those. Each participant is assigned a research participant ID number through the Survey Monkey platform so I will only be able to see this number. I will not be able to link between your research participant ID and your name or other personal identifiers. If the results of this study are published or presented, I will not use your name, or any other identifying information.

I may want to re-contact you for future related studies about ASD and schooling. Please indicate below whether you give me permission to re-contact you. Giving me permission to re-contact you do not obligate you in any way to participate in future studies.

If you have any questions about this research study, please contact Narinder K. Dhaliwal at 216-798-6523 or email nkd2@uw.edu. If you have any questions about your rights as a research subject, please contact my Doctoral Supervisor overseeing this project: Dr. Ilene Schwartz 206-616-3450 or email ilene@uw.edu.

Signature of investigator Printed Name Date

Participant's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask the investigator listed above. If I have questions about my rights as a research subject, I can contact Dr. Ilene Schwartz.

If you are 18 years of age or older, understand the statements above, and freely consent to participate in the study, mark the "I Agree" choice to begin the survey. If not, thank you for your time.

I agree	

I do not agree	

Clarify Responses (answers) from the survey

____ I give permission for the researcher to contact me to clarify information from the survey I completed. If you agree, please add your email here.

_____

____ I do NOT give permission for the researcher to contact me to clarify information from the survey I completed.

Future related studies

I give permission for the researcher to re-contact me about future related studies about ASD and schooling. If you agree, please add your email here.

_____

____ I do NOT give permission for the researcher to re-contact me about future related studies about ASD and schooling.

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