

The Experience of College Students Diagnosed with Autism Spectrum Disorder

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Author Note

I have no conflicts of interest to disclose.

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Abstract

The present study sought to gain an understanding related to the experience of college and university students in the Pacific Northwest who have autism spectrum disorder (ASD). The researcher explored, using a qualitative constructivist case study approach, the areas university students with ASD perceive as challenges or strengths, areas in which they desired more assistance or preparation, and their overall assessment of their collegiate experience. Current college and university students in the Pacific Northwest with ASD were interviewed using a semi-structured interview process.

The data were then coded and analyzed to identify emerging themes relevant to the defined research questions. Analysis of data revealed four major themes: 1) Increased Understanding of the Unique Needs of College Students with ASD 2) Inclusion in Higher Education 3) Educational Supports 4) The Need and Creation of Community. These four emerging themes serve as a framework for discussion and further exploration concerning the experience of college and university students with ASD.

The results of the present study demonstrated challenges and strengths regarding academic, social, and psychological functioning for students with ASD. The research revealed students are working toward educational goals and obtaining college degrees; however, their experiences include challenges from both their institution and in their personal lives. Results suggest strengthening academic support on campus and increasing education and advocacy would be helpful changes for students with ASD. In addition, implementing support to increase campus engagement and social opportunities were key needs for participants. Recommendations for further research are explored.

Keywords: autism, college students with autism, higher education, neurodiversity

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List of Abbreviations

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADHD	Attention-deficit/hyperactivity disorder
ASD	Autism spectrum disorder
HEA	Higher Education Act
HEOA	Higher Education Opportunity Act
IEP	Individualized Education Program
IDEA	Individuals with Disabilities Act
ISP	Individualized support program
SPED	Special Education

Chapter 1

Modern medicine and psychology have long studied diseases and disorders that profoundly impact the lives of those affected by them. In some cases, these disorders impact the global functioning of the individual and have lifelong impacts on how an individual lives their life. One such disorder is autism spectrum disorder (ASD). Autism spectrum disorder is a complex neurodevelopmental disorder defined by impairments in social interaction, developmental language, and communication skills combined with a range of restricted, repetitive behaviors (American Psychiatric Association [APA], 2013). The severity of symptoms associated with ASD can vary from minimal impairment to more global impairment that severely impacts an individual's ability to interact and communicate with others, access education, and live independently (Santhanam et al., 2015; White et al., 2011). Despite intellectual capability, individuals with ASD are less likely than their peers who fall into other disability categories – such as speech/language and learning disabilities – to enroll in postsecondary education (e.g., 2- or 4-year degree programs; Wei et al., 2013). Whereas approximately 60% of neurotypical students enrolled in traditional four-year universities graduate with a bachelor's degree (National Center for Education Statistics, 2019), only about 41% of individuals with a disability, including ASD, graduate (Sanford et al., 2011) from a bachelor's granting institution. Historically, and for this reason, many individuals with ASD have not accessed higher education or pursued a college degree. Increasingly, however, due to various laws and increased awareness and understanding of autism, access to higher education has become more attainable. Individuals with ASD are enrolling in degree programs at high rates, although specific data is not readily available at this time (Sanford et al., 2011).

Approximately half of the population diagnosed with ASD has average to above-average intellectual ability (Center for Disease Control and Prevention, 2014). As such, there are many young adults with ASD who are intellectually capable of earning an advanced degree. As the rates of individuals accessing college education increase, information regarding the needs, and how to more effectively support those with ASD in higher education is necessary.

Definition of Autism Spectrum Disorder

The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; APA, 2013) delineates the criteria an individual must meet to be diagnosed with ASD. Individuals must first exhibit deficits in social communication and social interaction across multiple contexts in three specific areas (APA, 2013). The areas include present deficits in social reciprocity, nonverbal communicative behaviors, and in developing, maintaining, and understanding relationships (APA, 2013). Challenges in all three of these areas must be present; however, at least two additional areas must also be impacted or present (APA, 2013): these include stereotyped or repetitive behaviors; insistence on sameness or inflexible adherence to routines; highly restricted fixated interests; or hyper or hyposensitivity to sensory input (APA, 2013). As well as the above symptoms, the *DSM-5* specifies that these features must be present in the early developmental period of an individual's life (APA, 2013).

Until the current revisions to the *DSM-5* (APA), a condition known as Asperger's syndrome was recognized as a distinct diagnosis (Kim et al., 2015). A diagnosis of Asperger's syndrome required at least two symptoms of social interaction impairment and one symptom of behavioral and interest restriction, a normative cognitive

functioning, and the absence of significant general delay in language (de Giambattista, 2019). To meet criteria for Asperger's syndrome, an individual could not meet criteria under autistic disorder. This distinction between the two diagnoses implied a differential separation, which was especially present in cases without cognitive delay, also known as high functioning autism (Klin et al., 2000; Klin et al., 2005). High functioning autism differed from low-functioning autism (i.e., individuals who had an IQ lower than 70) in terms of clinical presentation, prognosis, and need for support in daily life (Kim et al., 2015). When autistic disorder became ASD, other neurodevelopmental disorders, including AS, were eliminated and included under the *DSM-5* (APA) criteria. With this change, the conceptualization of functioning in terms of high and low was no longer clinically utilized. Instead, ASD is categorized by three levels that reflect symptom severity and impact on daily functioning (Kim et al., 2015). Level one is the mildest level of ASD (APA, 2013). Individuals in this level generally have mild symptoms that do not interfere greatly with work, school, or relationships. This level is what most closely translates to the terms high-functioning autism or Asperger's syndrome (Klin et al., 2005). Individuals who meet criteria at level two require more support in a broader range of areas in their life. Finally, level three is the most severe symptom presentation of ASD, and individuals who meet criteria require significant support across more domains of life (Kim et al., 2015).

Classifications, while helpful in some ways, have also contributed to some difficulties for individuals. For example, Alvarez et al. (2020) studied over 2,000 individuals with ASD and found that those described as high functioning, because they do not have an intellectual disability, often still struggled with daily living skills. Over

time, the term high functioning has become synonymous with expectations of greater functional skills and superior long-term outcomes, despite contradictory clinical observations (Alvarez et al., 2020). Grimm et al. (2015) reported that individuals exhibiting ASD without an intellectual disability were less likely to receive the support of a special education assistant and underwent a fewer number of consultations and treatment episodes. This expectation and presentation of higher skills have led to a relative gap in services being provided for those individuals who are in the level one severity level of ASD.

Implications of this mismatch between treatment and need can lead to individuals with ASD experiencing an unnecessary impediment in attaining higher levels of education and achievement (Alvarez et al., 2020). Including Alvarez et al. (2020), this has led to many researchers beginning to argue that the term high functioning autism is an inaccurate clinical descriptor since it is based primarily on intelligence quotient and does not accurately reflect the broader needs of the individual. Likewise, the *DSM-5* uses age-standardized adaptive functioning scores to gauge functional needs (APA, 2013). These scores encompass communication, interpersonal skills, social responsibility, personal care, and safety. These skills enable independence in the face of changing environmental demands. The difficulty, however, is that these age-standardized assessments are only indicated for autistic individuals who have an intellectual disability (Kraeper et al., 2017). Therefore, those who do not have an intellectual disability but who may benefit greatly from using adaptive functioning as a measure of their everyday skills and difficulties (as well as the assessment of potentially unmet needs) are omitted. In these individuals, cognitive skills as measured by their IQ scores are likely to mask the

extent to which they struggle to meet everyday demands (Kenworthy et al., 2010). This is true not only for adults but for children and adolescents whose adaptive functioning gains may not keep pace with those of their neurotypical peers (Pugliese et al., 2015). The gap between IQ and adaptive functioning may also be linked to mental health risks such as depression and anxiety, further supporting the idea that an average IQ does not protect against all factors that can lower quality of life for an individual with ASD (Kraepel et al., 2017). Summarily, an individual diagnosed with ASD can experience a broad range of challenges making it more difficult for them to function without support in the world. With adequate support, however, individuals with ASD have the potential to access the education, career, and lifestyle goals they want to achieve.

Prevalence Rates of Autism Spectrum Disorder

While every individual is vulnerable to relationship difficulties, has some preference for routine and personal space, a diagnosis of ASD is much more complex. While there are likely many individuals who have subclinical symptoms of ASD, there is a subset of the population that meets all the above criteria and demonstrates marked impairment in each of the previously mentioned criteria. According to the World Health Organization (WHO, 2018), an estimated 1 in 160 children has ASD (Bao et al., 2019; Dickerson et al., 2016). This estimate is representative of an average figure and it is important to note that reported prevalence varies substantially across studies, which makes it difficult to report rates that properly reflect real-world numbers (WHO, 2018). Also, the range of research reports available has stated higher prevalence rates than those documented by the WHO. However, reported figures have been difficult to properly quantify based on a variety of extenuating circumstances, including poor data, stigma in

reporting, and lack of adequate funding (Akhter et al., 2018). For example, the prevalence of ASD in many low- and middle-income countries is unknown due to improper or nonexistent data collection (WHO, 2018; Akhter et al., 2018). The WHO (2018) comprises its data from epidemiological studies conducted over the past 50 years and has thus summated that the prevalence of ASD appears to be increasing globally as compared to rates previously reported. The cause of the apparent increase in prevalence over the past 50 years is a source of debate. Some possible explanations for this apparent increase include improved awareness of ASD, expansion of the diagnostic criteria with the publication of the *DSM-5* in 2013, better diagnostic tools becoming available to clinicians and medical providers, and improved global reporting (WHO, 2018). While there has been an increased effort from many organizations to obtain more accurate data on ASD, the true numbers of impacted individuals may never truly be known because global and cultural awareness of ASD diagnosis, treatment, and education is still in much need of improvement, funding, and research.

In the United States, the Centers for Disease Control and Prevention (CDC) estimate the prevalence rate of ASD to be one in every 54 children (Maenner et al., 2020). In 1998, the CDC began tracking the prevalence of ASD, and the characteristics of children with ASD, in the United States (Christensen et al., 2016; Dickerson et al., 2016). In 2000, the CDC established the Autism and Developmental Disabilities Monitoring Network to collect data that would provide estimates of the prevalence of ASD and other developmental disabilities in the United States (Bagnell, 2019; Baio et al., 2018). According to the CDC, tracking the prevalence of ASD poses unique challenges due to the diverse range of symptom presentation, lack of biologic diagnostic markers, and the

change in diagnostic criteria (Baio et al., 2018; Christensen et al., 2016; Dickerson et al., 2016). For example, initial signs and symptoms of ASD are apparent in the early developmental period of life. However, social deficits and behavioral patterns often do not become fully apparent as symptoms specific to ASD until later in life when a child is more noticeably unable to meet social, educational, occupational, or other important life stage demands (Bagnell, 2019). Consequently, some features of ASD overlap with or can be difficult to distinguish from those of other psychiatric disorders, which can leave providers unsure about the etiology of the symptoms they are diagnosing in a child (Christensen et al., 2016; Dickerson et al., 2016).

The issues of estimating the prevalence of ASD are further complicated by the inconsistency and varied methods of the hundreds of studies the data is based upon. Crane and Winsler (2008) attribute a large amount of the difficulty in accurately estimating prevalence to studies that have not included information about other disorders that are now incorporated into the ASD diagnosis. For example, historical data obtained from older studies do not consistently specify inclusion criteria such as if children who were diagnosed with Asperger's syndrome or pervasive developmental disability-not otherwise specified were included in the study (Coo et al., 2008).

Children who are higher functioning and less likely to require a wide breadth of additional support services in schools or communities also often are not accounted for in data sets (Coo et al., 2008; Crane & Winsler, 2016). These children often require less intervention early in their lives and only come to the attention of parents or teachers as needing a diagnosis and support when they are older (Christensen et al., 2016; Crane & Winsler, 2008). Crane and Winsler (2008) suggest the inaccuracy or unreliability in

prevalence rates is also due to data being more often based on younger children.

Prevalence rates are typically based on children between the ages of three and ten years old, so individuals either younger or older than this range are missed in the estimates and are therefore less likely to be identified for appropriate services (Crane & Winsler, 2008) – for example, the CDC uses data tracked on 8-year-old children (Baio et al., 2018). In the end, it is helpful to have some broad idea of prevalence rates, but it is important to note inconsistency and gaps in the processes of calculation because it is likely that large numbers of individuals are not being accounted for in data.

Standards of Assessment and Diagnosis of Autism Spectrum Disorder

As with other diagnoses, the early detection and treatment of ASD have several documented benefits for the individual and family. The early years of development are undeniably sensitive to influences from both the environment and intervention (Blackman, 2002; Crane & Winsler, 2008). Although ASD manifests in the first few years of life, the average age of diagnosis remains over four years of age and is disproportionately older for children from diverse backgrounds (Baio et al., 2018; Guthrie et al., 2019). For those who are deemed at risk for developmental delay, whether due to poor living conditions or inadequate access to resources, early intervention aims to prevent delays from occurring or compounding as progress in development is made (Dickerson et al., 2016). Improving early diagnosis is critical because it can afford the opportunity for earlier intervention and increase positive outcomes across the lifespan. Overall, positive benefits have been associated with early intervention, which has led to professionals in the field emphasizing the importance of early detection and intervention for ASD (Blackman, 2002; Santhanam & Hewitt, 2015).

The vast majority of current research has focused on finding evidence-based assessment tools for early diagnosis of ASD (McClure & Le Couteur, 2007; Santhanam & Hewitt, 2015). The focus on utilizing evidence-based assessment tools has come from a desire to allow individuals with ASD to achieve their potential, reduce the risk of additional comorbid conditions, and provide resources to families to reduce the burden of care associated with having a child with special needs (Ozonoff et al., 2005). Ozonoff et al. (2005) highlighted specific practice parameters that have been established for the assessment of ASD in children and adolescents published by the American Academy of Neurology (Filipek et al., 2000), the American Academy of Child and Adolescent Psychiatry (Volkmar et al., 1999), and through a consensus panel including representation from multiple relevant professional societies (Filipek et al., 1999). The standards stipulate that best practice assessment for ASD should include two levels (Ozonoff et al., 2005).

The first level functions as screening and an early detection measure and should include routine developmental surveillance by providers of general services for young children, such as pediatricians (Ozonoff et al., 2005). The American Pediatric Association, for example, has recognized the critical role pediatricians play in screening children at risk for ASD and recommends autism-specific screening at 18 and 24-month well-child visits (Khowaja et al., 2015). The American Pediatric Association also recommends routine ASD surveillance and broad screening for other developmental disorders at these critical developmental periods (Khowaja et al., 2015).

The second level of recommended assessment consists of evaluation involving more comprehensive diagnostic assessments conducted by experienced clinicians for

children who are flagged as at-risk in the initial screening (Filipek et al., 1999, 2000; Volkmar et al., 1999). Autism spectrum disorder symptoms are typically most pronounced in early development (i.e., preschool age); therefore, many of the available early screening tools (e. g., Modified Checklist for Autism in Toddlers, Revised, with Follow-Up) are normed on children within this age group (Ozonoff et al., 2005; Santhanam & Hewitt, 2015).

A core aspect of evaluation is collecting detailed historical accounts of communication, social, and behavioral development (Ozonoff et al., 2005). This process is often guided by a relevant structured intake interview, such as the Autism Diagnostic Interview-Revised (Santhanam & Hewitt, 2015). Brief parent report screeners, such as the Social Communication Questionnaire and Adaptive Behavior Assessment-3rd Edition are also utilized at this stage to decipher the extent of impairment to functioning in a variety of domains for each individual (Santhanam & Hewitt, 2015). Further, it is common to include brief screeners of potential medical and psychiatric issues (e.g., anxiety, depression, attention-deficit/hyperactivity disorder, etc.) to rule out potential comorbid conditions (Ozonoff et al., 2005). Additionally, any available records (e.g., medical, school, previous testing, intervention reports, etc.) are reviewed to strengthen historical accounts given by the family or individual (Ozonoff et al., 2005). If possible, other significant professionals who interact with the individual (e.g., teachers, daycare providers, etc.) are consulted to provide their observations about the functioning of the individual. Finally, to set the stage for a holistic picture of the functioning, challenges, and strength areas of the individual, direct clinical observation and interaction with the individual is conducted (Ozonoff et al., 2005). The Autism Diagnostic Observation

Schedule is the measure strongly endorsed for use in the pursuit of observational data critical to diagnosing ASD (Santhanam et al., 2015; Lord et al., 1999). The most current version, the Autism Diagnostic Observation Schedule-Second Edition includes updated norms and algorithms (Santhanam & Hewitt, 2015). It should be noted, however, that the Autism Diagnostic Observation Schedule-Second Edition likely is not sensitive enough to accurately diagnose ASD in adults with average or above-average intelligence (Lewis, 2017).

Problems in the Assessment of Autism Spectrum Disorder

While several standardized procedures have been outlined in the assessment of ASD, there remain some areas in need of further research and improvement. Many of the gaps in relevant research involve the inadequate representation of older participants. For example, Ozonoff et al. (2005) highlight that guidelines have been established for assessment of social communication, but less is known regarding the ages and stages of pragmatic development, including non-verbal behaviors, turn-taking, and understanding of inference – especially within individuals in the school-age years and beyond. With the known importance of early intervention and the prevailing knowledge of age when symptoms are most pronounced, research trends have historically placed focus on the assessment of school-aged children or younger (Ozonoff et al., 2005).

In terms of overall representation in research, the number of individuals with ASD included in norming populations is small compared to other populations (Santhanam et al., 2015; Volkmar et al., 2014). In addition to a lack of initial inclusion, when individuals with ASD are included in the research there is often inadequate information about the disability status of individuals above the age of 18. These gaps

begin to demonstrate the inadvertent inconsistencies that need to be filled in research for clinicians to be able to help those with ASD more effectively, especially those in the 18 and up category.

Co-Occurring Diagnoses

Autism spectrum disorder is a neurodevelopmental disorder, which makes it difficult to capture all areas of its influence throughout an individual's life, especially given the variety of ways in which it can impact functioning (Trammell et al., 2013). Further adding to the complexity, ASD is often accompanied by one or more comorbid disorders (Christiensen et al., 2016; Levy et al., 2010). The Autism and Developmental Disabilities Monitoring Network reported that about 83% of individuals with ASD have at least one co-occurring developmental diagnosis, 16% have at least one co-occurring neurological diagnosis, 10% at least one psychiatric diagnosis and 35% are taking at least one psychotropic medication as treatment of ASD related symptoms (Levy et al., 2010; Soke et al., 2018). The most frequently reported comorbid conditions with ASD include intellectual disability, attention-deficit/hyperactivity disorder (ADHD), anxiety disorders, and depressive disorders (Bauman, 2010; Gurney et al., 2006, Levy et al., 2010; Soke et al., 2018; Trammell et al., 2013). Moreover, associated conditions often include behavioral difficulties, sleep issues, sensory processing difficulty, and gastrointestinal problems (Bauman, 2010; Soke et al., 2018; Trammell et al., 2013; Tudor et al., 2012; Wiggins et al., 2009). Finally, ASD is also associated with genetic conditions, such as Down syndrome and Fragile X syndrome (Bauman, 2010; Gurney et al., 2006; Levy et al., 2010).

These comorbid disorders and associated conditions can add to the levels of need individuals experience as they progress throughout life. However, some conditions may also appear or diminish at different developmental stages, so ongoing assessment of an individual's needs is an important component of providing a high quality of care (Soke et al., 2018). Additionally, the diagnosis of comorbidities can be challenging because many with ASD have difficulty recognizing and communicating their symptoms (Levy, 2010; Lundstrom et al., 2015; Trammell et al., 2013). For example, physical discomfort might prompt increases in self-soothing repetitive behaviors as well as irritability, aggression, self-injury, and other challenging behavioral issues, making it more difficult to understand the etiological foundations of symptoms (Simonoff et al., 2008; Wiggins et al., 2009).

In particular, ADHD, one of the more common comorbid conditions, can be challenging to distinguish from ASD since the core symptoms of ADHD can present very similarly to those of ASD (Levy, 2010; Soke et al., 2018). For example, attention problems or hyperactivity can present as a lack of eye contact or include repetitive behaviors (Lundstrom et al., 2015; Levy, 2010). Understanding the wide breadth of intersectionality and presentation of symptoms with other disorders and conditions and how they interact with the needs of the individual is an important component of meeting the varying needs of individuals with ASD across all areas of their life.

Treatment of Autism Spectrum Disorder

Research related to ASD is emerging and often somewhat inconclusive in terms of etiology or treatment. Due to the reports related to increasing rates of diagnosis, there has been an amplified sense of urgency for developing appropriate and effective services

for this population (Kasari, 2002). However, there are a variety of treatment options available that target helping an individual with ASD gain skills requisite to living an adaptively functional life within their given environment. The current accepted doctrine in both the medical and psychological fields support interventions primarily aimed at behavior specific to social communication and adaptive skill development (Blackman, 2002; Kasari, 2002). The prevailing wisdom in treatment also suggests that treatment be sought as early in a child's life as possible (Blackman, 2002). Early intervention has been shown to have the most effective results in terms of minimizing the lifelong impact of symptomology on the quality of life of the individual (Crane & Winsler, 2008), so the bulk of the recommendations related to treatment are focused on early developmental periods.

Role of Early Intervention

Evidence strongly suggests that early intervention programs are beneficial for children with ASD and can play a significant role in improving developmental functioning, decreasing maladaptive behaviors, and decreasing symptom severity at the level of group analysis (Rogers & Vismara, 2008). Overall, it can be concluded that data on the effectiveness of early intervention strategies specific to children diagnosed with ASD is promising; however, it is somewhat limited (Rogers & Vismara, 2008). These limitations are due in large part to the wide variability in the types of interventions that are available and implemented (Blackman, 2002; Crane & Winsler, 2008). The limited information collected on comparison variables can lack adequate breadth for accurate conclusions to be drawn (Blackman, 2002). What is more, few randomized controlled treatment trials have been completed and the few models that have been tested include

large differences in interventions (Rogers & Vismara, 2008). The inconsistency of the completed research creates the impression that the field is in the midst of a period of discovery related to determining the types of interventions that are most efficacious, the variables integral to moderating and mediating treatment gains, and improving outcomes following implementation of an intervention (Rogers & Vismara, 2008). Furthermore, research is emerging on the degree to which both short-term and long-term improvements can be reasonably expected when a given treatment option is introduced (Rogers & Vismara, 2008). Finally, there is a fundamental lack of longitudinal studies; research conducted with a wide range of populations and comparisons; and research completed regarding the efficacy of different interventions in relation to, or in combination with, one another (Rogers & Vismara, 2008).

Kasari (2002) examined ten early ASD intervention studies and found that all interventions, including both behavioral and developmentally based interventions, reported significant improvement in child behavior, cognition, and overall symptomology. Overall the studies reported improvement in at least 47% of participants through early adulthood (Kasari, 2002). In another broad review of early intervention programs, McConnell (2002) reported that researchers found intensive educational curriculums that maximize the strengths of the child, while also facilitating social situations with peers and family, were more likely to produce significant changes in the behavioral capabilities of children with ASD when administered early in life. However, McConnell (2002) noted that much of the longitudinal efficacy of the data was not robust or, in some cases, was presented to strengthen some of the claims to overall efficacy in the reduction of symptomology. Despite some of the weaknesses in research findings,

early intervention is most in keeping with best practices for treatment providers working with individuals with ASD (Santhanam et al., 2015). Since there is currently no single universally effective treatment for ASD, a multimodal approach to treatment is in keeping with the best practice stance as it is more likely to promote development, improve behavior, and reduce stress experienced by the child and family (Tonge et al., 2014).

As a part of the multimodal approach to treatment, there have been myriad claims by organizations and individuals regarding avenues parents can take to help their child with ASD. While research is continually emerging on the effectiveness of various treatment modalities, only those with the most significant amount of research (i.e., evidence-based) will be explored in this literature review. There are three primary areas in which interventions for ASD fall: namely, behavioral, environmental, and psychopharmacological.

Behavioral Interventions

Behavioral interventions are among the most researched and reputable interventions consistently recommended by diagnostic clinicians in the field due to their immediate applicability and widespread acceptance (Tonge et al., 2014). Applied behavior analysis (ABA) is the science of applying what is learned from careful analysis of behavior to understand the functional relationship between behavior and conditions (Jensen & Sinclair, 2002). One of the most researched applications of behavioral intervention, ABA, was developed for individuals with ASD (Tonge et al., 2014). Pioneered by Ole Ivar Lovaas, ABA is a model of early intensive behavioral intervention that uses repetitive practice and discrete trial training to teach measurable behaviors an

individual can use to increase adaptive functioning (Harris & Delmolino, 2002). Each intervention in ABA is tailored, using intensive manualized treatment plans, to meet the needs of the individual (Jensen & Sinclair, 2002). Each treatment plan is ideally designed to capitalize on individual strengths and build upon previously mastered skills (Jensen & Sinclair, 2002).

As ABA has undergone revision and adaptation since first introduced in 1987, it has utilized the recommendations of emerging research on the efficacious implementation of the behaviorism principles it is based upon (Harris & Delmolino, 2002). Research regarding the use of ABA as a tool for early intervention for children with ASD has consistently demonstrated significant positive benefits including an overall increase in functional skills and cognitive performance and a decrease in symptoms related to ASD (Harris & Delmolino, 2002; Jensen & Sinclair, 2002). The use of ABA is primarily implemented with children as a part of the early intervention approach; however, researchers are beginning to understand that ABA can assist adults with ASD to learn specific skills (Bishop-Fitzpatrick et al., 2013).

Environmental Interventions

Within the category of environmental interventions lay a variety of skills-based interventions that target specific areas of development that may be impacted by symptoms of ASD. Since symptom severity is wide-ranging (i.e., a spectrum) not all interventions are needed to the same degree for each individual. Many services are obtained within the public-school system through the Free Appropriate Education provisions of the Individuals with Disabilities Education Act (IDEA, 2004; Rubenstein et al., 2018). Within the school system, a child can be eligible for special education (SPED)

services and given an Individualized Education Program (IEP) to help them obtain appropriate skills or have curriculum tailored to their needs or ability level (Blazer & Miami-Dade County Public Schools, 2018; Turnbull et al., 2002). Services may include speech and communication therapy, occupational therapy, physical therapy, feeding therapy, and any other therapeutic interventions a child needs to better access their education (McDonald et al., 2019). Services through an IEP are limited, however, in the fact that children with ASD are only eligible for school-based services until they reach the age of 21 (Turnbull et al., 2002). At this time, they have aged-out of the SPED system and must seek services through private agencies if support is still needed (Kohler & Fields, 2003; McDonald et al., 2019). Additionally, SPED services are targeted at assisting an individual student target goals specific to academic readiness; therefore, they can be insufficient for some individuals with ASD who may require adaptive skills functioning outside of the academic environment (Kohler & Fields, 2003).

Special Education and Inclusion. Within the provisions of IDEA, through an IEP, students are required to be offered education in the least restrictive environment (Abate, 2017; Kurth & Mastergeorge, 2010; Seymour, 2017). The definition of least restrictive environment varies by individual, however, and there is an ongoing debate regarding which model of providing this provision of Free Appropriate Education best meets the needs of students – especially those diagnosed with ASD (Seymour, 2017). For many students with ASD, the least restrictive environment is an inclusive classroom environment (Furfaro, 2017). An inclusive classroom, a general education classroom in which students receive SPED serves alongside their typically developing peers, has gained momentum as a potentially effective manner in which to provide the least

restrictive educational environment setting required by IDEA (Abate, 2017; Seymour, 2011; Waddington & Reed, 2017). Parents of students with disabilities have advocated for access to the same schools and classes attended by general education peers (Kuntz & Carter, 2019). Legislative and policy advances in this area have opened access to neighborhood schools and demonstrated a strong preference for educational experiences that take place in general education classrooms as much as is feasible (Kuntz & Carter, 2017). Waddington and Reed (2017) and several others (Campbell, 2016; Harrower & Dunlap, 2001; Leach & Duffy, 2009) have supported the idea that students with ASD included in the general education classroom (i.e., an inclusion model of SPED) have the opportunity to interact with and receive similar educational experiences as their typically developing peers. These include increased opportunities for social engagement with typically developing peers, increased opportunity to develop and practice social skills, and increased overall social acceptance (Abate, 2017; Waddington & Reed, 2017). The Center for Autism Research (2016) has rationalized that the inclusive model is necessary because students with ASD have the right to be educated in the least restrictive environment, are deserving of equitable learning activities, and can learn social behavior from typically developing peers. Additionally, the Center for Autism Research (2016) states that the inclusive model provides the opportunity for general education peers to understand how to learn alongside students with ASD and that students with ASD live their lives in a typically developing world and should, therefore, be in a classroom educational environment that best prepares them for this reality. This is particularly relevant for those individuals pursuing higher education.

In terms of academic outcomes for students with ASD within the inclusive model, research has demonstrated mixed findings. Blazer (2017) and Abate (2017) support assertions that the inclusion models for students with ASD have higher achievement scores and better outcomes than those educated in more traditional segregated SPED models. Other researchers (Foster & Pearson, 2012; Kurth & Mastergeorge, 2010) demonstrated that some students with ASD have more measurable improvement in segregated classrooms or even demonstrate little or no measurable improvement as a result of an inclusive education model. Similarly, social outcomes for students with ASD in inclusive classrooms have been inconsistent. Some studies (Chaaya, 2012; Leach & Duffy, 2009) have found that students with ASD in an inclusive model of SPED engage in higher levels of peer social interaction, receive and provide greater levels of social support, and have larger social networks than peers in segregated SPED classrooms. However, other studies (Abate, 2017; Campbell, 2016) point out that students in inclusive learning environments are more likely to be on the receiving end, rather than the giving, of social interactions and are at an increased risk of endorsing feelings of loneliness, social exclusion, and incidences of bullying.

Opponents of the inclusion model argue that an inclusion model alone is insufficient to fully support or achieve positive results for a student with ASD (Waddington & Reed, 2017). Due to the high variation in presenting symptomology present in ASD, adding to a wide variation in cognitive and behavioral functioning, inclusion may not be considered the most effective model for every student with ASD (Abate, 2017). The impacts on typically developing students' learning is mixed (Chaaya, 2012). In some instances, typically developing peers are at risk for experiencing higher

rates of absenteeism, the exhibition of behavioral problems, and increased rates of anxiety and low self-esteem (Harrower & Dunlap, 2001). Though there are some associated benefits of inclusion models for typically developing peers (e.g., positive impact on academic and social performance, increased comfort around individuals with disabilities, and an increased understanding of other children's needs, etc.), whether or not the inclusion model works for a student with ASD is highly dependent on the individual child and the supports available within the inclusive classroom environment (Abate, 2017; Center for Autism Research, 2016). The continued debate and the relatively recent increase in adoption of the inclusion model results in students entering higher education with varying education experiences.

Transition Services and Higher Education. Transition services, or specific services provided to help a student prepare and be successful for life after they exit special education services, are also an important part of the available options for students with ASD receiving special education services through an IEP. Programming specific to services assisting students with disabilities moving from one phase of education to another was first introduced in the Education for All Handicapped Children Act in 1990, which was later titled the Individuals with Disabilities Act (IDEA; Johnson et al., 2018). The current understanding of transition services encourages an aspect of self-determination and autonomy of learners as well as the support necessary for the learner to move from one stage of learning to another (Sanford et al., 2011). In particular, students receiving services through an IEP are provided planning and services to help them as they move through their educational experience. Johnson et al. (2018) define a positive transition from SPED services as a multidimensional process that focuses on successful

outcomes in employment, postsecondary education, independent living, and self-determination. Transition services, therefore, are services available to a student that support a positive transition into the next phase of their life (Johnson et al., 2018). As a student preparing to enter into higher education, for example, participation in a transition program may include services such as training in skills related to personal independence, legal or advocacy skills or services, recreation and leisure skills, study skills, and financial or income education (Pierangelo & Guiliani, 2004). In 2004, IDEA was amended to require that transition services be a results-driven process that focuses on improving both the academic and functional achievement of the student (Johnson et al., 2018). With this change, educators became more accountable for the outcomes of students (Sanford et al., 2011). Students with disabilities, such as those with ASD, are eligible to receive transition services through their IEP, though the type and amount of services offered vary by district and state (Lipsomb et al., 2017). The IDEA requires that high school students receiving SPED services actively participate in the transition process while they are in high school (Johnson et al., 2018). However, the degree to which those services appropriately target the skills needed or the retention of the information learned as a part of those services is a factor in the overall success of the transition services. For example, Cawthon and Cole (2010) found that 91% of the students with disabilities they surveyed did not recall having an IEP while in high school, and of those students who did, the majority did not recall covering basic transition topics in their final IEP meetings before moving into higher education.

In the context of higher education, legal structures and transition programs also vary greatly at federal and state levels (Johnson et al., 2018). Although students with

ASD transitioning into higher education have access to academic accommodations and programs under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, adult students must self-disclose their status to receive services (Johnson et al., 2018; Madaus et al., 2012). Navigating this process and affording a college education can be an added challenge for students with ASD. Several higher education protections have been put in place to assist students with disabilities in accessing and paying for higher education. In particular, the Higher Education Act (HEA) of 1965 was enacted to strengthen the resources available to students with disabilities who were seeking higher education. It not only strengthened the educational resources available to students at colleges and universities, but it provided financial assistance as well (Johnson et al., 2018). The HEA contains several provisions directly designed to increase success to institutions of higher education for students with disabilities, including Pell Grants, supplemental educational opportunity grants, and assistance with financial aid to eligible students (Madaus et al., 2012). In addition to the HEA, the Higher Education Opportunity Act (HEOA) of 2008 bolstered services available to students with disabilities pursuing higher education (Madaus et al., 2012). Like the HEA, the HEOA primarily addressed improving access to higher education and authorized or reauthorized federal student aid programs (Madaus et al., 2012). A major benefit of the HEOA for students with disabilities was the focus on the affordability of higher education, which was exemplified by provisions ensuring students with disabilities would be eligible for federal work-study programs and grants to help pay for their education (Madaus et al., 2012). Additional funding was also provided through the HEOA for projects focused on the development of effective teaching methods, transition programs, and distance

learning opportunities for students with disabilities (Madaus et al., 2012). Finally, the HEOA also expanded the definition of higher education to include post-secondary education programs such as certificate programs and apprenticeships (Madaus et al., 2012). While being successful in higher education is still difficult and dependent upon an individual, these legislative changes have helped to make higher education more accessible for students with ASD and other disabilities.

Psychopharmacological Interventions

Psychopharmacological interventions are the third category of intervention available to individuals with ASD and there is an extensive amount of literature regarding this category (Bryson et al., 2003; Rogers & Vismara, 2008). Rogers & Vismara (2008) highlight the use of psychopharmacological treatments for ASD, but caution that many of the available studies are limited because they do not target young children, thus excluding a large segment of those being newly diagnosed. Furthermore, many studies report results with marked placebo effects (Bryson et al., 2003; Rogers & Vismara, 2008; Unis, 2002). Pharmacotherapy of ASD primarily involves the treatment of targeted psychiatric symptoms rather than addressing core ASD features (Rogers & Vismara, 2008; Tonge et al., 2014). Targets generally include hyperactivity, inattention, repetitive thoughts and behavior, self-injurious behavior, and aggression toward others (Bryson et al., 2003; des Portes et al., 2003).

Serotonin selective reuptake inhibitors are among the most effective in treating anxiety and obsessive-compulsive behavior in other disorders and have been studied in individuals with ASD (Rogers & Vismara, 2008). Results have been mixed and are

primarily conducted on adults or adolescent populations, so are considered not widely applicable or an early intervention treatment option (Rogers & Vismara, 2008).

Stimulant medications for hyperactivity have generally not been recommended because of increases in irritability and stereotypic movements (des Portes et al., 2003). However, some studies have reported improvements in children with ASD who exhibit significant ADHD symptoms, including a significant reduction in hyperactivity and inattention (Tonge et al., 2014). These studies also report fewer side effects compared to other medications (i.e., neuroleptics; des Portes et al., 2003; Tonge et al., 2014). Although this evidence suggests that children with ASD who have ADHD symptoms might benefit from serotonin selective reuptake inhibitors, Aman and Langworthy (2000) note that the response rate for this subgroup of children (e.g., 50%–60%) is generally lower than that of non-autistic, typically developing children with ADHD (e.g., 80%–90%).

Antipsychotics have traditionally been shown to improve symptoms related to aggression, social withdrawal, hyperactivity, and self-injurious behavior (Tonge et al., 2014). Their use has been explored in individuals with ASD; however, the reported increased risk of developing tardive or withdrawal dyskinesia, especially in children, is a major deterrent (Campbell et al., 1997).

Risperidone is one of the most investigated atypical agents in the treatment of ASD and has purported to have demonstrated improvement in several areas; however, there are very few published controlled studies demonstrating improvements in repetitive behavior and aggression toward self, others, and property (McDougle et al., 1998). The Research Units of Pediatric Psychopharmacology Autism Network (2002) completed an

8-week, randomized, double-blind trial of risperidone compared with placebo in 101 children and adolescents with ASD aged 5 to 17 years (Rogers & Vismara, 2008).

Risperidone reportedly improved self-injurious behavior, aggression, and agitation in 70% of the children and adolescents compared to the placebo (Rogers & Vismara, 2008). A caveat, however, is that several significant adverse effects were also reported, including increased appetite with associated weight gain, transient sedation, tremor, and drooling (Rogers & Vismara, 2008). Although this initial evidence could support the use of risperidone in treating ASD related behavior (e.g., tantrums, aggression, and self-injurious behavior) in children and adolescents with ASD, additional research is needed (Rogers & Vismara, 2008).

Cohesive research related to the intervention and treatment of ASD is varied in methodology and finding, lacking in many areas, and not as robust as is needed. In general, randomized control trial studies are lacking and even when published, they often report small sample sizes and examine treatments that are radically different in their delivery approaches, intensities, and duration (e.g., 12 weeks to 2 years; Rogers & Vismara, 2008). Many studies also use different measurement approaches, which make it more difficult to compare and contrast the utility of the treatments studied (Bryson et al., 2003; Rogers & Vismara, 2008). It is possible to conclude, however, that young children with ASD, as a group, demonstrate accelerated developmental gains in response to varied, focused, and daily interventions (Kasari, 2002). Interventions with a high frequency of administration also demonstrated increases in cognitive functioning (Kasari, 2002). Pharmacotherapy also has demonstrated some promise in the reduction of symptoms related to ASD, though some complicating factors continue to necessitate this

avenue of treatment being introduced on an individual basis. In essence, reduction in the severity of symptoms related to ASD has been demonstrated to occur when treatment interventions are introduced, especially when they are introduced in early developmental periods (Rogers & Vasmara, 2008).

College Experience for Individuals with Autism Spectrum Disorder

A growing number of individuals with ASD are entering college and the rates of enrollment among the population are expected to increase exponentially in the coming years (Kuder & Accardo, 2018; White et al., 2011). Many of these students are academically well qualified, have a strong desire for new knowledge, and wish to demonstrate their intellectual capacity. However, many students with ASD face considerable challenges in their pursuit of higher education (Kuder & Accardo, 2018; Volkmar et al., 2017; White et al., 2011). The challenges for college students with ASD are unique and not entirely met by traditional academic supports or disability support services offered by the institution (Jackson et al., 2018; Volkmar et al., 2017). Students with ASD often require significant preparation (e.g., transition programs, college preparatory courses, etc.) and numerous academic and non-academic supports once enrolled to assist in developing the skills required for a successful college experience (Kuder & Accardo, 2018; Volkmar et al., 2017; White et al., 2011).

Research specifically focused on adolescents and adults with ASD is limited and relatively new (Anderson et al., 2018). Several outcome studies have been conducted and suggest a strong potential for a marked improvement in outcomes with the introduction of some form of intervention (Anderson et al., 2018; Volkmar et al., 2014, 2017). Unfortunately, studies on adults after the early adulthood period are sparse, have limited

generalizability potential, and often lack the point of view of the student (Volkmar et al., 2014). In general, adult outcomes in ASD are considered very poor concerning social relationships, occupational potential, and living independently (Levy & Perry, 2011). However, the successful completion of a college degree is a significant predictor of positive outcomes in this population (Sanford et al., 2011). Volkmar et al. (2017) reported that the ASD-related challenges that most significantly impact the successful college experience are the increased academic expectations, adjusting to new social demands, poor planning and organizational skills, and difficulty adapting to an unfamiliar setting. Additionally, Gelbar et al. (2015) found that difficulties with mental health issues played a significant role in academic success.

The extant research suggests students with ASD struggle in three main categories: academic, social, and mental health or well-being (Jackson et al., 2018). Within each of these categories falls areas of functioning that can be difficult to navigate for an individual with ASD that are uniquely challenging within the post-secondary education context. While many of these challenges are present in earlier educational experiences, the added pressure of higher academic expectations, higher level or expectation of peer engagement, and characteristically absent or reduced adult support leave the college experience ripe for challenges. Many neurotypical students struggle with these very issues, but individuals with ASD are also wading through these experiences with a lack of skills or impaired ability to adjust.

Academic Experiences

While college students with ASD are often highly intelligent and academically capable individuals, many challenges are introduced in the college experience that can

derail progress. These difficulties can come as a surprise to students and their families, who are prone to base their expectations on high school performance (Borrell, 2018). Unlike with neurotypical students, strong academic performance in high school does not positively predict college success for students with ASD (Jackson et al., 2018). A partial explanation for this discrepancy is related to SPED programs in schools operating on a ‘success model’ in which curriculum is adapted and individualized to meet the unique learning needs of the student (Jackson et al., 2018). In contrast, colleges rely on an ‘equal access’ approach, which strives to offer the same learning experiences (e.g., same classes, same grading scale, etc.) to everyone (Jackson et al., 2018). College students who once had access to SPED services in high school lose access to SPED teachers, aids, and support staff, who often provided hours of personalized assistance and tutoring (Borrell, 2018; Jackson et al., 2018). VanBergeijk and Volkmar (2008) also suggest that students with ASD often not only underestimate their academic potential but underestimate the extent to which they may need academic supports to reach their potential in college. This lack of awareness or underestimation often leads to this population either opting to not pursue a college education in the first place or dropping out prematurely (Glennon, 2001; VanBergeik et al., 2008).

Students with ASD have a much higher dropout rate than their neurotypical peers and cite social isolation, difficulty with changing routines and new schedules, problems with living independently away from home, and lack of external monitoring and guidance as reasons for their choice (Glennon, 2001; Jobe & White, 2007). Academic-related demands, such as organization, planning, and flexibility may be inherently more difficult for a student with ASD, especially when they are also navigating changes in social and

emotional support (Glennon, 2001). As they encounter challenges of changing class schedules, new instructors, and a new set of classmates each term, their academic performance may be more difficult to manage, especially if they are also not accessing or do not have access to additional support services (Jobe & White, 2007).

According to Cimera and Cowan's (2009) analysis of data from the United States vocational rehabilitation system, adults with ASD continue to be a growing population, compared to adults with other disabilities and are among the costliest to serve (Cimera & Cowan, 2009). If their needs could be addressed through additional program supports or support services in environments such as colleges and universities, they would potentially be able to reduce these factors while also finding meaning, purpose, and the direction that higher education can provide.

Social Experiences

The college experience has become a part of popular cultural experiences in the United States. High school students are encouraged to cultivate their high school experiences in a manner that prepares them to be competitive applicants to their ideal college or university. Students with ASD are no different; however, there are some additional areas of the college experience that they may find more difficult than their neurotypical peers. Jackson et al. (2018) demonstrated that students with ASD often find the social aspects of the college experience more challenging than expected. For example, students with ASD reported an average of 1-2 close friends but reported feeling unsatisfied to some degree with that number (Jackson et al., 2018). Likewise, the social demands of campus life were often more unmanageable than many anticipated, especially in romantic-related relationships. Jackson et al. (2018) shared that most of the students

they surveyed had no romantic relationships and were generally dissatisfied with this situation (Jackson et al., 2018).

College student life is notorious for having a vibrant social scene for its students. Campus life is celebrated in college admissions brochures and the variety of events and clubs is shared on-campus tours. An authentic college experience often includes partaking in such events; however, this opportunity to engage and meet new peers also inherently exposes students to new threats and social situations (Van Schalkwyk et al., 2018). Peer pressure, substance use, and social demands to partake in parties, clubs, and organizations can be overwhelming (Van Schalkwyk et al., 2018). An individual with ASD may find it doubly difficult to maneuver if additionally trying to overcome difficulties with social skills and interpersonal relationships. Loneliness, in particular, is a common issue for students with ASD with over 75% reporting feeling left out, isolated, or lacking companionship (Jackson et al., 2018; Van Schalkwyk et al., 2018).

Furthermore, social demands can be difficult to interpret and navigate when dealing with peers who have a distinct lack of knowledge of ASD. The stigma of disability may be difficult for some to overcome or address directly with peers or academic professionals. Bullying is also an issue, though to a lesser degree (Jackson et al., 2018). For example, about 35% of the college-age participants with ASD surveyed by Jackson et al. (2018) reported exclusionary bullying, an additional 19% reported verbal, 14% reported provocative, and 3% reported experiencing physical bullying. DeNigris et al. (2018) noted that atypical mannerisms may increase the likelihood that college students with ASD experience bullying, or unwanted, intentional, and aggressive behavior. DeNigris et al. (2018) had similar findings related to bullying as Jackson et al.

(2018). DeNigris et al. (2018) found that bullying more often consisted of odd looks or verbal bullying rather than direct or sustained aggression.

Payne and Wood (2016) explored college students' perceptions of individuals with ASD. Although participants exhibited relatively high initial knowledge of ASD, misconceptions were very common (Payne & Wood, 2016). In particular, participants commonly confused ASD with other disorders, such as learning and intellectual disabilities (Payne & Wood, 2016). Students with ASD have described the experience of being around peers to be overwhelming (Bolourian et al., 2018). Not having sufficient means of communicating with peers in conjunction with peers having misconceptions about core parts of who one is would make it difficult for a student with ASD to properly maneuver some peer relationships. In general, being a student with a disability means one is a member of a minority group. Additionally, students with ASD are even more marginalized than individuals with other disabilities, especially on a college campus that is small or rural (Gillespie-Lynch et al., 2015).

The status of students with ASD as a minority group on campus may in part contribute to many students with ASD reporting that they often delay disclosing their disability status – not only to peers but also to faculty and the university (Anderson et al., 2018). This delay or hesitation to disclose their disability status can inhibit a student's ability to access services needed to thrive in school (Anderson et al., 2018). Anderson et al. (2018) found, however, that those students who chose to disclose to faculty found these conversations to be constructive. Disclosing in this manner often created an opportunity for the student to get to know their professor and provided a chance to reduce the stigma around neurodevelopmental disorders (Anderson et al., 2018).

Mental Health and Well-Being

For students with ASD, the barriers to graduation are quite often not solely about academic performance (Jackson et al., 2018). More than 75% of college students with ASD report feeling isolated or left out (Jackson et al., 2018). Another survey conducted by Anderson et al. (2018) found similar patterns among college students in Australia. Australian university students with ASD endorsed anxiety, depression, and loneliness to be their greatest challenges at school (Anderson et al., 2018). Equally important, one-third of the Australian students also reported that they were not getting the academic accommodations they needed, which added to their overall distress levels (Anderson et al., 2018).

In combination with the above, difficulties related to co-occurring mental health diagnoses are some of the highest reported experiences by students with ASD (Gelbar et al., 2015). Like their Australian counterparts, Gelbar et al. (2011) found that students endorsed anxiety, loneliness, and depression as their most difficult mental health issues (Gelbar et al., 2015). Moreover, about half are likely to have had suicidal thoughts (Jackson et al., 2018). A study exploring the mental health of students with ASD found that, of those that responded ($n = 41$, 74.6%), the majority experienced some form of suicidal behavior in their lifetime (Jackson et al., 2018). Finally, some of these students (53.6% of the total sample) also reported having thought about suicide in the past year (Jackson et al., 2018).

Rationale, Purpose, and Significance of the Study

Autism spectrum disorder persists throughout the individual's lifespan; however, services are often primarily focused on early intervention with children in grade school

(Santhanam et al., 2015). The increased identification of children and adults on the spectrum has generated a sense of urgency to develop appropriate and effective services for this population (Santhanam et al., 2015). Developmental delays in areas affected by ASD can persist for some individuals into adolescence and adulthood. According to Santhanam et al. (2015), many adolescents and adults with ASD experience significant deficits in the area of social communication or pragmatic thinking or reasoning.

Loukousa and Moilanen (2009) found that an inability to understand conversational rules such as taking turns, initiating, sustaining, and terminating a conversation are particularly difficult skills adolescents and adults with ASD are still learning to master. An inability to apply conversational repairs and revisions and an inability to understand the mental state of others can be difficult daily struggles for an individual with ASD no matter the age; however, as an adolescent or young adult in the college setting, these skills are particularly valuable (Santhanam et al., 2015).

Given the above information regarding students with ASD in college, the present study aims to explore the experiences of college or university students with ASD. The present study is designed to add to the extant literature and gain additional insight into the self-reported needs, challenges, and successes associated with the academic, social, and well-being or mental health experiences of college and university students with ASD. The present study aspires to acquire a broad understanding of the range of experiences of college students with ASD to further support professionals assisting this population to better meet their needs, recognize their progress, and collaborate to enhance the university experience of all students.

Chapter 2

Philosophical Worldview

The Constructivism worldview posits that individuals seek to understand and make meaning in the world in which they exist (Creswell, 2014). The constructivist researcher seeks to give the participants of their study a large berth of freedom in questioning as a means to let each participant assign their meaning to the event or experience in question (Creswell, 2014; Merriam & Tisdell, 2017). Within this worldview, the goal is to rely as much as possible on the participant's views of the situation being studied (Creswell, 2014). In addition, the constructivist researcher intends to interpret the meanings that others have about their world, especially within the identified situational context being highlighted (Creswell, 2014). For this reason, the researcher endeavors to provide the participants of the study with ample flexibility to ensure they are reporting as much of their point of view as possible. In short, the constructivist worldview focuses on how the individual interprets the world by examining the world through the experience of the participant (Creswell, 2014).

The goal of constructivist research is to understand how a particular group makes sense of their experience and gains an in-depth understanding of how they have solved problems or navigated their experience (Merriam & Tisdell, 2017). The constructivist researcher, therefore, is interested in how the individual has shared their meaning with others (Creswell, 2014). Finally, the constructivist worldview assumes that the individual is responsible for constructing his or her reality and that this reality is no more correct or wrong than any other (Creswell, 2014; Merriam & Tisdell, 2017). This reality can be changed by the individual's lived experience or gathering of additional information.

The constructivist worldview, in particular, is an appropriate fit for the present study because it is founded on the premise that the individual being studied has actively constructed their distinct meaning from their lived experiences (Merriam & Tisdell, 2017). The perspective constructed by the individual student with ASD is the main facet of study in the present research. On top of that, Jackson et al. (2018) and others have emphasized the need for additional research highlighting the unique experiences of university students with ASD. In particular, Jackson et al. (2018) noted that important data on the nature of the needs for college students with ASD – particularly input from the students' perspectives and the supports that would benefit them – is lacking (Jackson et al., 2018). Therefore, the primary purpose of the present study is to allow this population to highlight their experiences and draw attention to areas where they may benefit from additional supports. Finally, individuals with ASD may have difficulties communicating directly what they are thinking and feeling or interpreting a question's true meaning, therefore, a semi-structured interview, which allows a skilled interviewer to adjust to the individual needs of the participant and ask relevant follow-up questions seems most appropriate. In this way, the participant's true thoughts and experiences will more likely be reflected in the data collected.

This study utilized the constructivist worldview to investigate the participants' lived experience of being a university student with ASD. The participants offered an account of their overall experience, challenges they have faced, and sources of support. The participants had the opportunity to express their ideas and beliefs regarding how they and others could benefit from additional resources, assistance, education, or skills for navigating and thriving in an undergraduate setting as an individual with ASD. The main

objective of the current study was to achieve an understanding of how undergraduate students with ASD perceive their university experience and the need for additional services or resources within similar settings for others with similar needs.

For sampling, the constructivist worldview has no hard and fast recommendation regarding sample size (Merriam & Tisdell, 2017). The recommendation is to “sample to the point of redundancy” (Merriam & Tisdell, 2017, p. 101). Creswell (2014) suggests not to include “more than four or five case studies in a single study” (Creswell, 2014, p. 160). The present study endeavored to utilize a case study methodology; therefore, the sample size included four participants. The case study approach is often used in exploratory research and can help to illuminate connections between concepts (Crowe et al., 2011). Along with that, the case study approach is often utilized as an approach to assist in generating new ideas and theories and can be used to show connections between different aspects of participants' lives (Crowe et al., 2011). Crowe et al. (2011) assert that the case study approach is particularly useful when the goal is to obtain an in-depth perspective of an issue or when exploring a subject in their natural or real-life context. The present study endeavored to conclude an in-depth exploration of the lives of a sample of college students with ASD to better understand the challenges and helpful experiences associated with being in this unique population. Therefore, the case study approach was an appropriate model of exploration.

Purpose Overview

The purpose of this study was to understand the experiences of individuals with ASD who are currently attending a college or university in pursuit of a degree. The goal was to gain a better understanding of how these individuals perceive their college

experience and the factors contributing to daily challenges and successes. Finally, the present study explored which resources or additional information university students with ASD report would help them better navigate or would have helped them prepare for the college experience. There is limited research available on the specific challenges for university students with an ASD diagnosis aspiring to earn a degree from a college or university. To help meet the growing need for services in the university setting for students with ASD, the current study endeavored to help bridge the gap between the recognition of need and research highlighting the everyday lived experience.

Research Questions

1. What is the lived experience of college students diagnosed with ASD with respect to academic, social, and emotional functioning?
2. Which aspects of the college experience do students with ASD find to be the most challenging and the most helpful (e.g., social components, class discussions, residence life, etc.) to their success in their academic experience?
3. What services or supports do college students with ASD utilize, and how satisfied are they with those supports and services in their current college or university system?

Research Design

Population and Sample

Recruitment. Participants were recruited from traditional four-year universities or community colleges who were in pursuit of a degree in the Pacific Northwest (i.e., Oregon, Idaho, and Washington). The researcher facilitated a working relationship with various universities and organizations serving college students with ASD to help access

the target population. Participants were recruited using flyers posted around campus (e.g., department bulletin boards, public notice boards, campus advertising and/or general announcement boards, etc.), collaboration with university programs serving students with autism, social media (e.g., Facebook; see Appendix D), word of mouth, and parent referral as appropriate (see Appendix C).

The population sample was a sample of convenience but also has characteristics of unique population sampling (Merriam & Tisdell, 2017). Merriam and Tisdell (2017) describe a unique sample as being based on “unique, atypical, perhaps rare attributes or occurrences of the phenomenon of interest” (p. 97). Given that college students with ASD make up a small percentage of the overall student population and have atypical developmental needs, they can be classified as a minority group within the college population (Sanford et al., 2011), thus they are eligible to be included in the categorization of a unique population sample.

Each research participant was encouraged to agree to volunteer for the present study to contribute to research; however, in compensation for his or her time or involvement each participant was offered small monetary compensation (e.g., \$50 gift card to Amazon, etc.). Participants were additionally incentivized to share based on their desire to add to the richness and breadth of coverage of the topic and a recognition of the value of research in this area for both current and future students. Participation will contribute to the wider available research and help clinicians, organizations, and administrations at the university level better understand how to assist and support students with autism.

Participants. Participants were all currently enrolled in a 4-year college or

university-program or a community college program in pursuit of a degree. Eligibility for inclusion in the study was contingent upon the individual having a diagnosis of ASD prior to participating in the current study. Participants were 18 years or older. At the time of the interview, the participant had to have attended and been enrolled in a program of study at a university or college for at least one semester to ensure the individual had spent enough time as a university or college student to have encountered relevant experiences and developed impressions related to relevant topics covered in the study.

Sample Size. Due to the study design and the intention of the researcher to complete a qualitative study, the sample size was an evolving construct with the intent of achieving information saturation and redundancy (Creswell, 2014). Creswell (2014) suggests that qualitative case study research design “include[s] about four to five cases” (p. 189). Saturation is achieved when participants begin to offer similar responses to questions that offer no new insight or perspective than previously sampled participants (Merriam & Tisdell, 2017). Therefore, the present study endeavored to achieve a sample of four to five participants.

Methodology

Measures and Types of Data

In qualitative research, the researcher is considered the primary instrument for data collection (Merriam & Tisdell, 2016). Data is obtained through various sources of information, including interview transcripts, behavioral observations, and field notes (Merriam & Tisdell, 2016). Sources of data in the present study included transcripts from the individual interviews, field, and behavioral observation compiled by the researcher during and after the interviews, and audio recordings of the interviews.

Interviews. The present study was conducted in the form of face-to-face audio-recorded semi-structured interviews. Due to an unprecedented pandemic mandating sheltering in place orders at the state and national level, interviews were conducted via a computer-based interview meeting program (i.e., Zoom), and audio was recorded. One interview with each participant was conducted and was completed in approximately 60 minutes. Rather than deductive testing of hypotheses, qualitative researchers utilize in-depth interviews to build concepts, suggestions, or theories based on the data collected (Merriam & Tisdell, 2016). The present study utilized primarily open-ended questions (see Appendix A), which worked to guide the participant toward the areas relevant to the research questions, while also providing an opportunity for the participant to expand on their own experiences and direct the conversation toward areas of significance to the participant. This case study approach allowed the researcher to gain information about the area of study in as objective and unobtrusive a manner as possible.

A case study is an in-depth description and analysis of a bounded system (i.e., a unique, identifiable group) (Merriam & Tisdell, 2017). A case study aims to understand the identified group of individuals to the extent that the researcher gains deeper clarification of their perspective and lived experience (Creswell, 2014; Merriam & Tisdell, 2017). The unit of analysis and not the topic under investigation is the main characteristic of a case study; therefore, they are a bounded system in which one particular group is selected as the focus based on uniqueness and atypicality (Merriam & Tisdell, 2017). Due to the unique bounded group identified in the present study, the case study method of research is an appropriate avenue of exploration.

Field Notes. Data additionally included field notes taken during the interview by

the researcher as appropriate. Field notes acted to add comments regarding the behavior of the participant, any impressions, or non-verbal behaviors that may add to the themes and patterns of the verbal interview (Emerson et al., 2001). Fieldnotes of behavioral observations and non-verbal communication are widely recommended in qualitative research as a means of documenting needed contextual information (Phillippi & Lauderdale, 2018). With ASD being a disorder affecting social communication, data related to observable behaviors, and how participants responded to questions were particularly relevant. With the growing use of data sharing, secondary analysis, and meta-synthesis, fieldnotes help to ensure rich context of results beyond the original research (Emerson et al., 2001; Phillippi, & Lauderdale, 2018). Field notes in the present research comprised nonverbal behaviors noted throughout the interview (e.g., voice pitch, voice cadence, tearfulness, etc.), changes in affect when responding to interview questions, and notes on general appearance (Creswell, 2014; Phillippi & Lauderdale, 2018). Details regarding the collection, safe storage, and dissemination of field notes as part of the data collection process were included in the consent form (see Appendix B) and were reviewed with each participant before the commencement of the interview.

Audio Recording. Finally, data for the present study included the audio recording of the interview itself. The researcher reviewed the audio and made notes related to the way each participant responded to questions and general non-verbal communication (e.g., nervous laughter, stuttering, voice inflection, etc.) otherwise not noted in field note observations.

Study Procedures

Data were collected through a semi-structured interview. The interviews took

place separately at a time mutually agreed upon by the participant and researcher. Each interview took approximately 45 to 60 minutes to complete depending on the response length and pace of the participant. Each participant was provided with a consent form (see Appendix B) to sign before participation and inclusion in the study. Each participant was also reminded that they may opt-out of participation at the time of consent, at the beginning of the interview, and at the end of the interview (i.e., the interview process, being included in the study, etc.) at any time for any reason. Each interview was audio-recorded, and the researcher took field notes and noted behavioral observations either during or immediately after each interview session as appropriate (Phillippi, & Lauderdale, 2018). If relevant, the researcher confirmed each participant's enrollment in an individualized support program (ISP) for students with ASD. The ISP, like other individualized autism support programs at the university level, offers individualized support for university students at a particular university in the Pacific Northwest who are on the autism spectrum and who are seeking support beyond equal access and accommodations provided by the on-campus center for disability services (Scheef et al., 2019). To be accepted into the program, each student must apply and provide reasonable documentation supporting their ASD diagnosis. As significant stigma and fear of detection or special treatment remain, many students choose to not access university disability services or disclose their diagnosis to the university. Therefore, not all students have provided verifiable documentation regarding their ASD diagnosis. If a participant was not currently enrolled in the ISP and chose to participate, confirmation of diagnosis was provided by the participant through a copy of a relevant medical diagnosis document or psychological report, etc. The participant may have also chosen to sign a release of

information for the researcher to contact relevant parties to obtain a copy of the above-listed documents.

Protection of Human Subjects. Each participant received an extensive consent form (see Appendix B) detailing the confidentiality and protection of identification. All identifying information regarding the participants was protected. Confidentiality was maintained through the elimination of any personally identifying information from documents. Lastly, the audio file was password protected and placed in a locked storage container.

Promoting Study Reliability and Validity

Reflexivity and Credibility

The researcher comes from a background in special education and is currently enrolled in a graduate program at a university in the Pacific Northwest. The researcher was contracted to complete a doctoral internship at a university in the Pacific Northwest in the counseling and assessment center. Finally, the researcher has worked with individuals with ASD in a variety of settings. The researcher has taught, tutored, assessed, and acted as a therapist for individuals with ASD or those suspected of having ASD. Those roles were conducted in a variety of settings and with a wide range of age groups.

Reliability and Validity

Member Checking. The process of member checking was utilized as a means of promoting consistency in the research findings (Birt et al., 2016). Member-checking is a critical technique for establishing credibility in qualitative research (Creswell & Miller, 2000). The member checking process involves providing each study participant a copy of

their interview transcript, as well as the researcher's interpretations of the data, to allow the member the opportunity to clarify the results (Baxter & Jack, 2008; Birt et al., 2016). This was the primary purpose of utilizing member-checking in the present study. Member checking was also used to provide participants with an opportunity to address any unintentional misrepresentations of their experience and offered them the opportunity to contribute additional information regarding their experience. The member checking process was, therefore, an additional opportunity in the present study to promote the credibility of the research findings (Birt et al., 2016; Creswell & Miller, 2000). Through this process, personal assumptions, biases, and opinions were eliminated to the greatest extent possible. No major inconsistencies were reported, and no major changes were made to data after this process was completed.

Data Triangulation. Multiple data sources were employed to connect the themes revealed through the interviews to ensure external validity (Carter et al., 2014).

Triangulation may be conducted across all data sources (e.g., multiple participants) and methods (e.g., interviews, observations, etc.; Creswell & Miller, 2000). The multiple sources of data in the present study included audio-recordings of the interview, verbatim transcript of the interview, and field notes. Themes and patterns were compared with existing research in the area to gain a comprehensive and accurate view of the research topic, as it exists naturally (Carter et al., 2014). Lastly, the behavioral observations and field notes were used to support and supplement the emerging themes of the data generated from the interview transcript when applicable (Baxter & Jack, 2008).

Third-Party Peer-Raters. To establish reliability and validity within the data analysis process, a third-party peer-rater was utilized. Reliability in qualitative research

is ultimately achieved through consistency (Leung, 2015). A third-party peer rater (i.e., a colleague from a graduate program with experience coding qualitative research data) coded data to establish reliability of the study findings. The third-party peer rater independently coded the data sets, which was followed by a meeting where the third-party peer rater and the primary researcher discussed their independent findings and came to a consensus on emerging codes and theme categories (Baxter & Jack, 2008). A consensus was reached before coding was accepted for analysis. An acceptable Cohen's Kappa coefficient ($K = .67$) was achieved in this process (McHugh, 2012).

Summary

The current study interviewed current university students to gain a more thorough understanding of the unique experience of navigating college life as a student with ASD. The interviews were audio-recorded and then transcribed to examine them for themes and patterns. Confidentiality was maintained and prioritized to protect the participants. Special attention was paid to ensure validity and reliability of the case study. The perspectives and assumptions of the researcher are acknowledged, and specific efforts were taken to keep the bias of the researcher in the study as low as possible. The constructivist worldview, in which the researcher assumes the participants assign their meaning to the situation or topic of research, was employed. The participants of the study were ultimately responsible for the direction of the interview and they directed the content of the study's outcomes.

Chapter 3

Results

This study explored the experiences of college or university students diagnosed with ASD disorder using a constructivist approach to qualitative research. This research framework was used to give voice to the lived experience of these individuals and offer an opportunity for each participant to share their unique narrative. The catalyst for this research was the noted lack of attention given to the individual experiences of those with ASD in previous research. In particular, there was a void in research containing specific perspectives of the individuals in this population. More often, research was gathered from third-party representatives or in a closed-ended survey format that did not allow for individuals to expand on their responses. To explore the lived experience of college or university students diagnosed with ASD, the present study was guided by the following overarching research questions:

1. What is the lived experience of college students diagnosed with ASD with respect to academic, social, and emotional functioning?
2. Which aspects of the college experience do students with ASD find to be the most challenging and the most helpful (e.g., social components, class discussions, residence life, etc.) to their success in their academic experience?
3. What services or supports do college students with ASD utilize, and how satisfied are they with those supports and services in their current college or university system?

This chapter presents the findings that emerged through the process of data collection involving a total of four participants including college and university students

from institutions in the Pacific Northwest of the United States. The interview protocol used to guide the individual interviews with each of the participants provided with the ability to expand on the general themes pertinent to the overarching research questions. The semi-structured nature of the interviews allowed the interview to be guided by the experience of each individual to preserve the true perspective of the individual. Each interview was conducted one-on-one via a computer-based interview software (i.e., Zoom) and audio recorded.

Description of Participants

The requirements for participation in this study were individuals who had a pre-existing formal diagnosis of ASD who were enrolled in college or university. Individuals who had not been diagnosed formally (i.e., by a psychologist or medical provider) were excluded from participation in this study. The description of the four participants included in the present study is addressed broadly to protect the anonymity and confidentiality of each individual. See Table 1 for specific participant attributes.

Table 1

Description of Participant Attributes

Participant	Age	Gender	Race/Ethnicity	Type of Institution	Degree Program	Age ASD Dx
A	19	M	White	University	Bachelor	5
B	31	M	White	University	Graduate	25
C	38	M	Hispanic/Latino	Community College	Associate	27
D	19	F	Multiracial	Community College	Associate	14

Participants A, B, and C identified as male, and Participant D identified as female. The education level of the participants varied slightly. Participants A and B were enrolled in degree-seeking programs at the university level, while participants C and D were enrolled in degree-seeking programs at the community college level. Each participant was enrolled in an institution located in the Pacific Northwest (i.e., Idaho, Oregon, and Washington) of the United States.

Each participant, per inclusion criteria, had completed at least one term or semester of schooling; however, there was some variance in the number of years enrolled. Participant A was in the second semester of the first year of a four-year program, Participant B had completed the undergraduate years of education and was enrolled in the third year of a graduate program. Participants A and B were enrolled in the ISP for students with ASD. Participant D was enrolled in a support group at her institution for students with ASD similar to the ISP. Participant C was in the second term of the second enrollment attempt of an associate degree program at a community college and Participant D was in the third term of an associate degree program at a community college.

Participants included individuals from diverse ethnic backgrounds, including White, Latinx, and Multiracial. All participants identified as single-never married; however, Participant C is a father of one and co-parents with the child's mother. All participants were considered full-time students as per their credit requirements for their degree program. The age of initial diagnosis varied across participants. Participant A was diagnosed around the age of five, Participant B and C were diagnosed in their twenties and Participant D was diagnosed as an adolescent.

Data Analysis

Each interview was conducted one-on-one via a computer-based interview platform (Zoom) and audio recorded. Creswell (2014) stated that a key feature of qualitative research is that data analysis occurs throughout the data collection process (Creswell, 2014). An example of this is the use of both field notes and behavioral observations compiled throughout the research process (both during the interview and while listening to the audio recording after the interview) that are compiled to support emerging themes and patterns relevant to the research questions. The semi-structured interviews allowed the researcher to explore salient aspects of the interview related to the experience of college and university students diagnosed with ASD. The interview questions were a framework for the content; however, the flow of the interview was guided through the responses given by each participant. Comments were expounded upon as needed and clarifying questions were asked to ensure the true message of the participant was being captured.

After the initial recording of data via audio recording, each interview was transcribed verbatim. Following transcription, each line of the transcript was numbered or time-stamped to provide a reference point during primary (i.e., descriptive) level coding. Next, each interview was read in its entirety and compared to field notes and additional behavioral observations were made. Once each interview was completed and transcribed based on the audio recording, this researcher utilized a constructivist approach to data analysis. This approach involved carefully reviewing and coding the transcripts, field notes, and audio recording for emerging patterns, or categories, that portrayed commonalities in the lived experiences of the individuals that could be organized into

overarching themes in the research. Data were analyzed using the system outlined by Friese (2014), which includes two phases of analysis, descriptive-level, and conceptual-level, according to the Notice-Collecting-Thinking method for data analysis. The data analysis process resulted in the emergence of 12 categories, which were then placed under four overarching themes that conveyed the lived experience and needs of the participants.

The ATLAS.ti coding software was utilized as a primary analysis tool in the data analysis process of the present study (Muhr, 1992/2019). ATLAS.ti software does not code data automatically; instead, its primary function is the efficient storage and organization of the raw data, so it is accessible in one secure location for further management and analysis (Saldana, 2016). For example, each interview transcript was saved in the ATLAS.ti software (Muhr, 1992/2019). The researcher was then able to go through each transcript and proceed through the primary descriptive and secondary conceptual level analysis of the data. The ATLAS.ti software allowed the researcher to compare notes for each transcript in one location, which further aided in the efficient analysis of the codes and emerging patterns across the sources of data (Muhr, 1992/2019).

Data Coding

Each transcript was transcribed independently and coded for emerging overarching themes and subjects. After each interview was individually coded, all transcripts underwent secondary coding. See Table 2 for an example of the coding schema.

Table 2*Example of Coding Structure*

Participant	Data/Example Quotation	Primary Level	Secondary Level	Category	Theme
D	“I wouldn’t say it’s like the academics that’s challenging”	“Academics”	Academics not challenging		
D	“So not so much the academic, but like managing both [workload and academics]”	“Not so much the academic”	Academics not challenging		
B	“High school was easy because I was teaching myself, it was just me and my books”	“Teaching myself”	Accommodation needed for academics	More than Academics	Educational Supports
B	“Given enough time, no it’s not challenging.”	“Given enough time”; “not challenging”	Accommodation needed for academics; Academics not challenging		

Primary Level Coding. Initial coding, descriptive coding, was completed through the process of axial coding, in which the initial raw data was labeled using a set of codes developed by the researcher. During the process of primary descriptive level analysis, relevant sections of the interview were assigned a code, and notes were taken regarding the possible application of the theoretical lens to discern themes (Frieze, 2014).

Codes were identified as short phrases or single words that effectively summarized key characteristics of the participants' unique experience as college students with ASD. The codes representing the highest occurrences of topics relevant to the purpose of the study were highlighted. Likewise, the codes capturing the most relevant elements of the data as related to the research questions were dissected further. Codes consisted of descriptive aspects of the content of each participant response describing perceptions, thoughts, and conceptualizations of their own experiences. In-vivo coding was used to capture the essence of what each participant was conveying in their responses (Miles et al., 2019). In-vivo coding involves coding words and phrases from the participants' language and creating (Miles et al., 2019).

Notably, coding data in qualitative research is more than attaching a label to specific portions of text; instead, it can be captured as the process of creating tangible links between the raw data collected and the true meaning portrayed by research participants (Saldana, 2016). Patterns in the data can be defined as repetitive or consistent occurrences in the data that appear “at least more than twice in the research data (Saldana, 2016). For example, repeated (i.e., more than at least twice) use of the word “normal” and “flexibility” was coded. The initial raw data also consisted of a compilation of the researcher's field and behavioral observation notes, taken during the interview and the review of audio recording and interview transcripts.

Secondary Level Coding. Secondary coding involved conceptual level coding. Codes from primary level coding were condensed and organized into overarching categories relevant to the research question. The categories that emerged were further dissected to better understand their relevance to the research questions. Secondary,

conceptual, level coding involved the further examination of the codes from primary descriptive level coding (Friese, 2014). For example, as demonstrated in Table 2, “academics” and “not so much the academics” were primary level codes that became the code “Academics not challenging” in secondary level coding. The primary goal of the conceptual secondary level analysis was to identify thematic patterns and meaningful relationships in the codes formulated from the primary descriptive analysis of the data (Friese, 2014).

Category Construction. After both levels of coding were completed the category construction process took place. The researcher assigned codes to each piece of data relevant to the research questions. These codes, from the previous levels of coding, were organized related to their meaning and placed into thematic categories. The process was repeated for each set of data (i.e., each interview transcript) and the lists of categories that emerged were compared to identify overlap and areas where the codes could be further condensed under larger themes. For example, codes for “feeling misjudged” and “misunderstood” were categorized under the theme “understanding of unique needs.” The outcome, therefore, of conceptual analysis is the development of categories into a model or structure that summarily portrays the overarching themes of the raw data (Friese, 2014). These overarching themes function to organize the data in a manner that allows the researcher to connect the unique experiences and perspectives of each participant into a cohesive and meaningful narrative.

Emerging Themes

Theme 1: The Unique Needs of College Students with Autism Spectrum Disorder

Understanding the Diagnosis. Each participant described the process of coming to an understanding of what a diagnosis of ASD meant for them. This was a unique process for each individual; however, each participant had to figure out how they identified and felt about their diagnosis. All but Participant A were diagnosed with ASD later in life. Participants B and C were not diagnosed until they were in their mid to late twenties and Participant D was diagnosed as an adolescent. Participant C described his experience saying “When I heard about my autism, knowing that I have ASD or autism spectrum disorder, like three days I was crying. I was disappointed . . . It wasn’t easy at all. It was actually harder. I had to learn new things with a new, new way of thinking.” Participant B described his family as having a more difficult time with accepting his diagnosis because “In a lot of ways I fit the criteria, but then in some of the more obvious ways I don’t fit the criteria, and so, it’s easier for them to kind of say that’s silly I don’t think that’s quite right.”

Participant D shared that she was first “misdiagnosed with generalized anxiety disorder” but that her mother, who is a mental health professional, “kind of figured something was up with me . . . something more” so they pursued a diagnosis at a more specialized clinic. She stated that “when I first got diagnosed, I was like, okay, this makes sense.” Though Participant A was diagnosed before age 5, he described first knowing that he had ASD in middle school. He shared that he “started focusing and I finally got to learn” around that time. He also shared that it took him until then to “start learning” at grade level because “I didn’t have as much control [of behavior] back then . . . as I do now.”

Each participant described a level of struggle with understanding what the diagnosis meant for them, but overall each described that it helped them understand themselves better. Participant B specifically, shared that “I kind of dismiss it in a way because, one, it doesn’t really change anything, I’m not a new person because of the diagnosis, but I have found it helpful in understanding myself better.” Participant A shared that “well I guess it depends on the way you look at it as a person. I mean, I feel a bit of times when I get confused and I start blaming it [ASD], I started realizing that it also could be that I’m getting myself overly confused about stuff.” Having this more accepting perspective helped him to have the understanding that “whenever you’re an autistic person out there or in any sort of, any sort of social problems like that . . . I don’t think you should let that be a way of letting yourself down.”

Describing Diagnosis to Others. The process of first understanding and accepting the diagnosis in themselves was then continued when having to describe to others how their diagnosis affected them specifically. Each participant commented at some point in the interview process about the complexity of having to understand their diagnosis and then find the words to express it clearly to others so they can better understand what their diagnosis means for them. Participant A described the process of describing his autism to others saying, “It’s really complicated to say, I mean it just feels so strange.” Participant B stated, “that for me is the biggest source of conflict.” He continued by stating that attempting to describe it is “a way to start a dialog” toward more understanding and patience on both sides.

Before college, Participant C – who was diagnosed later in life – shared that he found it difficult to understand why he struggled in school prior to his diagnosis, and that

shared with others that autism is now a helpful way to describe the difficulties he has processing information and speaking. He shared that “I interpret and take in information rather differently than anybody else” and that “my mind is always thinking around it can never stop” to better explain why speech and processing information is more difficult for him. He also shared that there’s a “negative connotation . . . I felt like I was stupid [before the diagnosis].”

Participant D shared she tends to tell people that “it’s like I basically have every single common mental disorder put into one for the most part” so that she can most accurately help peers understand her daily experience.

More than one participant described having to justify or have a conversation about actually having ASD. In particular, Participant D shared that “there are like the ones who think that it’s fake . . . or they say the stories like ‘well I have a family member that’s autistic and he is nothing like you’ type of deal.” Participants B and Participant D shared that this pressure to prove they need help or have ASD goes beyond peers and is felt with staff and faculty as well. Participant D shared that “it’s like some professors, like at least I had one where she wouldn’t accept my online work [an accommodation on her 504 Plan] . . . she goes, ‘well, but you didn’t send in, you didn’t print out and turn in this one specific sheet’, so I failed the class.” Participant B shared that his primary struggle is professors, he stated that “professors, some are fantastic and understanding, and some think it’s their duty to make it harder on me to try to level the playing field because they think that I’m getting an undue advantage [due to his 504 Plan accommodations].”

Participants felt unwilling or afraid to disclose their diagnosis to the school; however, many ultimately felt they had to disclose their diagnosis to get access to needed

accommodations. When they used their accommodations provided to them through a 504 Plan, however, they encountered what felt like pushback or judgment from peers and professors. Participant D shared that she “asked about how my accommodations would work on there [online class format] and I just saw one of them [classmate] like roll his eyes.” She shared that others, will “not necessarily [think] that like it’s fake, but...they say the whole iconic line of ‘well you don’t look autistic.’” Similarly, Participant A shared that he is careful to discuss his autism with only the “ones [people] that I really trust.”

Understanding as a Person, not a Diagnosis. All four participants shared the experience of wanting to be understood as a unique individual, not simply as their diagnosis or as a stereotype of autism. In their way, each participant commented on their experience at some point in life with being verbally taunted, teased, made fun of, looked at oddly, or bullied. They expressed feeling misunderstood or stereotyped as not looking like someone expected a person with autism should look or for acting in a different way than peers.

Participant D shared she was bullied at different stages of her life. While the more overt bullying was more frequent when she was younger, she shared that the “robotic-ness” of some of her mannerisms drew criticism or unwanted attention or “because I know an unnecessary amount of information on certain subjects” peers “make comments about that part.” Participant C shared that “I am pretty sure I was . . . looked at . . . when I was walking . . . Looked at weird.” Likewise, Participant D shared that it does not happen frequently, but that “there’s at least one terrible person in a group of a hundred” that has made her feel odd or targeted for not being like others.

Feeling Abnormal in a “Normal” World. A common experience across all participants was an awareness and understanding that they are different and trying to pass as normal even though they know they are different in some respect due to being autistic. Participant A shared that he will “often go around . . . trying to act, acting my best as a normal person.” He also stated that “I’ve been an introvert working so hard to be, well an extrovert.” Participant C shared that he feels “hard on himself that I’m smarter than I portray that I am” and that “it feels like I can’t fit in right. I just can’t do it. That’s one of the hardest things.”

Participant B said that he struggles to connect with peers and that he has not shared with any peers that he has ASD. He stated, “I think I have more fear of sharing that just because it sounds a lot harsher than [learning disorder].” He cited being “more of a recluse personality” as one of the primary reasons he does not go out when his colleagues go out. He also shared that “as far as I know I’m the only one with any kind of condition in my program” so he “felt very alone” at times. Participant A also commented on feeling some anxiety about his college experience as “what a lot of normal people are like.” Participant C stated that at times in his college experience, while on campus, he has felt “looked at weird” when he was “trying to act like a normal human being, which I’m not normal.” Likewise, Participant D expressed some frustration and confusion about the way that peers can “function normally, like they can handle certain stressors and stuff” that she feels unable to handle in the same manner.

Theme 2: Inclusion in Higher Education

Institutional Inclusion. Each participant spoke in some manner of how they have had to create or find a space for themselves that was accepting and inclusive. At the

institutional level, at least three participants found that it was difficult to work with their college or university in this process. Participant B noted that the hardest part is “trying to convince these old school [professors] that I’m capable of everything they’re teaching, everything they’re expecting me to do.” He shared he thought it was “because there’s such a difference in thinking...just a big disconnect in what’s expected of a [science field] student, with no flexibility at all for someone in my position.”

In addition to feeling a need to “prove” or justify themselves to faculty, Participant B and Participant D spoke about the lack of flexibility in teaching or structure of classes to accommodate different learning styles. Participant B shared that he had more flexibility in high school, which allowed him to score very high on standardized tests and allowed him to learn and feel confident that he knew the material. He shared that he felt “college classrooms don’t conform to that [learning at own pace].” He also shared his thought that “the higher up you go in education, the less people like me I think there are, and so, there’s less knowledge of what’s helpful. So, the type of materials that they would have that would be helpful for both like a general student, let’s say, isn’t very helpful to me . . . yeah, I think it’s just the lack of practice.”

Participant A spoke of logistical aspects of familiarizing himself with campus as a student. He made sure to “find the right places to work out and [do] your day, [do] daily routines before classes. Finding ways to have breakfast, lunch, and dinner.” These were things his peers also had to figure out at some level, but that were more vital to his ability to feel confident on campus on his own.

For his part, Participant C shared that he felt colleges could do a better job helping students with ASD navigate and successfully learn in the classroom or on campus with more understanding from peers and faculty:

I think that colleges need to be open more minded to everybody, including with people who have autism or Asperger's . . . 'cause I don't think the public knows or even the school knows what it is or how to deal with it and they're [people with ASD] doing the best they can. But like I even said earlier, person A and person B with autism are different . . . It just varies. It is good to be open-minded with these things.

Each participant also shared in some way that a critical part of being as successful as peers in courses hinged on their ability to be organized and stay on top of their academics; however, these were all areas each struggled with maintaining on their own. Participant D shared that she had a strategy of using a planner and would use the online class dashboard, but that "it's not exactly effective" all the time, especially when she forgets about a smaller assignment. Participant B also shared that he has a generally unorganized approach and that when he was able to utilize a self-study approach that allowed him to work at his own pace, he was much more successful. For example, he shared that when he was able to re-read chapters or have an additional day to study and ensure he learned the material covered in a chapter he was able to learn the material at a deeper level. For each participant, they felt they lacked the skills to successfully master this aspect of being a college student; however, each felt that if they were able to get help that was more individualized to their own needs (e.g., extra reading time, separate

location to take an exam, etc.), they would be more successful overall and be able to keep up with peers.

Peer Inclusion on Campus. Several participants described difficulty with initiating peer interactions. Though each participant expressed a strong desire to have a connection with peers, they were overall less engaged with their peer community than they wanted. In particular, Participant B shared that though he was focused on his studies, he believed the reason he did not engage more with peers was that he was not invited. He shared he felt he was “more of a recluse personality so that [being invited] doesn’t happen as much.” He also said, “I don’t tend to invite myself” but that every time he has specifically been invited, he has participated, but to date that has happened “maybe five times a year.”

Participant C specifically shared that he felt socially isolated and that this was in large part because he “just went to college one day. Went home.” This was exacerbated by his feeling that speech is more difficult for him and people were not patient with his need to “gather his thoughts.” He wished that he could have the “opportunity to speak about autism and what it is so that other people can know what autism means to me and what, how it affects me.” He went on to say that in high school “I was more of an isolated person that liked a lot of people but didn’t have many friends at all. I was the person who everybody knew in school,” but since he also just went from school straight home he felt as isolated socially as he does in college.

Participant A felt more socially connected than other participants. A key component of this seemed to be that he was able to live in dorms, though his parents live

in the same town and his father works at the university, and he had the opportunity to be invited by a peer to join a group:

I often join this group of students that come together on Thursdays, to interact with each other . . . I got involved with it at first . . . when this one person came to interact with me at lunch and he was really nice and he offered me to be there. And when I got to interact with the people they were . . . really nice people.

Participant A also shared that his parents and he regularly attend campus events, so he feels connected to campus life, especially theater. However, he added that he feels left out by peers at times. He said, “Well, to be honest . . . a few times I do [feel left out] and I’m mostly focusing on some other stuff on myself.” indicating he feels he needs to change aspects of himself in order to not be left out by peers at times.

Participant D shared that the hardest part of college she experienced was “having to interact with others . . . having to do group projects.” She shared that she has a group of friends she is “satisfied with” and “will sometimes” do non-academic related things with them. She shared that she can “tell who truly is a terrible person and who isn’t” and who might be a potential friend based on how they react to her disclosing her ASD diagnosis with them. If they can “accept the fact that . . . not everyone’s the same and that, you know, then welcome to my circle.”

Theme 3: Educational Supports

More than Academics. The purpose of higher education is primarily to expose students to new information and to academically challenge them in a way that will help them be prepared for their post-graduate goals. Therefore, higher education is arguably academically challenging to some degree for every student at some point; however, each

participant shared that the academics were not “the most challenging” aspect of higher education. Most participants felt, and grades demonstrated, they were intelligent enough to handle the academic challenges; however, the structure of learning or the other aspects of college are what made the overall experience a challenge for them. Participant B stated that he has struggled some because “I was used to . . . learning on my own time [in high school]” and college has not been the same. Participant B specifically chose to attend a junior college prior to enrolling in a university program to help ease into the transition from being homeschooled and having a “lot of flexibility.” He has needed “quite a bit of practice” to adjust to university level demands and has contributed to him taking longer than expected to finish his education:

High school was easy because I was teaching myself, it was just me and my books . . . It was a complete different thing in college where you have to read X chapters by this date, and if you don't there's not another day to catch up, they're moving on and you just don't know it. And then when they're building on the previous chapter and you still don't know it, even if you read all the words but you don't quite understand it, you just have to keep moving, and I wasn't used to that at all. I used to be able to like, 'I don't quite understand that, let me go back a chapter and re-read that. Okay, now I got it.' Move on. That worked very well before and that's not an option in college.

He also shared that he felt “unprepared for college just because the structures were completely different” and shared that when he had more flexibility (e.g., self-study course) he was more able to learn and master the material. He went on to say, “given enough time, no, it's [college] not challenging. What is challenging is keeping up and

learning at the pace that I'm supposed to be learning at." Participant B felt that "if you [professor] just give me one more day, to study for the exam, I'm going to do very well. If you don't then I'm going to do very poorly because I just haven't read all the material yet." However, he felt he had to balance his need for more time alongside trying to demonstrate he is as capable as other students. He summarized sharing that he has a "perpetual fear that I won't be able to keep up with my studies and that the university will give up on me."

Likewise, Participant D commented that for her the academic part was not the challenge or what she was most worried about when it came to confidence about the reality of graduating. She shared, "I wouldn't say it's like the academics that's challenging. I would say it's more of the workload" from managing multiple classes at a time at varied schedules in various locations to adding an after-school job and other responsibilities. She noted that "taking my classes that are for my actual degree" are less challenging for her and elicit less anxiety for her "because it's with the same, like two or three professors and basically I've been with the same group of people for like the past year and a half."

Participant D, like Participant B, commented that she preferred courses that were online or self-study because of the "independence factor . . . I feel like I'm doing a lot better with online classes." Participant D added that college felt more challenging than high school and increased her anxiety because of a perceived lack of academic supports for students like her:

It's more of the fact that how in college, everyone, is equal. It's like they've gotten rid of . . . special needs programs and all that . . . they do have

accommodations, but like, you know, some of the help that some of us need is no longer available.

She concluded by sharing her wish that professors and the college, in general, exercised more flexibility to help her and students like her meet the demands of college.

Participant A echoed the comments of Participant B and D and stated, “the hardest part of being a college student personally is . . . trying to stay on track on top of things and just keep[ing] track of whatever you’re doing.”

Transition. Participants felt their experience of the gap between the challenges of college and their abilities could be closed with the addition of a transition focused program, at the college level, tailored to address their needs as students with ASD.

Participant C, who is in his second attempt at an associate degree, felt not fully prepared for the transition from high school to college, especially the first time he enrolled. He stated, “a program or two to help me transition from high school to college . . . I would appreciate it.” He felt this would be useful in part because “high school didn’t help me to where I need to be.”

Similarly, Participant D said she would have appreciated a program that provided more information about what to expect in college or that prepared her for the differences between high school. Despite using both campus disability services and other resources on campus, she felt unprepared for the lack of support and the different demands of college, such as organization, time management, and self-advocacy skills often required to be a successful college student.

Both Participant A and Participant B were enrolled in a comprehensive individualized support program for students with ASD, a program at the university they

attend specifically in place to aid students on the autism spectrum as they navigate college. Both Participant A and B expressed their gratefulness for the support of the program and credited it to their general success in college. Participant A shared he uses the ISP as a primary source of support “when I feel like I’m having trouble.” Participant B, unlike Participant A, was not introduced to the ISP at the beginning of college. Before being connected to the ISP, he shared he did not feel as supported and was more isolated as a student with ASD. He shared that if he had the opportunity to be a part of the ISP, or a similar comprehensive program, “the transition [from high school to college] would have been much smoother” and it may not have taken him as long as it will to graduate.

Existing Campus Disability Services. More than one participant commented at least once about the need for additional supports for students on the spectrum within their current institutional system. Traditional disability services, available to all students with disabilities or special needs, were not able to offer as wide a range of services for students on the spectrum as needed. Participant B used the on-campus disability services office but felt a more comprehensive program would have better met his needs as an ASD college student. For example, a program that offered peer support, study tools specific to individuals with ASD, or mentorships. Furthermore, he shared his desire for those disability support offices to have more clout and ability to advocate for students:

I wish that the advocacy type office had more power so they can sort of suggest to my professors, but they are intimidated I think . . . and even things they agree on that should be happening in my case, like on extra day to read the chapter before the exam, one, they don’t have the power just by statute, but even if they did . . .

because they do have more power than they use, I think they're afraid to wield it just because they give a lot of deference to those who are powerful.

Participant D also felt support beyond those offered by the traditional campus disability support services would be helpful for her college success:

For the most part, like the programs . . . I don't qualify for them cause like I'm considered too high functioning and because like, I never had any support for most of my life . . . so they're kinda like, well, you've been fine for X amount of years."

However, she shared that she ended up disclosing to her college because "I know that I need help to get through . . . I realized I can't go on without some sort of accommodations . . . I knew that I was going to have . . . basically everything against me." Participant C also utilized disability services but stated that although he felt he was trying his best he still struggled and "it seems like that [disability services] didn't help" because he had to drop out for a time.

Support for Future Life. All participants were determined to go to college and felt not only capable but that they belonged. They just felt they needed more support to be as successful as they knew they could be. Each participant had aspirations of mainstream careers that would contribute to the fabric of society in a meaningful way. Participant A aspires to be "an actor, a director, and a writer in theater, and, and maybe film if I can." Participant C took into consideration the "job outlook and what I want with the pay" so he can support his daughter. He is hoping to capitalize on his previous training toward a degree in residential and light commercial carpentry.

Participant B, a physiology major with minors in chemistry and physics, states the end goal is to be a doctor in medicine. He commented that for him it felt like “a natural progression to continue learning in college” because he has a strong love of learning and his “favorite pastime as a kid was reading the encyclopedia.” He added that both of his parents went to university, but that it has been more of a “practice and trial” experience since it has been some time since his parents were in college and because he did not know entering college that he has ASD. Though it always felt like an inevitability that he would go to college, he shared “the process certainly [has taken] more effort than I’m sure most people do.” Participant D is on her way to earning a degree in geomatics, or the study of gathering, storing, processing, and delivering geographic information (Paras Fernandez & Lopez Caloca, 2017) because she was aware she needed a college education to “get somewhere because I can’t really do much without a degree.” She shared that she and her mother worked to decide where to go, but that she ultimately decided to go to her current institution because it “it’s the only like community college in the area for the most part.”

Theme 4: Campus Life and Engagement

Campus Engagement. More than one participant shared that, though they only did so in a limited capacity, they took advantage of some of the activities offered on campus to some degree. In several instances attending these activities was an avenue for helping the participant create a stronger connection with the campus community and peers. Participant A shared that he often attends as many plays as he can and will try to see films offered on campus as well. Finding a common group of theater students was the primary way he engaged with a peer group on a weekly basis. He shared, “I often join

this group of students that come together on Thursdays, to interact with each other.” He added that he attends plays and other campus events with his parents on weekends or evenings.

Participant B shared he has a small group of friends, but shared he is focusing on his studies primarily right now. He added that he has attended a football game with peers and a few trivia nights at a local restaurant. He also added that “usually someone would have a birthday party and we’d meet up at a restaurant,” but that this was a very occasional occurrence. Currently, he attends a “bible study group that meets once a week, and that’s kind of my social activity.” He used to be a part of the choir on campus to add opportunities for socialization to his routine. Participant A also shared in addition to the ISP he uses other services like the campus writing center and considers himself “dependent on it. I’d be nothing without it, I’d say”

Participant D remarked that she has a small group of friends that are similar to her and who are supportive. Participant D has also attended “random events on campus for like de-stressing and stuff that I’ll sometimes go to.” She also joined an American Sign Language “club for a term, but then I couldn’t do it the next term because I got a job.” She then joined a “Pacific Islander Student Association last term” but added that it was disrupted due to not being able to go on campus due to the current health crisis.

Participant C shared he did not actively attend any on-campus events or social groups and was the only participant who expressed a clear lack of community and a struggle to fit in with peers. He joined a bible club the first time he attended his college to “relax my mind somewhat” but it is reportedly no longer active on campus. Participant C

also utilized campus counseling services to help him navigate his mental health, bullying, and other life events.

Clubs and Support Groups. Another commonality across all participants was a desire for a club, support group, or program for students on the autism spectrum. Both Participant A and B communicated their appreciation for the ISP and the support it has offered them. Each alleged that it was the most helpful support they had in helping them be successful in college. Participant B shared that joining the ISP has “connected me to other college students of various types [and it] has been reassuring that I’m not the only one.” Participant A shared that the existence of the ISP as a resource on his campus was a contributing factor to him and his parents deciding to move from another state so he could attend his current university.

Participant D further shared that her college’s ASD peer support group was helpful. She shared, “I know that my school does have like an autism like club basically at the counseling center that I do go to.” She added that they “basically just discuss about how we handle everything . . . it’s basically just a way for other autistic people to make friends and stuff.” She shared this was helpful for her because she felt more understanding on campus was needed about students with autism. She said, “it’s kind of like an invisible thing cause you can’t see it and because one person with autism is completely different than another person with it, which makes it really confusing for people to grasp.”

Participant A shared that his main message to all students, but especially those with ASD, is to not give up and to work hard to achieve what they want:

I want to communicate my message . . . about respecting people who are different from others and give them [a message] . . . you should just work your way to show how much you support people, how much you care for others, and just be whatever you can be and work hard to get there.

Field Notes and Behavioral Observations

Field notes and behavioral observations documented by the researcher during and after each interview were utilized to enhance interpretation and analysis of participant experiences. The addition of field notes and behavioral observations provides further information as to the body language, tone of voice, and observable behaviors of the participants during the interview process. Field notes can add depth and meaning to the data that would otherwise be missed in the written words of the transcript. Several themes emerged throughout the collection and analysis of field notes and behavioral observation notes, which are included in the present study to offer a richer framework for understanding the experience of college students with ASD.

Enthusiasm and Appreciation

At both the beginning and the end of the interview, each participant expressed some thankfulness and appreciation for the existence and purpose of the present study. Participant B, for example, conveyed his appreciation that research was being done and that there was awareness in the research community of the needs of college students with ASD. In addition, Participant A's parting comments were primarily messages of hope and perseverance for other university students with ASD. Both Participant A and B both added that they would have been willing to participate and share their experiences even if

there was no compensation being offered because they felt so excited about having the opportunity to share their experience.

At the end of his interview, Participant C conveyed his appreciation for the researcher adding to the available research out there on college students with ASD. He also shared his difficulty with finding resources that were specifically tailored to him as an adult college student with ASD in his area. He was happy to learn there were some resources available and was interested in the ISP information the researcher was able to share with him post-interview. After his interview ended, Participant B shared an anecdotal experience with a peer in his program who had shared with him that she had ASD but did not want to share with the school for fear of negative repercussions. He shared that she dropped out and later found out she had died by suicide. He did not conjecture as to the causation; however, he shared that he knew she was struggling and was not utilizing resources because that was one of the last conversations they had together. He extended his thanks for research like the present study because he suspected many students in higher education were hiding their diagnosis or disability from peers and the university, like this woman, who struggling and unhappy end up dropping out or worse because they are not getting the support they need.

Careful Consideration

It was apparent in how each participant responded that they were carefully considering their words and being intentional about the message they conveyed. Care and attention were made in responses and it was clear to the researcher that the subject matter was important to each participant. Every interview was conducted using the computer-based platform; however, the reverence and respect each participant had for the interview

were clearly communicated. The participants took the subject matter seriously and they were honored to be given the opportunity. For example, Participant A and B each asked for clarification of a question when they were unsure of the intent or theme of what was being asked. Participant B additionally requested a question be repeated so he could be sure he heard the researcher correctly. Likewise, Participant C often paused before he responded to thoughtfully collect his thoughts to best convey his views. The researcher noted a similar approach of intentionality with the other three participants as well.

Similarly, Participant A asked the researcher to wait a moment so he could consider his response to a question. While speaking, participants often looked away and avoided eye contact with the researcher; however, when the researcher was asking a question or speaking, each participant offered occasional intentional eye contact to convey their attention and interest.

Subdued Tones

During the interviews being conducted via a computer-based interview platform, the researcher observed behaviors that appeared to be made to express sadness or low mood in response to questions that carried more weight for the participant. For example, when sharing his story and concern for his former college, Participant B used a lower, more intentional tone of voice than he had for the entirety of his interview. Additionally, when he spoke about concerns about confidentiality prior to the interview commencing, he used a muted volume while asking for confirmation about how the researcher would conceal his identity for fear of negative repercussions from his current program.

Each participant adopted a lower voice volume and began to trip over words somewhat more when responding to questions related to their experiences with bullying

or harassment. During these questions, each participant also averted eye contact much more frequently. Participants also made gestures or nonverbal noises incongruent with their affect during more sensitive questions. For example, Participant D offered a nervous laugh incongruent to her affect after sharing her experiences with peers being rude or inconsiderate of her feelings. These responses appeared to the researcher to be representations of how uncomfortable and sad the participants were to have to experience those things in their lives. It also spoke to their uncomfortableness and lack of opportunity to share these experiences with other individuals in their lives.

Genuine Openness

A final observation made across each interview was the genuine openness of each of the participants in their willingness to share deeply personal experiences. Each participant responded, often at length, to each of the questions asked of them during their interviews. Each participant was additionally willing, despite being reminded they were not obligated, to share their most vulnerable and challenging experiences of being a student with unique needs in the college system. Participant responses appeared genuine, honest, and were always approached with a willingness to help other students like themselves not have to experience the same types of struggle and frustration they have as a college student with ASD. Finally, several of the participants kindly offered to further discuss the topic with the researcher should the need arise in the future to clarify any remaining research questions.

Chapter Four

Discussion

The present study utilized a case study approach with a constructivist lens to explore the experience of college and university students with ASD in the Pacific Northwest. The research aim was to illuminate the lived experience of college students using their unique descriptions of their lived experiences as college students. This research offers perspective into the experiences of individuals with ASD as they navigate college academics, social situations, and emotional functioning. This study explored aspects of the college experience that participants found helpful or challenging concerning being successful in their academic experience and explored the services or supports they utilize to help them as students on the autism spectrum. The purpose of the present study was to contribute to the extant research and literature related to the lived experience of college and university students with ASD.

The present study is among a small body of research highlighting the unique perspectives of college students with ASD. The lived experience of four college and university students with ASD currently residing in the Pacific Northwest were explored through data obtained using computer-based face-to-face interviews. This chapter aims to interpret the data obtained through this research and to integrate the present research with existing literature on this topic. Furthermore, this chapter will explore the strengths and limitations of the current study, as well as provide recommendations for further research exploration with this population.

Interpretation

Strengthening Academic Support on Campus

Current Campus Supports Lacking. Through federal and state laws, such as the Americans with Disabilities Act and IDEA, colleges and universities are mandated to provide a standard of disability services on college campuses (Madaus, 2011; Shaw & Dukes, 2001). More specifically, Section 504 of the Rehabilitation Act of 1973, Americans with Disabilities Act of 1990, and its reauthorization in 2008, mandates colleges and universities to provide disability accommodations and access to education (Shaw & Dukes, 2001). These laws, and those associated with them, allow students with disabilities in higher education access to reasonable accommodations, which provide them the opportunity to access education more effectively (Simon, 2000). Services traditionally include access to assistive technologies, housing accommodations, classroom accessibility, and hearing impairment services (Madaus, 2011). These services allow students with permanent or temporary disabilities the ability to participate in their education in a way they would not be able to if those services were not available. The standard, however, is for those services to primarily target learning disabilities, ADHD, and physical disabilities (Shaw & Dukes, 2001). This misses the needs of the wider range of individuals seeking support, including those with ASD.

In primary and secondary education structures, students have access to special education services throughout their educational experience (Collins et al., 2019). During this time, they are part of a system that has an individualized approach to meeting their educational needs to set them up for academic success (Turnbull et al., 2002). Once a student reaches higher education, the structure reduces significantly and moves from an individual model to an equity model in which all students are required to meet roughly the same set of standards to obtain a baccalaureate, masters, or doctoral degree (Collins et

al., 2019). As a neurodevelopmental disorder, ASD is a lifelong diagnosis in which impairments are present at each stage of life, including during early adulthood or the years in which traditional students are enrolled in institutions of higher education. However, students with ASD, especially those with high academic ability, are not traditionally served through the services offered at their campus disability support services office (Sarrett, 2018). If students were able to access supports, the supports often do not adequately address the unique social, emotional, or adaptive functioning supports needed by students with ASD (Hees et al., 2015; Sarrett, 2018).

Each participant in the present study utilized their disability support office on campus. Participants B, C, and D acknowledged that they had accommodations through a 504 Plan. However, each participant additionally noted that these supports were not as targeted or comprehensive as they felt were needed to meet their unique needs as an individual with ASD. The present study highlighted the need for wider availability and a broader range of services that might better meet the social, emotional, and developmental needs of students with ASD.

In particular, Participant D felt additional support services would benefit her as she did not qualify for many of the existing services because “I’m considered too high functioning” and since she had not previously utilized or needed additional supports for the majority of her education. Participant B also felt that his needs were not fully met in his program and that when he needed additional support, he often encountered the disability office not having as much power or deferring to other departments. Participant C also utilized disability services; however, he also felt that they did not address his needs as a student with ASD as effectively as he needed. He shared that he used disability

services, but “it seems like that [disability services] didn’t help” since he ended up having to drop out for a time before returning to try a different major.

Research addressing the needs of students with ASD often includes recommendations for accommodations or supports specifically aimed at serving the autistic population (Sarrett, 2018). As stated above, the disability services are often accessed by students with ASD; however, on their own, they do not adequately meet the individual needs of students with ASD. Studies that identified social-emotional needs suggested the use of mentors, disability support groups, private living spaces, and increased access to counseling services (Cai & Richdale, 2016; Gelbar et al., 2015; Zeedyk et al., 2016). Services that address areas associated with an ASD diagnosis, such as sensory sensitivities, are also suggested areas where institutions of higher education could better meet the special needs of autistic students (Fabri et al., 2016). An increased need for visual educational support is another area a student with ASD would benefit that is not as widely addressed in traditional service offerings (Zeedyk et al., 2016).

Gelbar et al. (2015) highlighted the increasing awareness by both students and institutions of the need for supports to be in formats students with ASD can access that offer peer support or foster a sense of community distinct from those of peers. Peer support groups, for example, where students can safely and without fear of repercussions from the university, discuss their unique challenges would both assist them in reducing the psychological demands of the college experience but would help then increase their social connections on campus (Fabri et al., 2016).

There is a growing trend toward campuses developing more inclusive and specialized supports for students with ASD (Sarrett, 2018). Both Participant A and B

shared they belong to an ISP at their university that has helped them feel more connected to peers with ASD and not feel as isolated and alone as a college student with ASD. These more comprehensive programs generally offer services related to meeting the needs of students with ASD in the areas of academic coursework, social skills, daily living skills, and emotional support (Sarrett, 2018). Such programs generally offer services related to academic work, social skills, daily living skills, and emotional and psychological well-being (Sarrett, 2018; Simon, 2000).

For Participant D, her campus did not have a comprehensive program such as an ISP; however, her counseling center offered a peer support group that she found helpful and regularly took advantage of on campus. Participant C in particular desired a stronger more comprehensive program on his campus. Even with limited resources, an institution could potentially more adequately meet the needs of their students with ASD by forming a more comprehensive offering of services. For example, group social skills development sessions, group study sessions, academic success skills in a one-on-one or group format to teach academic and organizational skills such as time management, planning, and academic coaching. Services such as residential assistance, organized social activities, or subject-specific tutoring could also be utilized by students with ASD within existing formats with additional training and education provided by campus psychological services. Unfortunately, services such as these are often not easily accessed by students due to financial constraints, limited availability, and fear of stereotyping or negative consequences of disclosing their diagnosis (White et al., 2016). There is also evidence supporting peer mentoring programs as both beneficial to the needs of both the mentor and mentee, especially in the areas of goal setting and organizational strategies (Sarrett,

2018). At the most basic level, the existence of programs that address the specific needs of students with ASD reflects the growing awareness of both the increasing enrollment of autistic students in higher education and the need for additional support.

Creating easier access to services would additionally help reduce the impact of mental health issues for students with ASD (Simon, 2000). Participant B shared his concern and frustration with his lack of services before finding the ISP. Likewise, Participant C shared his struggle to stay enrolled in his program due in some part to the lack of engagement he had with similar services. Each participant had a strong desire to graduate and obtain a degree. Participant B and C noted that this process was unexpectedly taking them longer than anticipated. The introduction, or in the case of Participant B the earlier introduction, of a more comprehensive program for them as a student with ASD would likely help them graduate and build successful careers.

Advocacy and Academic Opportunity

A key aim of the present study was to explore the experiences of students with ASD on college and university campuses in terms of their ability to feel accepted, understood, and welcomed as a part of the community. As stated in the literature review, increasing numbers of individuals with ASD are pursuing degrees of higher education (Raue et al., 2011). This is a positive trend; however, research has also indicated that students with ASD have lower rates of graduation and lower rates of post-graduate employment compared to peers (Gelbar et al., 2014; White et al. 2016). Thus, students with ASD are increasingly being offered the opportunity to improve their lives but often find the process is made more difficult through the lack of education and understanding of ASD from peers and faculty. The specific needs of an individual with ASD, along with

a lack of general advocacy for the population on college campuses, have contributed to it being more difficult for students with ASD to thrive on campus.

Faculty and Peer Education. More than one participant shared their experiences of feeling misunderstood or stereotyped by both faculty and peers on campus. The shared experiences of feeling compelled to justify their diagnosis or explain why they did not look and act according to another autistic person that someone knew. Participant D shared how she felt hesitant to request clarifications on how her accommodations would be met due to the dismissive gestures of a peer. Participant B shared the challenge he felt with faculty regarding a perception of an “undue advantage” he had due to accommodations he was receiving. He also shared his fear that the university would “give up” on him and see him as “incapable.” Participant C shared his experience of the perceptions of others misunderstanding his diagnosis of ASD and his speech impairment as him being “stupid.” Each participant also shared a version of their message for others to remember that not every person with ASD looks the same or has the same symptom presentation. training and visible presence on campus, sensitivity training for faculty, and administration.

Sarrett (2018) highlighted the need to provide better training on autism to staff, professors, and peers. Diminishing stereotypes and increasing understanding would positively impact campus attitudes about ASD and potentially give individuals with ASD an opportunity to provide their input and perspective (Sarrett, 2018). Some suggest college counseling centers should act as a primary facilitator in coordinating supports among faculty, disability services offices, peer mentors, and parents (Gelbar et al., 2015; Pillay & Bhat, 2012). These centers on campus already function in providing services to

students with a variety of needs and psychologists are in a unique position on campus to offer research-based accurate information regarding ASD.

Several studies report the need for improved faculty and staff training on ASD and the needs of students with ASD in higher education (Sarrett, 2018). Researchers, both in the United States and Australia, have noted a general misunderstanding of ASD by university staff (Sarrett, 2018; Zeedyk et al., 2019). In particular, campus-wide education targeting misinformation or misunderstanding on ASD would help reduce discriminatory assumptions about students with ASD (Collins et al., 2019; Fabri et al., 2016). For example, Knott and Taylor (2014) found that university faculty and staff significantly underestimated the significance of sensory and daily living needs of students with ASD.

Previous studies have investigated perceptions about students with ASD by surveying their typically developing college peers and found students with ASD to be stigmatized, misunderstood, and excluded (Grogan, 2015; Sarrett, 2018). Academic engagement has been positively associated with academic achievement (Gelbar et al., 2015). It could be concluded that students with ASD who have a more positive experience on campus, with peers and with faculty, were therefore more likely to do well on academic achievement. Increasing peer awareness of ASD could lead to stigmatization and an increased understanding of the differences between ASD and other conditions, such as intellectual disability, ADHD, and SLD. For students with ASD, especially those experiencing social difficulties, engaging with faculty who are sensitive and educated on ASD could prove to be the difference between a successful college experience or dropping out. Tipton and Blacher (2014), for example, conducted a campus-wide survey at a 4-year university and asked both students and faculty general knowledge questions

related to ASD. They found that though most were aware of the increase in prevalence rates, most incorrectly attributed that rise to vaccine exposure in childhood (Tipton & Blancher, 2014). Additionally, overall, the study results revealed that both faculty and peers had very limited knowledge about autism (Tipton & Blancher, 2014). Campuses intending to create environments that are more welcoming and accepting of all students may, therefore, want to consider increasing education and understanding for this growing portion of their population.

Advocacy. Like other non-physical disabilities, ASD has been categorized as an invisible illness or disability (Sarrett, 2018). A component of having ASD can also include difficulties with self-advocacy and social skills (APA, 2013; Baird et al., 2003). That, along with a fundamental lack of general education about what ASD is, necessitates the need for increased advocacy on college campuses for individuals with ASD. Participant D discussed her struggle at times to advocate for herself and that the invisible nature of her struggles sometimes made it more difficult for her to interact with peers and feel accepted and understood by peers and faculty. Likewise, Participant B felt that he was coming up against barriers in his education because of the invisible nature of his difficulties. College campuses are working toward being more inclusive for many other misunderstood or marginalized populations (e.g., LGBTQ+, first-generation students, people of color, etc.); however, advocacy for students with disabilities, including those with ASD, is not necessarily as robust. Sarrett (2018) found that the most frequently cited need for college students with ASD on campus was increased ASD awareness and advocacy on campus. Sarrett (2018) also recommended that to best meet the needs of students with ASD, campuses should gather input directly from them about their most

current needs to ensure supports accurately address their concerns. The present study directly asked participants about their perceived needs regarding this area and the general message was that of increased need for understanding and patience. Participant A added a message for fellow students with ASD to not give up and to stay strong in their quest to achieve their goals:

I want to communicate my message about . . . respecting people who are different from others and give them [a message] . . . you should just work your way to show how much you support people, how much you care for others, and just be whatever you can be and work hard to get there.

This type of advocacy for both individuals with and without ASD can help to bridge the gap between misunderstanding and underrepresentation. Participants additionally commented on the difficulty of knowing the proper channels to advocate or achieve the change needed to better meet their needs. Several participants had successfully identified their needs and had secured documentation showcasing accommodations they had documented need for; however, in more than once instance they had difficulty getting them due to a perception of limited power or professors who were reluctant to provide them adequately. Zeedyk et al. (2019) also spotlight that a significant benefit of increasing awareness of the experiences of students with ASD is that students with related disabilities may also benefit. For example, improved classroom structure, a wider range of support services, and clearer communication would benefit students with other neurodevelopmental disorders or mental health problems such as ADHD and anxiety. It is unrealistic to expect that all individuals on campus will be

experts on ASD, increasing advocacy for students with ASD can help to bring the concept of neurodiversity into the spotlight on college campuses (Zeedyk et al., 2019).

Engagement and Career Opportunity

Increased education and advocacy about issues related to ASD have the potential to benefit more students with ASD. A key factor in advocacy and education related to students with ASD is that these students are invested in being a part of higher education. Each participant in the current study expressed their desire to obtain an education and degree. Participant C expressed his desire to provide for his daughter. Participant A wanted to earn his degree to increase his opportunities in the entertainment fields. Participant B was working his way toward a career in medicine. Finally, Participant D knew that she needed an education to better her life circumstances and increase her earning potential. Each participant shared that some aspects of their educational experience had been more difficult at times than they had anticipated; however, they each continued to persevere. Their overarching message was that they wanted to be viewed as contributing members of society just like peers but felt that undue obstacles made it more difficult for them at times. Higher education can be an arduous process; however, the additional social, psychological, and academic challenges experienced by students with ASD can make the process more difficult, take longer, and ultimately cost more (Gelbar et al., 2014; Raue et al., 2011; White et al., 2016).

As mentioned previously, students with ASD have higher drop-out rates and lower post-graduation employment rates than peers. Therefore, changing the direction of these statistics through increased advocacy and supports on campus can help increase their potential to achieve their goals for the future (Gelbar et al., 2014). Van Hees et al.

(2015) and offers several recommendations for institutions of higher education to expand opportunity and employment for students with ASD. Chief among them is the recommendation for more extensive and effective coaching of students with ASD. They emphasize the need for supports to extend beyond academic interventions to encompass collaborative transitional services that engage students in student life and offer support for daily living skills. Van Hees et al. (2015) recommend that coaching is individualized and can be a point of contact for the student difficulties or issues related to well-being arise.

Mental Health and Social Opportunity

Under consideration in the present study was whether participants described experiences affecting their mental health or well-being. Each participant described a variety of instances that either directly or indirectly had a potential effect on their psychological well-being. Instances of bullying, feeling viewed as something other than “normal”, feeling lonely or isolated, and encounters with peers and faculty who misunderstood their needs were reported by all participants. Participant B directly spoke of his anxiety about the “university giving up” on him despite how hard he has been working to earn his education. Further, Participant C spoke of feeling misunderstood and isolated or misunderstood. The above summative findings would collectively help to address or improve the overall social experiences of the participants and the student population they represent. Co-morbid psychological conditions, though not directly addressed in this study, may potentially be improved for students with ASD as well. For example, Participant B specifically spoke of feeling targeted and of being the only student like him in his program as far as he knew. In general terms, participants alluded

to anxiety, stress, and concerns related to their educational experience. Participants C and D spoke of feeling lonely and isolated due to misunderstanding and bullying from peers.

While each participant noted obstacles and challenging experiences as a student, they also described reasons for feeling motivated to continue to pursue their education. Participants B and C spoke of their education taking longer than expected; however, each remained enrolled in pursuit of a degree. Participant A spoke of his general encouragement for students and individuals feeling discouraged and Participant D remained in her program despite not feeling understood by some groups of peers. Though the participants spoke of hardships they encountered as students with ASD, each was carving out space for themselves in their current institution and were taking part in social activities to some degree.

If campuses, both nationally and internationally, approached education, advocacy, and incorporating more comprehensive and specific supports at their institutions, mental health outcomes for students with ASD may likewise improve. Some of the most cited instances for drop out and poor mental health among college students with ASD are loneliness, isolation, and lack of strong social supports (Gelbar et al., 2014; Sarrett, 2018). Students with ASD are likely not the only students on campus experiencing these more negative aspects of college life. Creating a more collaborative inter-departmental approach to meeting student needs could help to better address these concerns for not only students with ASD, but the larger student population as well. Nationally, the rate of suicide for individuals of college-age has been on the rise, therefore increasing supports for this population, creating more opportunities to address mental health concerns, and

promoting safe inclusive space on campus may have a positive impact on the larger mental health concerns across campuses (Schwartz, 2006).

Several studies highlight the need for adequate individual and group psychological or counseling supports to assist students in addressing mental health issues and other difficulties as they arise during their years in education (Friedman et al., 2013; Pinder-Amaker, 2014; Van Hees et al., 2015). McGillivray and Evert (2014) in particular found a cognitive-behavioral therapy-based approach to group therapy was particularly effective in addressing both depression and anxiety symptoms for young adults with ASD. This would likewise offer potential structured opportunities for individuals to socialize with peers. Finally, adding ASD specific services or advertising for students with ASD may additionally help to engage this population in existing campus services.

Implications of Research

The present study may offer a direction or point of focus for college campuses, including disability services and student counseling offices, for future or continuing services development. This study sought feedback directly from students living with ASD and navigating their college education. In this way, it offers a direct perspective of what individuals with ASD experience and hope for in their experience as college students. Expanding the scope of services offered in higher education to better address the needs of students with ASD would also secondarily increase services and programs for the larger campus population. If campus partners support the needs of a student with ASD and offer appropriate support and accommodations in education, student life, and daily living, retention rates could improve and students may experience an enhanced quality of life.

(Van Hees et al., 2015). Listening to the input from students with ASD may likewise benefit other students and more accessible and inclusive education experiences for all.

This research is contributing to a growing body of research expounding on the needs of individuals in this population. Jackson et al. (2018) along with others (Anderson et al., 2018; Dymond et al., 2017; Scheef et al., 2019) have begun to heighten awareness of the need for providing increased funding and support to universities willing to be a welcoming and safe environment for students on the autism spectrum. More education and understanding about this population may likewise help to decrease bullying, targeting, stereotyping, and undue stress for the individual and the general population both on and off-campus. This shift in peer and faculty education could also begin with high schools empowering students with ASD to expand their goals and seek higher education. Higher education institutions may in turn do more to support and facilitate graduation of students with ASD. This could be done through programs such as peer mentoring or coaching, individualized academic supports, and social experiences (i.e., camps, theater groups, intermural sports, etc.) aimed at promoting inclusive diverse experiences for both individuals with disabilities and neurotypical peers. Activities such as this could provide scaffolding for students with ASD to begin to expand their social skills, create larger groups of support, and become more engaged on campus. This in turn could potentially help to address potential mental health concerns, social isolation, dropout rates, and overall work to improve the college experience for students with ASD.

The participants in this study confirmed what is already known through existing research regarding the importance and value of finding community and peer support (Anderson et al., 2018; Cai & Richdale, 2016). The presence of a community of peers

who understood their perspective and lived experiences was a significant benefit for Participants A, B, and D. For Participant C, who did not have such a community, the lack thereof was sorely missed. One way to help achieve this could be through the creation of a neurodiverse space on campus that acted as a safe inclusive space on campus for a wide range of students (Sarrett, 2018). This space could offer sensory-sensitive spaces, opportunities to socialize and facilitate normalizing the inclusion of more diverse learners on campus (Sarrett, 2018).

Previous research, such as that conducted by Kuder et al. (2018), has addressed the higher risk for drop out for college students with ASD. Research like this and like the present study may help to facilitate the changes at the university and community level to help address this concerning fact. As stated in the literature review, the population of neurodiverse students entering colleges and universities is on the rise, which makes it all the more important to highlight the challenges current university students face. If not addressed, as enrollment rates increase, institutions of higher education may have increased incidences of drop-out, bullying, and poor mental health outcomes within this population on their campuses. By improving the experiences of students with ASD on campus, the education experiences of other populations will likely improve as well. Finally, the improved lived experiences of students with ASD will also likely increase the effectiveness of the institution itself in meeting the brief of educating individuals who can go on to provide much-needed services in the community.

Study Limitations and Recommendations for Future Research

It is important to note several limitations of the present study. One central limitation is the limited number of participants. While the method was a case study

approach, more voices and experiences of what it is to be a college student with autism are needed to more accurately generalize conclusions for the larger population. In addition, the participants included in the study have somewhat varied backgrounds; however, more diversity and variety in the demographic background, age, age of diagnosis, services used pre-college, and other information would better inform future research. Additionally, ASD is a spectrum disorder (APA, 2013), and as such symptoms and presenting concerns are varied among individuals. The impact and experiences of the included participants may therefore not entirely reflect the experiences of the larger population. For future research, collecting data from participants who identify with more diverse categories and from a larger sample size would contribute a more robust data set that would have greater potential for generalizability.

An important limitation of the study was also that each participant self-selected for participation. This could be due to their own unique experiences or an unaccounted-for purpose they may have had for choosing to participate. Likewise, as noted in the previous literature (Levy et al., 2010; Soke et al., 2018) comorbidity among this population is notable. It would be important for future literature to further examine the intersection between co-morbid diagnoses and other factors that were taken into consideration in this study, such as mental health and access to services. Furthermore, participants were drawn from a limited region of the United States. All participants were located in the Pacific Northwestern states of the United States. Results, therefore, may not be as generalizable to other areas and regions of the world as easily. Future research encompassing a wider geographic area either nationally or internationally would be beneficial.

The structure and time allowed for the interview were, in most cases, sufficient for gathering information pertinent to the research questions of the present study; however, more time and additional follow up may have allowed for more clarity and detail pertinent to the purpose of the study. Future research directions may potentially allow for more time to explore at length the examples of each participant. Likewise, the qualitative methodological approach of the present study is considered both a potential strength and weakness. While the qualitative approach allowed for flexibility and opportunity for a more in-depth exploration of participants' experiences, a quantitative methodology may create the opportunity for greater generalizability. Future research may, therefore, benefit from a mixed-methods approach to mitigate those concerns. Adding to that, recruitment was somewhat of a challenge in the present study, therefore future research on this population may want to carefully consider their access to the population and create ways for potential participants to feel more comfortable with participation.

Finally, data were collected for the present study during an unprecedented viral pandemic. This necessitated the change from in-person interviews to computer-based face-to-face interviews. Although the researcher did not notice any apparent irregularities, it is possible that some behavioral observations were missed or that the computer-based platform interfered with rapport and therefore the content of the responses provided by the participants. Similar research in the future should therefore strongly consider conducting in-person interviews if given the opportunity.

Conclusions

The results of this study offered experiences of four college students with ASD. Through sharing their experiences, common threads or themes were identified. The overall message from the present study that can be considered when addressing the needs of the larger populations is that more work is needed to help students with ASD navigate college successfully. While there are already some supports in place, additional education and services may be the key to further improving the academic, social, and emotional well-being of college students with ASD.

The present study, along with those similar to it that capture the voices of students with ASD, helped highlight how offering continued support for existing programs for students with ASD is vital for assisting them – not only in achieving their dreams of college education but in increasing the wellness and social support of the overall population. In addition, the present study offers support for the creation of additional programs and supports for students in this population. Not only would the academic, social, and psychological well-being of students with ASD likely improve through the creation of these programs, but society at large would benefit from the addition of capable and qualified professionals.

Finally, advocacy and education related to individuals with ASD and individuals with special needs are important both on and off-campus. Outcomes are better for individuals who have a college education. Individuals with ASD already have lower projected outcomes for obtaining degrees and employment, so increasing their supports is not only needed but could help improve societal outcomes over time and reduce strain on community resources. When seeking to serve a population, it is important to include the perspective of the individual who is being served and it is important to facilitate growth

and change both in and out of higher education. We can better serve the needs of an individual if we first take the time to understand their experience and perception of their needs. In this way, better support for the development of skills, educational achievement, and career advancement can become the focus. This study is helping to facilitate that process with the goal that the larger higher education community will more readily adopt integrating increased support for this population.

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Appendix A

Interview Outline

1. Welcome and Introductions
2. Explanation of Study and Informed Consent, including contact with RSP and/or providing other documentation to verify diagnosis.
 - a. If you do not have a verified diagnosis, what have been the barriers to obtaining one?
- 3. Demographic Information Gathering**
 - a. What is your major or area of study?
 - b. What year are you (e.g., freshman, sophomore, etc.)?
 - c. How old are you?
 - d. Are you a full-time student?
 - e. How did you make the decision to attend college?
 - i. Who did you talk to about if and how to apply?
 - ii. How did you decide where to apply?
 - iii. Who helped you with this decision (e.g., parent, teacher, school counselor, etc.)?
- 4. Questions Specific to Individual Experience of ASD**
 - a. How old were you when you were diagnosed with autism?
 - b. How open was your family about you having ASD?
 - c. How old were you when you knew you had ASD?
 - d. How do think about your diagnosis? How do you describe it to other people?

- e. Did you use any type of transition or special education services (high school to college)?
 - i. What did you find helpful?
 - ii. If no, do you think a program that gave you more information about what to expect about college or a class that prepared you for the differences between high school and college would have been helpful?
- f. Do you remember getting extra help with certain things in school? (e.g., attending a group? or meeting with a teacher to help you with certain subjects?)
- g. What was your favorite part of high school? What was the hardest?

5. Questions Specific to Being a College Student with ASD

- a. Academic Experiences
 - i. Have you shared with the university that you have ASD?
 1. Why did you decide to do this? Did you ever consider not telling the school? What contributed to this decision?
 2. Do you use on-campus disability services (e.g., center for disability access and resources)?
 - ii. Have you found the academic part of college challenging?
 - iii. What has been the easiest/hardest part of the academic experience of college?
 - iv. Do you have any strategies for keeping track of assignments and turning them in on time? (e.g., planner, tutoring, scheduling, etc.)

v. Have you taken advantage of services the university offers, such as counseling, library events, career center, academic coaching, etc.?

If no, is there a specific reason why you haven't?

b. Social Experiences

i. Do you have a roommate? Do you get along with them? Have you ever had to talk with them about things you need that they don't understand? What bothers you about them?

ii. What do your peers know about ASD?

iii. Have you shared with friends/peers that you have ASD?

1. What was that experience like? How did they react?

iv. Have you joined any clubs, groups, or school-sanctioned group activities?

1. If no, can you share why you have chosen not to?

v. Tell me about your relationships with your friends.

1. What are they like? How satisfied or dissatisfied are you with your friend relationships?

vi. Do you attend college social events (e.g., sports, theater, guest speakers, etc.)? Can you explain what you mean?

c. Mental Health and Well-Being

i. Have you ever experienced verbal taunting or teasing on campus?

ii. Do you ever feel anxious about anything specific to your college experience? Can you tell me more about that?

iii. Do you ever feel left out by peers?

iv. Have you ever felt you were bullied or targeted on campus for being different? For having ASD?

1. How did you deal with it?

6. General Experience

- a. Are there any services you wish your university/college offered that would help you as a student with ASD?
- b. Are there any specific experiences that you feel have made your experience as a student with ASD easier? (e.g., going to a workshop, talking to parents, academic coaching, touring school before starting, etc.?).
- c. Are there any supports you feel are lacking in your current university system that they feel would help you navigate college more successfully?

7. Closing Remarks

- a. Is there anything about your experience as a college student with ASD that we haven't discussed that you would like to bring up?
- b. Do you have any questions for me or additional comments?
- c. Reminder about consent terms and right to revoke

Appendix B**Consent Form*****The Experience of University Students with Autism Spectrum Disorder***Doctoral Dissertation, *Northwest University****Connie Zollner***

You are invited to participate in a research study conducted by a doctoral psychology student at Northwest University. The study is being conducted in order to fulfill the requirements for graduation in the Doctor of Psychology program in Counseling Psychology. The purpose of this study is to explore in more depth the experience of university students who have been diagnosed with autism.

If you agree to participate in the study you will complete a short interview with the researcher, which will take approximately 45-60 minutes. Interviews will be scheduled according to the most convenient time for the participant and will be conducted via computer-based online communication software (Zoom) or via telephone. Interviews will be audio recorded and then transcribed verbatim as a source of data for the study. After the completion of the research project (no later than January 30, 2021), the audio recordings and notes will be destroyed. In addition, by signing this form you are giving your permission for the below researcher to contact the university you are attending to gain access to paperwork confirming you have a diagnosis of autism spectrum disorder, a prerequisite for inclusion in the present study. The researcher will be confirming your diagnosis of ASD by contacting the INDIVIDUALIZED SUPPORT Program (ISP) coordinator at the UNIVERISTY NAME. If you do not have an official diagnosis but are enrolled in the Raven Scholars Program you are consenting for the researcher to contact the program coordinator to confirm your enrollment in the program. If you are not enrolled in this program, or do not want to consent to coordination with the INIDVIDUALIZED SUPPORT Program (ISP), you are agreeing to provide a copy of your psychological assessment report or other official document confirming your diagnosis of ASD as this is an integral part of you being included in this study. Please note, no other information will be exchanged, provided, or received from or with the ISP.

There are minimal risks associated with participation. Some individuals may be uncomfortable answering personal questions, however, every precaution will be made to make this experience as comfortable for the participant as possible. In the rare event participation causes distress, it is recommended you find or contact your mental health provider or contact the National Suicide Prevention Crisis Line (1-800-273-8255) or Text HOME to 741741 from anywhere in the United States anywhere about any type of crisis. As you are student of a university, it is also likely you are eligible for free services included as a part of your tuition. For UNIVERSITY NAME students, you may contact the Counseling & Testing Center (office: 208-885-6716 or Crisis line: 208-885-6716). The benefit of taking part in this study is the opportunity to participate in a study that will help inform what universities and other agencies can do to better support individuals with

autism in the university setting. In addition, you will receive a \$50 gift card (or e-gift card) to Amazon or equivalent.

Participation in this study is voluntary. You may choose not to participate in this study at any time and for any reason. There will not be any negative consequences for you if you refuse to participate. You may refuse to answer any questions asked. All responses are anonymous and any identifying information will be removed or redacted. By signing this form, you are giving permission to use your responses in this research study.

The results from this study will be presented anonymously in a written doctoral dissertation and as a part of doctoral dissertation defense presentation. All data forms will be destroyed on or before January 30, 2021.

If you have any questions about this study, contact Connie Zollner via email or phone listed below. If you have further questions, please contact my faculty advisor, Nikki Johnson at the email address listed below. You may also contact the Chair of the Northwest University IRB, Dr. Cherri Seese, at cherri.seese@northwestu.edu or 425-285-2413.

Thank you for your consideration of this request.

Connie Zollner, M.A.
Doctoral Student/Researcher
Connie.zollner15@northwestu.edu
503-980-8260

Nikki Johnson, Psy.D.
Dissertation Chair
Nikki.johnson@northwestu.edu

Signature of Consent

By signing on the line below, I agree to the terms stated above and have been given adequate information regarding my participation in the above listed study.

Participant Signature

By signing below, the researcher confirms that all relevant information has been shared with the above participant. No deception or coercion has taken place and all

identifying information will be concealed and protected to the best of the researcher's ability.

Connie D. Zollner, M.A.
Researcher Signature

Appendix C

Sample Recruitment Letter

Dear ___ (e.g., parents of a student in an individualized support program, Training Director, Director of Student Services, etc.),

I am a doctoral student completing a Psy.D in Counseling Psychology at Northwest University in Kirkland, WA. As a part of my research for a doctoral dissertation, I am completing a qualitative study exploring the experiences of college students on the autism spectrum.

I am asking for your assistance in finding participants for my study. I am looking for individuals who meet the following criteria:

- Currently enrolled full-time college or university
- Be over the age of 18
- Must have a diagnosis of autism spectrum disorder
- Have completed a minimum of one semester/quarter of coursework

Participants will be asked to take part in a 30-45-minute interview via Zoom answering questions related to their experience as a college student on the autism spectrum.

Participants will be asked to review a consent form prior to participation. Questions will be related to the academic, social, and mental-health or well-being aspects of the student's experience. Participant responses will be kept anonymous. The study has Northwest University Institutional Review Board approval.

As an incentive for participation, each participant will be offered a \$50 Amazon (or other equivalent) gift card as compensation for participation. Participation will contribute to the wider available research and help clinicians and administrations at the university level better understand how to assist and support students with autism.

If you know of an individual who meets criteria and is interested in participation, please have them contact me via email or phone. Attached is the consent form participants will be asked to sign for inclusion in the study. If you have any questions, please feel free to contact me.

Kindest regards,

Connie Zollner, M.A.
Doctoral Student/Researcher
Northwest University
connie.zollner15@northwestu.edu
503-980-8260

Nikki Johnson, Psy.D.
Dissertation Chair
Northwest University
Nikki.johnson@northwestu.edu

Appendix D

Sample Social Media Recruitment Post

Research Participation- Call for Participants: I am a doctoral student completing a Psy.D in Counseling Psychology at Northwest University in Kirkland, WA. As a part of my doctoral dissertation, I am completing a study exploring the experiences of college students with Autism.

I am looking for individuals who meet the following criteria:

- Currently enrolled full-time college or university student
- Be over the age of 18
- Must have a diagnosis of autism spectrum disorder
- Have completed a minimum of one semester/quarter of coursework

Participants will be asked to take part in a 30-45-minute interview via Zoom answering questions related to their experience as a college student on the autism spectrum.

Participants will be asked to review a consent form prior to participation. Participant responses will be kept anonymous. The study has Northwest University Institutional Review Board approval.

As an incentive for participation, each participant will be offered a \$50 Amazon (or other equivalent) gift card as compensation for participation. Participation will contribute to the wider available research and help clinicians and administrations at the university level better understand how to assist and support students with autism.

If you are or know of an individual who meets criteria and is interested in participation, please private message me for details.