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The Transition into Higher Education for Students with Autism Spectrum Disorders

Abstract

There are more students with autism spectrum disorders (ASD) in higher education now than ever before and these students need to be supported in ways that will guarantee their success. The purpose of this qualitative study was to examine the experiences of six students with ASD as they transition into higher education through the use of semi-structured interviews. What was discovered is that students with ASD typically overestimate the difficulty of academics and underestimate the amount of social interaction they will encounter at the college level. These students are able to identify aspects of themselves that help them to succeed while also developing strategies to manage their stress. This research found that on-campus supports are underutilized by students with ASD due to a lack of knowledge of the supports, difficulties attaining support, or fear of stigmas associated with support. The participants of this study discuss their experiences before and during college, as well as their decision-making process regarding disclosing their diagnosis of an ASD. This study developed a theoretical model to visually understand the experiences of this population. Real-world implications are discussed along with recommendations for those supporting these students in transition, from a variety of different perspectives.

Degree Type

Dissertation/Thesis

Degree Name

Master of Science (MS)

Department

Counseling and Higher Education

Thesis Director

Dianne Timm

Thesis Committee Member

April Jackson

Thesis Committee Member

Danny Gourley Fischer

Keywords

autism spectrum disorder, ASD, ASD disclosure, transition theory

Subject Categories

Academic Advising | Disability Studies | Higher Education | Secondary Education | Social Justice | Special Education and Teaching

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Tj Estabrook

Department of Counseling and Higher Education, Eastern Illinois University

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There are more students with autism spectrum disorders (ASD) in higher education now than ever before and these students need to be supported in ways that will guarantee their success. The purpose of this qualitative study was to examine the experiences of six students with ASD as they transition into higher education through the use of semi-structured interviews. What was discovered is that students with ASD typically overestimate the difficulty of academics and underestimate the amount of social interaction they will encounter at the college level. These students are able to identify aspects of themselves that help them to succeed while also developing strategies to manage their stress. This research found that on-campus supports are underutilized by students with ASD due to a lack of knowledge of the supports, difficulties attaining support, or fear of stigmas associated with support. The participants of this study discuss their experiences before and during college, as well as their decision-making process regarding disclosing their diagnosis of an ASD. This study developed a theoretical model to visually understand the experiences of this population. Real-world implications are discussed along with recommendations for those supporting these students in transition, from a variety of different perspectives.

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DEDICATION

This study is dedicated to the students who inspired me to conduct this research.

ACKNOWLEDGEMENT

First, a sincere and humble thank you to each and every person who got me to this point. I will do my best to pay respects to everyone who played a part in this journey, but if I were to say all that I feel I should, this section would be just as long as the study that follows.

Thank you to my parents for teaching me to never stop learning. I would be nowhere near where I am today without your encouragement.

Thank you to MacKenzie for keeping me sane and focused. You inspire me every day and I could not imagine going through this process without you.

Thank you to Daniel, Coleman, Connor, Chandler, and Logan for reminding me that all work and no play truly does make you dull.

Thank you to Dr. Timm for being the embodiment of patience with me through this process. You pushed me when I needed to be pushed.

Thank you to April and Danny for being the most supportive committee members I could have asked for, even if I may have tricked you into it.

Thank you to everyone in my cohort for reminding me that I was not alone in this process. Our friendships and memories will stay with me forever.

Thank you to the CHE faculty for guiding me to this point. I hope you are able to look back on whatever mental anguish I may have caused you as positively as I will.

Thank you to all of EIU's Housing and Dining staff for allowing me to continue to grow my professional passion in such an amazing community.

Thank you again to the countless others who have made positive impacts on my life. You are all the reasons why I am where I am today, and I could not have done it without every single one of you. This work is as much yours as it is mine, and I hope you all can view it as such.

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CHAPTER I

Introduction

In the United States approximately 59% of those enrolled in higher education complete their bachelor's degree (National Center for Education Statistics, 2014). That number drops to about 41% for higher education students with disclosed disabilities pursuing the same degrees (Newman et al., 2011). Postsecondary enrollment for individuals with disabilities has increased dramatically, from 9% in 2000 to almost 20% fifteen years later (Foley, 2006; National Center for Educational Statistics, 2021). In the 2004 Individuals with Disabilities Education Act (IDEA) K-12 institutions were mandated to provide students with disabilities an Individual Education Plan (IEP). IEPs ensure that students with special educational needs are given the same opportunities to succeed as other students: utilizing personalized goals and detailed outlines, support teams, and descriptions of needed resources (Kurth & Mastergeorge, 2010). Upon entering an institution of higher education these same means are no longer required. According to the Rehabilitation Act of 1973 (Civil Rights, 2020), colleges are not obligated to identify students with disabilities and those students are also not required to disclose their disability status (Civil Rights, 2020). Though they are required to inform students about disability services and aids that are offered, colleges and universities are not allowed to require students disclose their disability status prior to admission. While the protections afforded by the Rehabilitation Act are necessary, they can create unintentional barriers for students in need of disability support who may simply be unaware of the services that are available to them.

Even as barriers are broken down and new legislation is passed, many students with disabilities still struggle with the transition into higher education (Jansen, et al., 2017). Without the requirement of IEPs in postsecondary institutions other measures are needed to set the

student up for success. Colleges do provide disability support for students who disclose, and these offices are in place to provide support and advocate for this population (Van Bergeijk, et. al., 2008). Some institutions have even gone as far as developing specific programs for students with disabilities, such as Project Success that supports students with dyslexia at the University of Wisconsin Oshkosh; The STEP program for students with autism at Eastern Illinois University; Heartland Academy for Learning Opportunities for students with cognitive disabilities at Heartland Community College; and the Career Skills Institute for students with mild intellectual disabilities at Harper College. The creation of support programs that focus on establishing self-advocacy and goal-setting behaviors in students with behavioral and learning disabilities, such as autism have risen in need and prominence (Wolanin & Steele, 2004).

Though support services for students with disabilities exist, students with autism spectrum disorders are not required to utilize them, or even to disclose their diagnosis to their institution, despite the academic risks that come with that decision (Hudson, 2013). In addition to simply understanding the opportunities afforded to higher education students with autism spectrum disorders, it is equally important to understand their experiences in the higher education setting. Understanding why students make the decision to not disclose a diagnosed disability can help to inform student affairs professionals about the services they provide to these students and what improvements can be made.

Purpose of the Study

The purpose of this study was to explore the experiences of college students with autism spectrum disorders at a four-year, public higher education institution. Higher education students with autism spectrum disorders are a frequently at-risk, yet often overlooked campus population (Van Hees, et. al., 2015). Due to this discrepancy, understanding how this population is served,

and how that service can be improved, is a key area of growth for many higher education institutions. This study provided an opportunity for professionals at higher education institutions to understand the experiences of students with ASD. In addition, this study looked to add to the body of literature regarding autism spectrum disorders and the transition for students with autism spectrum disorders into higher education.

Research Questions

This study explored the experiences of college students with autism spectrum disorders, how they describe their transition into higher education, the resources they utilize, and their process of disclosing their diagnosis of ASD.

RQ1: How do students on the autism spectrum describe their experiences of transitioning from high school to higher education?

RQ2: What support and resources do college students with autism spectrum disorders describe using while in college?

RQ3: How do college students on the autism spectrum describe their experiences disclosing their diagnosis at their campus?

Significance of the Study

Looking at any mission statement, one can see that the primary duty for an educational institution is to ensure the education of its students. Therefore, it is in the interest of these institutions to identify growing student populations that require additional attention. As the barriers for, and stigmas surrounding, individuals with neurological differences are being combated, the number of students with autism spectrum disorders enrolling in higher education has been growing (Bakker et al., 2019; Randall et al., 2016). While students with autism

spectrum disorders can succeed in a higher education environment, they may still require additional assistance that other students may not need.

This study identified the ways these students are challenged, especially through the transition into college, and how they can better be supported. Understanding the factors that affect students with autism spectrum disorders allows universities to better ensure the success of this growing population of students.

Limitations and Delimitations

While the aim of this study was to gain insight into the transition to college for students with ASD, it was limited by low access to study participants. This research was conducted at a midsized, four-year public institution which will be referred to as University A from this point forward. With that being the case, this study was limited in terms of its generalizability. One way this limitation was minimized is that because the population studied is relatively small, having a representative sample will provide a perspective into the transition experience.

Another limitation for this study was access to students that have received a formal diagnosis of an autism spectrum disorder who have disclosed that diagnosis to the University. University A's Student Disability Services office only had the information of students who had disclosed their diagnosis to the University, and because the goal of this research was to understand the experiences of students with ASD as they transition to college it is important to get those that have disclosed, are aware of, and utilize the disability services provided at the institution.

Another limitation was that of the students' transparency. Because the information gathered from this study was personal, some students may have been less willing to disclose their experiences than others. This was mitigated through the structure of the questions asked, which

began with broad, low risk information and got more introspective as the interview progressed. The building of rapport was crucial with participants, so they felt the trust necessary to discuss sensitive information. The questions used in this study incorporated topics the students might never have considered before, which may have made it difficult share for them to share. Some participants may have needed more time to think about and respond to questions, and the interviewer took this in to account and provided space for the participant to think about and respond to questions as they were comfortable. This was lessened in a similar way, through the structuring of questions, the building of rapport, providing space for reflection in the interview, and offering resources and support in their analysis of their experiences.

The findings of this study may not be generalizable to other institutions with differing student body and demographics. University A is a mid-sized institution in the rural Midwest and the characteristics of its student, staff, and faculty populations will likely be very different when compared to other universities of varying size, type, and geographic location. This will not be an issue, however, as this was a qualitative study and therefore not intended to be generalizable, instead focusing on the unique, individual student experience.

Finally, this research was conducted in the Fall of 2022, after over two years of the COVID-19 pandemic impacting the delivery of education in the K-12 and collegiate environments in the United States. Each school was left to develop its own policies and regulations for how to manage the pandemic and participants may have been in high school as the pandemic began and transitioned to college during this time. At University A the institution did everything to provide in-person learning but because of health concerns some courses were transitioned online. Along with this, orientation and support programs may have been more virtual than in-person in design. The participants may have also been in unique learning

environments because of COVID-19 prior to attending college. All this needs to be considered as the participants share their stories and experiences of transitioning to college, which may play a larger role than anticipated. This was included in the interview process and in how their responses were analyzed.

Definitions of Terms

- **Accommodations.** An accommodation is when an existing process or structure is altered in some way to minimize the effect that an individual's disability has on their engagement with said process or structure. In higher education, examples of accommodations would be additional time or alternate locations for test-taking, alternative formats for instruction materials, or assistance with notetaking during classes (Ketterlin-Geller & Johnstone, 2006).
- **Autism spectrum disorder (ASD).** The most recent Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) combines the various names given to the disorders that would place an individual on the autism spectrum under the term autism spectrum disorder (ASD). This term will be used throughout this paper when discussing the condition in a modern setting.
- **Autism support programs.** These programs are geared towards students with ASD and aid in the transition into higher education through an array of aids, depending on the institution. These programs place an emphasis on self-determination, self-advocacy, and goal-setting behaviors.
- **Disability Services.** Disability Service offices at higher education institutions ensure that reasonable accommodations are being made for students with

disabilities. These offices also serve as advocates for students with disabilities on college campuses (Ketterlin-Geller & Johnstone, 2006).

- **Individualized Education Plan (IEP).** An IEP is a document afforded by the Individuals with Disabilities Education Act to guarantee that children attending elementary and secondary schools receive the specialized services that they need to succeed (Guide to the Individualized Education Plan).
- **Individuals with Disabilities Education Act (IDEA).** This act recommends that public schools create IEPs for students in need of specialized instruction and additional resources due to an ASD (Individuals with Disabilities Education Act, 2004).
- **Section 504.** Section 504 of the 1973 Rehabilitation Act outlawed discrimination in the United States based on the grounds of ability and was the first piece of American legislature ensuring the civil right of individuals with disabilities (Civil Rights, 2020, n.p.).

Summary

More students with ASD are enrolling in higher education institutions than ever before. Thus, it is of growing importance that these students are being supported in ways that will ensure their success. The purpose of this study was to examine the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them. In the subsequent chapters, a review of the literature will be provided to identify how this study fits into the existing body of literature, followed by an outline of the methods that will be used when conducting the research, then an analysis of participant responses will be conducted. Lastly, a model that was developed from the

data collected will be presented, followed by implications of the study and recommendations for further research.

CHAPTER II

Review of Literature

The purpose of this study was to examine the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them. This literature review will outline disability support in the K-12 system as well as into higher education. In addition, it will define autism spectrum disorder, as well as give an overview of its history and the development of its field of study. This chapter will also discuss the ways in which students on the autism spectrum experience college. The types of support programs that are offered to these students will be examined along with the ways they perceive the help they are receiving. Particular attention will be paid to the process of disclosure for students with autism spectrum disorders as well as the impact higher education transition programs have for these same students. This chapter will conclude with a discussion of Gibson's (2006) disability identity model and Schlossberg's (1984) transition theory and their applicability to the current study.

Disability Overview

Through the 1960's, close to twelve percent of all children with disabilities were not enrolled in school; and of those that were, more than half did not receive the services they required to ensure their success (Fleischer & Zames, 2001). In the following decades, many steps were taken to guarantee an education to those children that had been left behind by the American school system. This section will cover an overview of legislation for individuals with disabilities, Individual Education Plans (IEPs), autism spectrum disorder (ASD), and support for students with disabilities in higher education.

Legislation on the Civil Rights of Individuals with Disabilities

Many significant moves were made towards equality for individuals with disabilities in recent decades. Much of this has come from activism on the part of those with disabilities and their advocates (Feinstein, 2011). From this civil rights movement have come legislative changes that have paved a path for access. Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and the Individuals with Disabilities in Education Act will be further explained below.

Section 504 of the Rehabilitation Act. In 1973, Section 504 of the Rehabilitation Act was enacted to protect the rights of individuals with visible and hidden disabilities “in programs and activities that receive Federal financial assistance” (Civil Rights, 2020, n.p.). This was a landmark moment in the fight for the civil rights of individuals with disabilities, as it banned discrimination on the grounds of ability, following suit with previous laws outlawing discrimination based on sex, race, and ethnicity (Mayerson, 1992). Prior to this ruling, it was widely believed that the obstacles faced by individuals with disabilities were simply results of the disability, rather than a result of society’s wider prejudices (Burch & Sutherland, 2006).

While the passing of this act was a major step forward for individuals with disabilities, in a time when civil rights legislature was being fought for each day, that step was not without its challenges. Through the end of the 1970s, higher education institutions were gradual in their implementation of the new law (Kalivoda, 2009). Believing that the process would be too time- and resource-intensive, many schools hesitated to make changes altogether (Madaus, 2000). This trend was supported by Supreme Court cases like *Grove City v. Bell (1984)*, which ruled that Section 504 of the Rehabilitation Act did not apply to entire institutions, but only to specific federally funded programs (Madaus, 2000). In 1987, under the Civil Rights Restoration Act,

Section 504 was amended to reverse previous rulings and stated that if any programs received federal funding, Section 504 applied to the entire institution (Madaus, 2000).

Despite this progress, however, the reach of the Rehabilitation Act was limited and continuously narrowed by the increasingly conservative political landscape of the late 1970s (Davis, 2015). When Ronald Reagan was elected president in 1981, he sought to undo a majority of what the previous Johnson administration had accomplished, including Section 504 of the Rehabilitation Act of 1973 (Davis, 2015). When these plans were made public, activists from Disability Rights Education and Defense Fund and the Disability Rights Center fought to not only save Section 504, but also pushed for more comprehensive legislature (Davis, 2015; Fleischer & Zames, 2001).

Americans with Disabilities Act (ADA). The Americans with Disabilities Act of 1990 (ADA) was signed into law by George H. W. Bush nine years later, a historic moment for individuals with disabilities (Brandfield, 1990). Where the Rehabilitation Act protected the rights of individuals in federally funded endeavors, the ADA expanded those protections to the private sector (Essex-Sorlie, 1994). Additionally, due to its effect on the facilities, programs, and services at higher education institutions, the ADA played a significant role in the increasing number of students with disabilities going to college (Madaus, 2000). The ADA is made up of five sections, or titles, each with its own set of regulations and protections.

Title I: Employment. Prohibits the discrimination based on level of ability in the workplace and necessitates that academic environments and employers with fifteen or more employees make reasonable accommodations for individuals with disabilities (ADA, 1990). Making worksites accessible, providing reserved parking, and allowing for flexible training and scheduling are a few examples of reasonable accommodations under ADA. While students or

employees are not entitled to disclose their disabilities, if they choose to, their institution or workplace is required to comply with Title I and must work to ensure equal opportunities (A guide to disability rights laws, 2020).

Title II: Public Services. Ensures that individuals with disabilities cannot be denied service or involvement in services or programs that are offered to those without disabilities. It also makes sure that public transportation systems are made accessible to all levels of ability (ADA, 1990). In addition, it ensures that colleges are unable to deny admittance, programs, or services to students with disabilities (Hawke, 2004). On college campuses, programs and services must be accessible for students with disabilities, and if they are not accessible due to facility restrictions, they must be moved to a suitable location for that population (A guide to disability rights law, 2020).

Title III: Public Accommodations. Title III applies the guarantees made by Title II to the private sector, including hotels, restaurants, private transportation services, etc. In addition, it mandates that existing structures be made accessible where available and that all future projects be designed with accessibility in mind (ADA, 1990). This means that higher education institutions must consider who is entering and work to make accommodations where and when they are able. Private higher education institutions are governed as private businesses and are therefore covered by Title III (Hawke, 2004).

Title IV: Telecommunications. Requires that all phone service companies develop services for those who are deaf or hard of hearing (ADA, 1990). For colleges this means that they are able to provide the same services and equipment for the students, faculty, and staff on their campuses. This is not as big of an issue as it used to be because so many people have cell phones that are fully equipped in making these accommodations.

Title V: Miscellaneous. Directly prohibits threatening or coercing those with disabilities asserting their rights established under the ADA (1990). This helps to reinforce that institutions make a good faith effort to accommodate those individuals they serve and when they are not able, they fully disclose why they are not. Then, if an individual threatens the institution knowing they have made every effort to accommodate the individual it becomes an issue.

Reasonable Accommodations. One of the guarantees of the ADA is that of employers and service-providers to make reasonable accommodations for individuals with disabilities. Because the scope of services offered by higher education institutions is so broad, instead of defining what is considered a reasonable accommodation, Jarrow (1997) supposes that it may be easier to define what is not and offers three guidelines for what accommodations are not considered reasonable under the assumption that anything else is reasonable. Dr. Jane Jarrow has been a leading authority in the field of disability in higher education for more than 35 years, founding Disability Access Information and Support, serving as the Executive Director of the Association on Higher Education and Disability, and giving countless presentations on college campuses on the issues of support and accommodation for students with disabilities.

Direct Threat to the Health or Safety of Others. While individuals with disabilities can put themselves at risk in the same manner as anyone else, it would be unreasonable to make accommodations for those individuals when others would be presented with a significant risk of harm. Jarrow (1997) makes it a point to establish that the mere existence of a disability is not itself a direct threat to safety. For example, a blind individual could not be prevented from taking a hiking class, even though they may fall and suffer an injury. However, in situations where individuals are responsible for each other's safety through visual means, such as a scuba diving lesson, that same blind individual may be denied participation (Jarrow, 1997). Individuals cannot

be denied entry to college because they have a disability. They do, however, need to be informed of the services and accommodations available so that they can make a decision regarding whether or not they can attend.

Substantial Change in an Essential Element of Curriculum. In higher education, if making an academic accommodation would result in a substantial change of curriculum material, that accommodation would not be considered reasonable. This decision is typically made collaboratively between administrator, student, and service provider (Jarrow, 1997). For a student majoring in communication, the removal of a math course in favor of a public speaking class may be deemed reasonable, as the math course is neither essential nor substantial to the overall degree, while another student studying international relations may be denied substitution of a foreign language class that is deemed both a substantial and essential piece of the curriculum (Jarrow, 1997).

Substantial Alteration in the Manner in Which Services are Provided. An institution is not expected to make an accommodation if that action would substantially alter the way that institution provides its services. These alterations typically focus on either the opportunity of these services or the manner in which they are provided (Jarrow, 1997). For example, a commuter-focused institution that does not offer housing opportunities to any student is not expected to develop housing facilities for students with mobility-based disabilities requesting a place to live close to campus (Jarrow, 1997). To provide another example, consider an academic building that is over 120 years old that has no elevator but is three stories high. For a student who is mobility-challenged, making a substantial alteration, such as building an elevator, is not reasonable. Instead, the university can work with the instructor and student to identify a classroom location that is more accessible, thus avoiding a substantial alteration. Now, if that

same building was going to be renovated, an elevator must be considered to bring the building up to standard for today.

The creation of the ADA has forced educational institutions to evaluate how their operations can better serve students with disabilities and where accommodations can be made. It also requires them to consider these titles as they work to develop and expand their campuses and the way services are offered, including courses.

Individuals with Disabilities Education Act. While the Rehabilitation Act of 1973 and ADA ensured the rights of individuals with disabilities, they did not set specific mandates or guidelines for public elementary and secondary schools on how they educated individuals with disabilities. In 1975, Congress passed the Education for All Handicapped Children Act (EAHCA) which ensured all children with disabilities a free K-12 education in the most accessible environment possible (Huefner, 2000; Kalivoda, 2009). Parts of the EAHCA require that it be reauthorized every four years, providing various changes to the delivery of special education in the United States (Katsiyannis, et. al., 2001). When the EAHCA was amended in 1990, its title was changed to the Individuals with Disabilities in Education Act (IDEA).

Divided into four parts, the IDEA set stricter, more comprehensive guidelines for the K-12 education of children with disabilities (Katsiyannis, et. al., 2001). Part A of the IDEA outlines the law as presented to Congress and offers justification for its creation. In addition, it contains a brief history of students with disabilities in education before the IDEA as well as definitions and terms used throughout the document (Individuals with Disabilities Education Act, 2004). Part B sets funding and educational guidelines that educational institutions must follow, as well as protections to guarantee that parents can be involved in their child's education (Individuals with Disabilities Education Act, 2004). Where Part B applies to children ages 3 to 21, Part C extends

those assurances to children from birth to two years old. Lastly, Part D establishes additional services to enhance the education of children with disabilities (Individuals with Disabilities Education Act, 2004). One of the most vital aspects of the IDEA for children with disabilities is the guarantee of evaluation, resulting in the creation of an Individualized Education Plan (IEP; Individuals with Disabilities Education Act, 2004).

Individualized Education Plans. An IEP is an individualized document created to help ensure that students attending elementary and secondary schools receive the specialized services that they need to succeed (Guide to the Individualized Education Plan, 2019). After a child with a disability is identified, they are evaluated to determine their eligibility for special education. Once the necessary tests have been conducted and eligibility has been established, an IEP meeting is held between the child, the child's parents, and appropriate or designated school staff and teachers (Katsiyannis, et. al., 2001). Together, this group discusses the child's needs to determine what accommodations the school will provide and what goals the IEP team should be helping the child achieve. Per the IDEA, school districts provide a range of classroom settings to ensure that students can be educated in the least restrictive environment (LRE; Katsiyannis, et. al., 2001). While for students without disabilities, specifically without learning disabilities, nearly any classroom could constitute an LRE, this is not always true for students with disabilities. Schools provide alternative options like specialized classrooms and resource rooms to fit the needs of their students, and it is the IEP team that makes the decision on the student's placement (Katsiyannis, et. al., 2001). An essential aspect of the IEP is that the group that created it is required to meet at least once a year to review the plan and assess its effectiveness in helping the child succeed. In addition, the child is reevaluated every three years to track the

change in the level of support that the child needs (Individuals with Disabilities Education Act, 2004; Kurth & Mastergeorge, 2010).

While the IDEA has played an important role in ensuring the education of students with disabilities through secondary institutions, the tools that it provides are not required once the student enters higher education, as colleges are not obligated to identify students with disabilities (Civil Rights, 2020). Though they are required to make information regarding disability support services known to students, it is up to the student to reach out to these services to disclose their disability and attain the accommodations they need. This process can be particularly difficult for students whose disabilities may affect their interpersonal and self-advocacy skills, traits that are common among individuals with autism spectrum disorders.

Disability Support in Higher Education

Disclosing one's disability is a vital first step for receiving the accommodations and supports necessary for success and students may weigh many varied factors in the decision (Rocco, 2001). Disclosure is important for students with ASD in higher education because if this action does not happen, there is no way for their institution to know they need assistance, making it very unlikely that they will receive the help they need. However, as several research studies have identified, many students diagnosed with ASD may be hesitant to make that disclosure (Adreon & Durocher, 2007; Anderson, et. al., 2018; Shattuck, 2014). When it occurs, this reluctance stems from several reasons, such as a belief that the support gained from disclosure was not necessary, that students are unsure how to make that disclosure, or from fear of being stigmatized because of their diagnosis (Anderson et al., 2018; Anderson et al., 2019).

Historically, autism and other developmental disorders have been stigmatized due to the perceived differences between traditionally developing individuals and those with conditions

such as ASD (Grinker, 2020; Murphy, 1987). Recently there have been increasing efforts to combat these stigmas on a broader scale. One of the most notable examples was the inclusion of a character with autism on *Sesame Street*, introduced to serve as an advocate for children with ASD and their families.

Jaswal and Akhtar (2019), in a review of literature, challenged the assumptions made about students with ASD regarding social behaviors. They found that researchers are more likely to assume that study participants with ASD are socially uninterested than participants without ASD who exhibit the same behaviors. These assumptions are not only inherently problematic but could have negative long-term effects when they are made with students with ASD, and this speaks to the way higher education professionals may also treat this population. Heasman and Gillespie (2019) worked with a group of adults to study the ways individuals with ASD create shared senses of understanding. The researchers watched the participants while playing video games together and found a higher potential for unconventional forms of communication and social relating among individuals with ASD. In a study by Sasson and Morrison (2019) on the first impressions that adults with ASD make on adults without ASD found that interpersonal perceptions of those with ASD improved when their diagnoses are disclosed. This means that when they disclosed their ASD, the relationships they formed were better than if they had not disclosed the diagnosis.

Making assumptions about the behaviors of students with ASD in higher education can be detrimental to their development. Because these students may create meaning and understanding differently than other student populations, it is important to understand their development. Since it is becoming more common to see students with ASD in higher education,

it is likewise becoming more understood, less stigmatized, and increasingly accommodated for (Grinker, 2020).

Disability Support Programs. Higher education institutions are often driving forces for the dissemination of knowledge, cultural advancement, and social change. Though students with disabilities are seen as vital to the pursuit of these agendas, if not given the necessary support, they may end up left behind (Strauss & Sales, 2010). Taking this into consideration, student disability services offices typically create specific accommodations and programs dedicated to the success of their students with disabilities. These offices may collaborate with other campus professionals, such as those in residence life, student life, admissions, TRIO, and more to promote accessibility (Evans, et. al., 2017). By working collaboratively with other groups, disability services offices are able to make accommodations to support students with disabilities that might not be available otherwise. Many institutions across the United States have begun to implement specialized programs for individuals with different disabilities (dyslexia, ADD/ADHD, hearing impairment, autism, and so on). For example, the office for Accessible Campus Community & Equitable Student Support (ACCESS) at Southern Illinois University Edwardsville, in partnership with academic advising and the Student Success Center, has developed the Bridging Universal Inclusion & Leadership Development (BUILD) program. BUILD works to bridge the gap between high school and college for students with disabilities through mentorship and professional and personal development. As the population of students in higher education with disabilities grows, the need for specialized support programs grows with them.

Autism Spectrum Disorder

Like many developmental disorders, autism exists on a spectrum and affects everyone who identifies on that spectrum in diverse ways, although it primarily affects people's tolerance, control, and connections (Harrison, 1998). While this disorder has in the past been referred to by different names, such as autism disorder, Asperger's disorder, and pervasive developmental disorder, the most recent Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) combines them under the term autism spectrum disorder (ASD), which will be used throughout this paper when discussing the condition in a modern setting. This section will discuss ASD and its history, how students in higher education are affected by ASD, and how these students are supported.

History of Autism Spectrum Disorder

Because autism spectrum disorders are neurological, it can be assumed that they have always existed, even before we had a name for them. While cases dating as early as the 1720s describe behaviors we would now attribute to ASD, "autism" as a term was first used in 1911 by Dr. Eugen Bleuler, who defined it as a type of schizophrenia (Feinstein, 2011). Bleuler's definition of autism, however, is almost entirely different to how the modern disorder is classified. Until the late 20th century, the leading theories regarding autism were that it was psychogenic, caused by environmental, psychological, or emotional factors. Parenting was largely thought to be to blame for the development of autism until researchers in the 1960s began to establish the condition as being biological (Cook & Willmerdinger, 2015). Even though this mode of thinking has been the generally accepted standard since its discovery, there has still been controversy regarding the development of ASD. Perhaps the most notable example was an article published by The Lancet in 1998 which indicated that the measles, mumps, and rubella

(MMR) vaccine was a cause of autism in children (Wakefield et al., 1998). It has since been shown, however, that not only does the MMR vaccine not cause autism, no other vaccines have been verifiably linked to autism (Thimerosal in vaccines, 2014).

Recently, rates of ASD have been climbing, from 1 in 150 in 2007, to 1 in 110 in 2009 (Baio, 2012), to the most recent estimate of 1 in 68 in 2014 (Sarrett, 2018). The most probable explanation for this increase is offered by the CDC, who attribute the rise to improvements in screening and diagnostic efforts, as well as an increased public awareness (Pinder-Amaker, 2014), as opposed to an actual increase of ASD. Since the late 1990s, there has been a rise in the use of the term neurodiversity to push back against the stigmas and negative connotations that come with terms like disability (Armstrong, 2012). Many neurodivergent individuals are pushing for a narrative that does not include the existence of neurotypical brain function, instead supporting the idea that everyone exists somewhere on a spectrum of cognitive abilities. This development has helped to change the way people with ASD are perceived and therefore has allowed them to enter and excel in more endeavors than ever before.

Autism Spectrum Disorder in the College Setting

The number of students entering higher education institutions with a diagnosis of an autism spectrum disorder has seen a dramatic rise around the world (Bakker et al., 2019; Randall et al., 2016). Because of this, it is of ever-increasing importance to understand how these students are affected by ASD in the higher education environment.

While it could be said that ASD creates difficulties for students in higher education, it also offers certain strengths to students. Through a systematic literature review of research on higher education students with ASD, Anderson and colleagues (2019) found that these students possess excellent attention to detail and a passion for their field of study. In addition, students

with ASD tend to be able to more accurately and efficiently identify and remember small details within larger, more complex patterns (Gaus, 2011), a useful skill for the analysis and critical thinking required in higher level college classes. Despite this, research has shown that students with ASD are typically required to exert an added level of effort compared to students without ASD to reach similar levels of success (MacLeod, et. al., 2018). They conducted interviews with sixteen college students with ASD and found common themes in their responses. One of the most common responses was that the students possessed an “I’ll show you” mentality. This way of thinking can stem from many situations, but the most-cited reason among participants was being written off by educators who expected them to fail (MacLeod, et. al., 2018) This subconscious barrier can represent an unintended hurdle for students with ASD to overcome that their classmates may not ever be faced with. While there may be stigmas associated with ASD and a tendency to expect that these students may inherently struggle, that is not the case.

In conjunction with the shift towards neurodiverse modes of thinking, the drive to recognize and develop these students’ strengths pushes students with ASD and other members of the higher education community to create more positive environments that are accepting of ASD. Beyond academic and detail-oriented strengths, children and students with ASD, and other disorders, have been found to exhibit enhanced creative tendencies and musical abilities (Armstrong, 2012; Levitin et al., 2004). To allow these students to effectively practice these strengths, inclusive learning environments should be, and are being, constructed across all levels of education (Denning, 2013). These safe spaces allow students to showcase and build their strengths; even the creation of said spaces is an opportunity to showcase strength, as students with cognitive disabilities have shown increased entrepreneurial and innovation-driven skills (Armstrong, 2012).

Despite the strengths possessed by these students, some of the aspects of ASD can pose significant challenges, both in and out of the classroom, and as a result, students with ASD are more likely to struggle with the transition into a higher education institution than students without ASD (Jansen et al., 2017; Sefotho & Onyishi, 2021). Jansen et al. (2017) recruited 43 students with ASD, 43 typically developing students, and 30 student counselors, who were experienced in advising students with ASD. Each participant was given a questionnaire to assess the issues that they face in higher education, or in the case of the student counselors, what issues faced students with ASD. The students with ASD typically reported having problems more frequently across the board than students without ASD, which was supported by the responses from student counselors. The most prevalent issues for these students were problems with verbal and non-verbal communication, oversensitivity to change, and problems distinguishing details. These problems can be mitigated, however, through the incorporation of reasonable accommodations into higher education settings. Sefotho and Onyishi (2021) interviewed 10 first-year college students with ASD to identify the specific struggles that students with ASD face when transitioning into higher education. They found that students with ASD report feeling significant challenges in the changes from high school to higher education, namely academics, structural differences, mental health, and a more prevalent lack of resources, they also felt that their classmates without ASD typically do not struggle as much as they do.

Several studies have identified challenges for students with ASD that generally fall under the categories of academic achievement, social interaction, and mental health (Adreon & Durocher, 2007; Cai & Richdale, 2016; Carrington et al., 2003; Hughes et al., 2018; Sefotho & Onyishi, 2021). Adreon and Durocher (2007), in a paper outlining ASD and examining the transitional needs of students with ASD in higher education found that both social interaction

and academic achievement were challenges that had an influence on student success. They also took time to point out that stress, depression, and other mental health factors impact student success. Cai and Richdale (2016) conducted focus groups with 23 higher education students with ASD and their family members and found social interaction to be a significant barrier to student success. In addition, they also supported the importance of academic supports for students with ASD.

Carrington et al. (2003) sought to understand the meanings that students with ASD create from their experiences, emphasizing personal reflection on friendship. Through interviewing students with ASD, they explored specifically the role that social interaction plays in their success. They found that in social settings, students with ASD may tend to *masquerade*, or mask the behaviors they feel makes them different from others (Carrington, et al. 2003). When these students develop close friendships, including those with and without ASD, they are less likely to alter their behaviors to fit social norms. Carrington, et al., found that because they are less focused on *masquerading*, socially connected students with ASD are able to focus their energy in other areas, such as academics or mental health. As discussed above, Sefotho and Onyishi (2021) interviewed higher education students with ASD about the transition into higher education. They identified that not only do students struggle with academic achievement, social interaction, and mental health, these three areas can significantly hinder student success. If we want students to succeed in these areas, we need to ensure they are being supported in the ways they need. Without proper support, students with ASD can be subjected to increased levels of stress, anxiety, and relational difficulties, which is a compounding issue, since ASD already contributes to these issues, as discussed above.

Academic Achievement. Various skills commonly cited as being beneficial tools for success in the classroom are inhibited in some way for students with ASD. Many students with ASD may experience difficulties with organization-related tasks, stemming from inhibited executive function abilities. Azano and Tuckwiller (2011), in a peer-reviewed journal article, found that some of the most common functions that students with ASD struggle with are goal setting, planning, and self-initiating. These struggles can make it hard to stay on track with coursework and ensure that homework is completed on time. Students with ASD may also lack effective self-regulatory skills, as Hill (2004) found in a literature review on the topic of executive dysfunction and how it manifests in individuals with ASD. Specifically, she identifies a difficulty with mental flexibility and being able to adapt thought processes to changing situations. In the higher education setting they could encounter unique obstacles, such as sticking to a class schedule, maintaining a daily routine, and finding a useful work-life balance. In a study conducted with 120 students with ASD by Ehlers et al. (1997), it was found that these students can struggle with understanding and communicating abstract ideas, which can lead to struggles with in-class discussions, high-level writing, and inference-based activities.

Another aspect of ASD that can affect a student's academic achievement is an increase in sensory sensitivity. Certain stimuli, such as noise, lights, and imagery, can be very distracting to students with ASD as shown by Cai and Richdale (2016), who surveyed 23 students with ASD on their needs in higher education. This can be a compounding problem, as Crozier and Tincani (2005) showed in their intense narrative study on a student with ASD. They found that certain coping mechanisms, like staring at a table or doodling, could be interpreted by professors as not paying attention to the class. In an online survey conducted by Anderson and colleagues (2020), to determine the academic support satisfaction of higher education students with ASD, it was

found that nearly half of their respondents cited academic requirements to be their biggest concern.

Social Interaction. Struggles in social interactions are viewed as another characteristic of ASD (American Psychiatric Association, 2013). In a study on social challenges and supports, Müller and colleagues (2008) interviewed 18 adults with ASD and found that while they often desire and seek out meaningful interpersonal relationships, they may lack the social skills needed to build those relationships. These individuals may also not notice subtle, nonverbal, cues like gestures and body language, as Adreon and Durocher (2007) showed in their works on the transition needs of students with ASD. What they identified was that not being able to pick up on these things put them at an elevated risk of being misunderstood by their peers and perceived to be disrespectful or uninterested, furthering their social struggles.

Entering a new level of education, such as secondary or postsecondary, is an important time in the development of all students, but especially students with ASD. These individuals have an increased need for social support from peers, so their interaction with other students is vital, as Carrington et al. (2003) found through their interviews with students with ASD. At the same time, however, it is just as important to receive the right types of interaction, because for students with ASD, many social situations and activities can become a source of stress, where they might not for students without ASD. Glennon (2001), in a paper analyzing the lived college experience of students with ASD, found that social relationships and activities can be some of the biggest stressors of the higher education environment. Much of college is built around social interaction which could impact the students with ASD experience.

Mental Health. Mental health is an incredibly important aspect of life for all students, but especially for those on the autism spectrum. ASD can severely affect students' academic and

social skills, both of which have been shown to be factors related to student mental health (Hughes et al., 2018). In a study conducted by Hedley et al. (2018), 185 individuals with ASD were surveyed and were shown to be at increased risk of loneliness, suicidal ideation and behavior, depression, anxiety, and stress. Jackson et al. (2018) supports these findings, with their study that surveyed 56 adults with ASD. They found that over half of participants had, in addition to ASD, some other psychiatric diagnosis. These diagnoses included depression, generalized anxiety disorder, and obsessive-compulsive disorder. In turn, these diagnoses can have a negative effect on academic and social performance, which then affects mental health, leading to downward loop that can leave students feeling helpless.

This loop can be reversed, however. Even beyond social acceptance, personal acceptance is just as important. Chamberlain and Haaga (2001) examined the self-acceptance of 107 adults and found that unconditional self-acceptance was inversely related to levels of anxiety and narcissism. They also found that individuals with more self-acceptance maintained better moods when exposed to upsetting scenarios. Flett et al. (2003) utilized the same questionnaire as Chamberlain and Haaga (2001) with 94 students. They found that increased self-acceptance is conducive to student success. Their findings also show that accepting oneself helps to decrease the effects of depression and anxiety, which can lead to more positive social and academic outcomes.

Studies have examined the relationship between identification with ASD and self-esteem. What has been found is that people who identify as having an ASD generally view autism in a more positive, accepting way, boosting their own self-esteem (McCauley et al., 2019). Kapp et al. (2013) investigated the perceptions of ASD in groups with varying relations to ASD. They found that individuals with ASD and those who identified in support of individuals with ASD

typically viewed ASD as a positive identity that should be embraced. This, coupled with decreasing stigmatization, can lead to environments that are more tolerant and encouraging to the success of those with ASD. Cooper et al. (2017) analyzed mental health in individuals with ASD and found not only that their identification of autism to others boosts their self-esteem, but it also helped alleviate symptoms of anxiety and depression. In turn, this increase in self-esteem can have a positive effect on individuals' social interactions, as feeling more comfortable in yourself make it easier to talk and relate to others, which Jonsson (2006) confirmed in a study of 48 students. Jonsson found that individuals with high self-esteem may feel more emotional return from social interactions, in addition to being able to relate to others.

Special Programs for Students with ASD

Transition and support programs in higher education typically fall under some variation of the students with autism spectrum disorders transitional education program moniker. Each institution that hosts one of these programs will have their own name for it, so this study will refer to all such programs as autism support programs. These are typically selective programs which students apply for and commonly pay additional fees to participate in. These programs are geared towards students with ASD and aid in the transition into higher education through an array of supports, depending on the institution. Some programs incorporate tiers of support, with tier one beginning in high school to educate students on what they can expect in the university setting and tier two beginning on their arrival to the institution (White et al., 2017). In a study by Wei et al. (2016) of almost 700 students with ASD who were starting the transition process from high school to higher education, it was found that involvement in an autism support program not only increased the odds of retention in higher education, but also increased academic and social success.

One key feature of almost all autism support programs is an emphasis on self-determination (SD), the ability to set and realize one's own goals. This skill has been shown to positively affect school performance, which is explained by Getzel (2014) in a report on the effects of self-determination in higher education. She also pointed out that increasing engagement in students can help to establish a feeling of self-determination. To aid in the development of SD, higher education autism support programs work to establish self-advocacy and goal-setting behaviors. Autism support programs utilize strategies to ensure the success of students with ASD, most notably mentoring. Mentoring can be an effective way to develop academically, professionally, and personally, as well as to learn about various occupational opportunities and to be able to make more informed decisions (Law, 2020). Daughtry et al. (2009), a team which includes Jennifer Gibson, the author of a disability identity model used in the theoretical framework of this research to explore this idea on mentoring individuals with disabilities. They add that youth with disabilities who receive mentorship are less likely to use drugs or alcohol, have better attitudes toward school, and are more likely to have improved relationships and social skills (Daughtry, et al., 2009).

Theoretical Framework

This study builds on the work of two theoretical foundations: Gibson's (2006) disability identity model and Schlossberg's (1984) transition theory. Gibson's model is utilized to understand where individuals may be in identifying their ASD and how that impacts their ability to ask for help and utilize resources as well as their comfort level with disclosing their diagnosis of ASD. Schlossberg's theory is used in this research to look at the transition from high school to higher education from various perspectives. They are further explored below.

Disability Identity Model

This theory has previously been used in the context of ASD identity development by Gobbo & Shmulsky (2016), who examined the impact of ASD acceptance on each stage of development. In addition, Cohen (2019) utilized this theory to determine the levels of student disability identity development in a study on disability support programs. Both themes will be explored in this study.

To understand what may be impacting the experiences of students with ASD in college, it is important to first understand how they may come to see themselves. Gibson's (2006) three-stage disability identity model is like other models of disability identity development (Davidson & Henderson, 2010; Johnstone, 2004; Mahler, 1968; Stern, 1985) and focuses on the progression of students with disabilities and how they build an understanding of their identity with respect to their, and others', disabilities (Gibson, 2006). Gibson's model, however, goes further than older theories by including stages related to self-acceptance, while not complicating the process to the extent of other models developed around the same time. For the purposes of this study, Gibson's model strikes the desired balance between in-depth analysis and thoughtful succinctness.

Passive Awareness. In stage one, *passive awareness*, where while the medical needs of the individual are being met, they lack a solid role model and learn to avoid drawing attention to their disability and interacting with other individuals with disabilities (Gibson, 2006). In college students with ASD, this may show up in them not sharing their diagnosis with others, not providing information to the disability resource person or instructors. Most students coming to college will likely be aware of their diagnosis but still may work to not draw attention to themselves or their ASD.

Realization. Stage two is *realization*, in which individuals begin to incorporate their disability into their identity, possibly resulting in anger or self-consciousness (Gibson, 2006). In college students with ASD this may present as denial or frustration in having to share. It may mean that they begin to see their difference from peers. And, although they are in a place where they are acknowledging this identity they may not share with others for fear of judgement or special treatment.

Acceptance. The last stage of Gibson's theory is *acceptance*, with individuals shifting their perspective of their disability, viewing themselves in a positive light, involving others into their lives, and potentially becoming advocates for disability activism (Gibson, 2006). These are the college students who readily share about their disability and acknowledge it to those around them. They are more likely to seek out support and mentorship and engage in helping others like them. Students with disabilities in higher education can be prone to regression through the stages due to many factors, including learning the procedures of school policy and social interactions, as well as learning the physical layout of campus and individual buildings (Patton et. al., 2016), thus potentially affecting their satisfaction with the support systems offered by the institution.

Transition Theory

Schlossberg (2008) stated that transition can be a major life disturbance which, even when the overall outcome is positive, requires conscious adaptation. Due to the changing roles and identities that accompany transition, individuals in transition can often feel like they do not matter (Schlossberg, 1989). The goal of Schlossberg's (1984) theory was to create a framework through which to understand and assist individuals in transition and help them "uncover new options and take that next step in search of growth and change" (p. viii). Schlossberg (2008)

theorized that those experiencing transition could manage the adjustments by analyzing certain aspects of transition, which she called the *four S's*: Situation, Support, Self, and Strategies.

Situation. Understanding the situation in which a transition occurs is the first step in assisting students in transition. Schlossberg (2008) discussed three types of transition that students face: anticipated, unanticipated, or nonevent. *Anticipated* events are those that are known about beforehand, that students could logically prepare for. For example, being accepted into college and moving into a residence hall is something that is typically expected, thus an *anticipated* event. *Unanticipated* events are those that could not have been expected or planned for beforehand, such as moving in with a roommate that one is incompatible with and finds themselves moving weeks into the new semester.

While it may be easier to prepare for anticipated events, and even unanticipated events; sometimes one prepares for an event that does not happen. Schlossberg (2008) referred to these as *nonevents*. *Nonevents* are those situations that have not come to pass. For example, a student may expect that disclosing their ASD will result in a reaction and when nothing happens it is a *nonevent*. This could occur in disclosing to instructors, peers, and even disability services.

There are some other considerations that Schlossberg (2008) identifies in understanding the situation. These include the previous experience, trigger, timing, control, concurrent stress, role change, duration, and assessment of the situation (Schlossberg, 2008). If the individual has had a previous experience with this type of transition it may make it more manageable. For students with ASD, they have likely spent most of their time in school informing teachers, friends, and family members about their diagnosis so this may not be of issue to them. However, some students may come to college not wanting to disclose and then they are triggered in class and find themselves needing support and having to find those services. If a student with ASD is

in control, it may make their transition easier, while if there are other stressors impacting their situation, it may make it more difficult. For instance, being at college is a situation where there are many concurrent stressors, with worrying about class schedules, financial aid, extracurricular activities, etc., but a student with ASD may be able to make their transition easier with a sense of security by controlling the disclosure of their diagnosis. It is also important to consider the role change and duration of the transition. For students with ASD, their role is changing from being given government-mandated support to being required to seek out assistance and the short duration of the transition can have a significant impact on how students navigate it.

Support. Support is about gaining assistance through the transition and analyzing the support they need and receive. Though everyone experiences the stress of transition differently, a solid support system can assist students through the process (Schlossberg, 2008). Disability support offices are one way of providing intentional support to students with disabilities. Higher education institutions may design specific programs that target certain populations, like an autism support program, with intentional, built-in support mechanisms.

The stage of life an individual is in during transition may also impact the supports they need. Specific programs are typically developed to help with the first year or two of college, when students are in most need of support and structure. Barclay (2017) identified that children may be most reliant on support from family members, and by the time they are entering higher education their needs will have shifted to relying on their peers and others in their college community. Developing programs that build support from multiple facets can be quite helpful.

Self. Anderson et al. (2012), working with Schlossberg to expand on the original theoretical work, stated that understanding oneself and one's experience is the way individuals make sense and meaning in the world. Assisting students in transition must involve reflection on

the part of the student to assess their beliefs, abilities, and perceptions of the world. Anderson, Schlossberg, and Goodman proposed two paths to assessing oneself: understanding personal characteristics and psychological resources. The intersection of one's identities and personal attributes has an incredible impact on the way the world is perceived. For example, in the higher education setting, a student with ASD who struggled to get into college may view their attendance as more of a luxury, and place more value in the experience, than a student without ASD for whom attending college is a more typical occurrence. Barclay (2017) identified that understanding oneself includes awareness of the psychological resources an individual possesses for navigating transition, including maturity, life outlook, and level of commitment to the transition. For example, if a student naturally possesses a negative outlook on the college experience, they may be less likely to cope with the transition to higher education. Anderson, et al., identified that understanding self will assist them in understanding their mindset and in turn help them understand their place in the transition. If, for example, the student with ASD has been prepared for the transition and know what their strengths and limitations are, they may move through the transition with greater confidence.

Strategies. The fourth S in analyzing transition is strategies, or to what degree individuals are able to navigate transition (Schlossberg, 2008). To assist a student, they must be aware of how they approach transition. There are four strategies students can use to work through transition: modifying the situation, controlling the situation before stress occurs, controlling the situation after stress occurs, and deliberate inaction (Schlossberg, 2008). Modifying the situation attempts to address the source of stress in the transition and can include seeking advice, taking actions to positively impact the situation, and negotiating for a more favorable outcome (Anderson et al., 2012). Controlling the situation before stress occurs can also

mean controlling the meaning behind the stress. This can involve making positive comparisons or connecting the stress to a more positive memory of a time when the source of stress was overcome. In addition, selectively ignoring aspects of the stress that cannot be impacted can help to diminish the overall difficulty of the transition (Anderson et al., 2012). Controlling the situation after stress occurs deals with managing stress, and not being overwhelmed by it. This can be accomplished by discharging emotions, whether by participating in a hobby, leisure activity, or even yelling. Also, engaging in discussion or debate is an effective way to manage the stress that can occur during a transition (Anderson et al., 2012). Lastly, individuals may take deliberate inaction, or intentionally make no efforts to address a change or source of stress. Schlossberg (2008) would suggest that engaging in inaction prevents large amounts of personal growth that could occur from transition.

As an example of varying strategies, in attempting to find classroom locations, some first-year students may explore campus the week before school starts (controlling the situation before stress occurs), while returning students could preemptively choose their classes based on where they are on campus (modifying the situation). Others still may work with their advisor after classes start to improve their schedule (controlling the situation after stress occurs) or simply put up with a schedule that does not work for them (deliberate inaction). Because unlike high school the student may have to move from building to building, preparing them for identification of buildings and classrooms is helping to control the situation before it becomes a source of stress. It is unlikely to have classes back-to-back like a student may have had it high school, providing for what is seen as free time between classes. Programs designed to support ASD will help the student structure their day so they can modify what happens and help them

manage stress before it occurs. Identifying opportunities to help students create schedules and manage how they move through their day can be an important strategy.

Considering the first three S's is important, but even two otherwise identical students may adopt differing strategies to cope with the same transition. Though the experiences of college students are constantly changing, one of the biggest strengths of Schlossberg's (1984) transition theory is its general nature and its applicability across higher education. Wherever there is a transition, this theory can be utilized to both understand and support the students experiencing it.

Summary

There are more students with ASD enrolling in higher education institutions than ever before, nearly 1 in 68, (Sarrett, 2018), which means it is important to ensure that the effort is being made to provide the proper supports that will allow this population to succeed. ASD can present students with significant challenges in their attainment of academic and social success, as well as with the development of their mental health, but it can also afford them with meaningful strengths. Students with ASD self-identify focus on schoolwork and passion in study areas as key strengths in the higher education experience. Federal legislature requires that before reaching higher education, students be provided an IEP to ensure an equal access to proper education. In higher education, however, that same requirement no longer applies, and it is up to the student to choose whether to disclose their disability diagnosis. In addition, it is also their choice as to which university disability services they utilize. Therefore, it is of the utmost importance to analyze the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them.

CHAPTER III

Methods

This study was conducted to examine the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them. This chapter begins with a description of the methods that were used in the study, including the study's design, participants and sampling, research site, instrumentation, data collection, and treatment of data.

Design of Study

This study employed a general qualitative approach to understand the experiences of students with ASD transitioning into higher education through their own voice. A qualitative approach to this research was appropriate, as this research focused on the complex personal experiences of individuals in a particular situation (Creswell, 2017). This research was accomplished using semi-structured, one-on-one interviews. Participants were asked demographic questions in addition to open-ended questions pertaining to their experiences in higher education.

Research Site

This study was conducted at a midsized four-year state university in the rural Midwest in a community of about 17,000 residents. As of spring 2022, total full-time undergraduate enrollment was 3,496, with 61.2% ($n = 2,139$) being male and 38.8% ($n = 1,357$) being female (University A, 2022). This institution was chosen because it hosts one of the few autism support programs in the Midwest, and therefore ideally has more prevalent community of students with ASD, in addition to being the most convenient institution to access in the region. This institution's autism support program admits a capped number of students with ASD each year

and provides supports beyond the reasonable accommodations made by the institution, such as program-specific housing and one-on-one mentoring. The program pairs its students with peer mentors to improve the executive functioning skills that help to ensure social, academic, and personal success. Interviews were conducted face-to-face in a private, enclosed office in order to encourage the sharing of personal information.

Participants

The participants of this study were six students with a diagnosis of ASD at a 4-year public higher education institution in the rural Midwest. An email (Appendix A) was sent to the Director of Student Disability Services to be sent out to all students who have disclosed their ASD. A brief demographic form (Appendix B) to determine eligibility and solicit additional information was attached to that email. Students participating in the residential ASD program were considered for selection if they met the qualifications. To have been considered, participants must have been diagnosed with an ASD prior to enrollment in higher education and must have completed at least one year at a college or university.

Below are descriptions of the participants and in Table 1 is information about the participants.

Table 1

Participant Information

Participant	Year in College	Member of Autism Support Program	Attended Other Institution Previously	Registered with Disability Services
Gordon	Senior		Yes	Yes
Henry	Senior	Yes		Yes
Edward	Graduate Student		Yes	
Mavis	Sophomore			Yes
Toby	Senior		Yes	Yes
Percy	Sophomore	Yes		Yes

Participant 1

Gordon is a male senior undergraduate student at a four-year institution. After graduating high school, he was enrolled at a community college for three years before transferring to his current institution, where he is currently in his second year. He was diagnosed with an ASD when he was four years old. He is not enrolled in his institution's autism support program but has disclosed his diagnosis to the Disability Services office.

Participant 2

Henry is a male senior undergraduate student who enrolled at a four-year institution in the fall after graduating from high school. He was diagnosed with an ASD before high school. He is currently enrolled in his eighth semester of his institution's autism support program, though he no longer lives on-campus. He has disclosed his diagnosis to his institution's Disability Services office.

Participant 3

Edward is a male graduate student. He attended two private four-year institutions to complete his undergraduate degree before attending his current public four-year institution to pursue his master's degree. He was not enrolled in an autism support program nor disclosed his diagnosis to the Disability Services Office at any of the institutions he attended.

Participant 4

Mavis is a female sophomore undergraduate student who enrolled at a four-year institution in the fall after graduating from high school. She was diagnosed with an ASD when she was 19 years old, during her senior year of high school. She is not currently enrolled in her institution's autism support program but has disclosed her diagnosis to the Disability Services office.

Participant 5

Toby is a male senior undergraduate student at a four-year institution. After graduating high school, he was enrolled at a community college for three years. After completing his associate degree, he took a gap year before enrolling at his current institution. He was diagnosed with an ASD when he was a child. He is not enrolled in his institution's autism support program but has disclosed his diagnosis to the Disability Services office, though he has not utilized any official accommodations.

Participant 6

Percy is a male sophomore undergraduate student who enrolled at a four-year institution in the fall after graduating from high school. He was diagnosed with an ASD when he was three years old. He is currently enrolled in his third semester of his institution's autism support program and has disclosed his diagnosis to the Disability Services office.

Instrument

There were several instruments used in this research. The first was the informed consent document that was shared with and explained to the participants. As participants agreed to be a part of the research, they were asked to complete a brief demographic survey (Appendix B) prior to the interview. This document was used to determine the qualifications of the participants and determine if they were the right candidate for this study. It asked questions like year in school, age of ASD diagnosis, hometown, etc.

An interview protocol (see Appendix C) was developed as a guideline for the semi-structured, one-on-one interviews. The questions were created to explore the transition experiences that students with ASD have into higher education institutions. The protocol was designed to begin with questions that help to build a connection with the participants where

foundations of trust can be started. Then, as the interview progressed, more personal questions were asked to gain insight into the participant experience. A set of primary questions was developed to ask more broad and engaging questions and then a second set of questions was provided under those to help guide the conversations with each participant in similar directions. This was done to intentionally make sure the researcher gets similar information from each participant.

Researcher's Reflexivity

The researcher is a vital aspect of the research process, for without them, the research does not happen. This being the case, it is equally vital to the process for the researcher to leave out their biases to build as accurate a body of knowledge as possible. Berger (2015) noted three effects that a researcher's personal demographics, such as gender, sexuality, age, race, and ethnicity, can have on their research. The first and second effects state that if the respondent is different in one or more of these aspects from the researcher, they may be less likely to freely share their experiences, whereas they may be more likely to share with a researcher who shares one or more of their identities (De Tona, 2006, as cited in Berger, 2015). Third, because each researcher possesses a different worldview with varying experiences, the lens through which they choose to view and how they construct their understanding of the world could therefore also affect the conclusions they draw from their research (Kacem and Chaitlin, 2006, as cited in Berger, 2015).

I conducted this research through the lens of being a White, cisgendered male without a diagnosed disability. Because I had a different life experience, I naturally possess a different worldview to those I studied. This disparity could potentially cause my participants to feel more hesitant to share their experiences with me. I attempted to minimize this limitation by

acknowledging my differences, establishing rapport, and allowing my participants to guide the research through our conversations.

I chose to study autism in higher education due to the interactions I had with members of this population while working in residence halls. Due to this being an at-risk population, I always felt the need to understand the aspects of higher education that benefit these students, what holds them back, and how their experiences can be improved. I recognized that I possess experiences that are different to those that I researched. The main identity difference that was universal between myself and my research participants was that I have never been diagnosed with an autism spectrum disorder. Beyond this, the differences varied from participant to participant. To determine the effect these differences will have on the researcher-researched relationship, I will look back to those identified in the previous paragraph. Because I have had a different life experience, I naturally possess a different worldview to those I wish to study. This disparity could potentially cause my participants to feel more hesitant to share their experiences with me. One way I mitigated my inherent bias involved in this study was to let my participants guide the interactions that I had with them while gathering data. In this way, by listening to my participants and gathering their perspectives, I was able to remove my worldview from the research and present a well-rounded final product.

Data Collection

Semi-structured one-on-one interviews were utilized for data collection in the fall of 2022. Interviews lasted approximately 60-90 minutes, audio-recorded for documentation with participant permission, and were conducted in a quiet, private location. Each of the interviews consisted of open-ended questions, allowing participants to fully explore their answers. At the time of the interview, I collected the participants' informed consent forms, providing them with a

new copy if they no longer had one. I also allowed time before the interview for participants to ask questions and ensure they fully understand what was going to happen during the interview. Each participant was assigned a number that was used in all tracking of information and materials related to that participant. As interviews were transcribed and research was written, the number was changed to a name that protected the identity of the participant. Additionally, all other identifiable names (i.e., buildings, instructors) were changed to help maintain anonymity.

Data Analysis

The recorded interviews were transcribed and imported into Microsoft Word to begin analysis after the interview. Each interview was examined through the lens of the theoretical framework and research questions looking for common themes in participant responses. Common trends and themes were assigned a code or short phrase to condense and group the data (Saldaña, 2013). All names and transcripts were kept confidential.

Treatment of Data

Treatment of the data of this study was conducted in accordance with University A's Institutional Review Board protocols. Interviews were transcribed and evaluated to explore the factors that go into the transition to higher education for students with autism spectrum disorders. Next, that data was organized into themed categories, which were then discussed. Pseudonyms were given to each participant, and to ensure confidentiality. In addition, all identifiable participant information was removed and stored on a password-protected device.

Summary

This study employed a qualitative approach, utilizing semi-structured interviews to examine the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them. This

study provides an opportunity for professionals at higher education institutions to understand the experiences of students with ASD and gain insight into the supports that are needed to ensure the success of this at-risk population.

CHAPTER IV

Analysis

The purpose of this research was to examine the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them. This chapter will analyze findings from the data collected through one-on-one interviews with six higher education students with autism spectrum disorders who have completed at least one full year at an institution of higher education.

Experiences Transitioning from High School to Higher Education

The participants were asked questions regarding their experiences transitioning from high school to higher education. As participants shared personal stories, the themes that were revealed were strongly tied to the situation of their transition, including the unanticipated, anticipated, and nonevents they experienced. In addition, responses were strongly tied to the participants' sense of self and how they viewed themselves in their transition.

Situation

In discussing their transition to higher education, participants spoke about the aspects that made up the situation of their transition. They identified what events they had not anticipated like the rigor in their classes; moving to college is an example of what they had anticipated. The last of the situations can be categorized as what they had expected but did not occur, or nonevents; these are combined with anticipated in this study.

Unanticipated Events. As participants spoke about their transition, they identified what they expected college to be like and the experiences they anticipated, however some of those did not pan out and other things happened to them that they did not anticipate. Themes developed as

participants shared what was unanticipated in their transition to higher education, including academics, social life, and administrative processes.

Academics. When asked about what was unexpected about college when compared to high school, nearly every participant began by discussing academics. Participants found that they were anticipating college to be more difficult than high school but found it to be easier than they had expected. Edward, now a graduate student who attended two different private institutions for his undergraduate degree, offered the perspective that he was the source of his conceptions of college, saying “I thought college was supposed to be hard, but it ended up being easier than high school...I just figured, if you’re going to college, it’s going to be challenging.”

The participants also identified where these perspectives came from as they anticipated what college would be like. They shared that the biggest influence came from the teachers at their high schools. “My teachers over the years made it sound like I was entering a World War or something. They were just like, ‘It’s going to be extremely hard; you’re going to be battling every single day,’” Gordon said. Toby offered “In high school, they made professors sound very mean and very unforgiving of things.” Henry and Percy spoke about hearing high school teachers talk about how much harder college was going to be. After beginning classes, however, participants shared that the academics were easier than they had anticipated. “The minute I started college, it was nothing how they described. My very first semester here was amazing. I got the highest grades I’d ever gotten in school,” Gordon shared. In addition to better grades, Percy, who is a member of the ASD program, appreciated the increased flexibility in the structure of college classes.

It was interesting how chill [professors were] because the consequences are built into the society. So, like, if you’re late to class, you miss the lesson and that’s the punishment. If

you need to get up and do something in the middle of class, you can get up and do that, but then you're missing that information and you have to get it from someone else.

Despite the decreased academic rigor, Edward, the graduate student who completed his undergraduate at private schools before attending his public graduate institution, spoke about how college professors were less likely to be engaging than high school teachers, saying "I don't think I realized how bad professors would be at making stuff interesting. Those professors are very rare."

Social Life. Participants also discussed the aspects of social life they encountered in the transition to higher education. The participants identified this as unanticipated because it played a larger role for most of them than they had expected. Percy, enrolled in the ASD program, spoke about being surprised by the number of things he was finding himself dealing with.

I thought the focus was going to be a lot more on academics. It's definitely more of a social thing. You have to manage your social life, and you have to manage the events you go to. You have to manage when you go eat and stuff like that.

Edward spoke about his transition to his first undergraduate institution and struggling to adapt:

The social dynamic of the school is like, we have to make sure that we get these students involved because otherwise they're just going to shut themselves up in their room and they're never going to talk and that's not good for them. So there was always a lot going on and I think it was really hard to balance that with the academics.

Mavis, who was diagnosed at the end of high school, spoke about sharing a room with someone for the first time, and how her roommate did not have ASD. Mavis also talked about the increased social aspect of college as something she had not anticipated. Mavis shared,

I was definitely not expecting it to be this fun. Like, I love college. I love it more than I did high school, and I've always loved education. I've always loved learning. But I love college more, and I think it's because there's less pressure on it.

Participants identified that they were not anticipating the acceptance and engagement they felt from their peers. Toby, who completed an associate degree at a community college before transferring to the four-year institution shared how he expected difficulties connecting with others and making friends in college, but said he found it easier than in high school because "people no longer really care as much about who you were growing up or what kind of imperfections you have." He stated that as he has gotten older, his classmates have as well, making it easier to interact with and relate to others. Percy identified that connecting with others was different in college, sharing, "it's easier to socialize with people that are like, 'This person's different, but I'm going to appreciate them for what they can bring to the table.'" As a member of the ASD program, Percy spoke about how instead of being forced to adapt, others included him as he was. Percy also went on to highlight the more accepting nature of his college peers, saying "I screwed up really bad and they still say 'Hi' to me whenever I see them, which is unheard of because in high school I would have just been ignored for the rest of the year by those people."

Processes. Another area that proved to be a source of unanticipated events were the day-to-day processes of higher education that participants experienced in their transition. Toby, now a senior, discussed the stress he felt when registering for classes.

Making sure you have everything for your major can be very difficult because you've got advisors that are dealing with hundreds of students, and they're expected to get all of them signed up for the right things all the time and there's a lot of room for human error

in that and I expected it to be a lot easier than it was. Especially as someone who has Asperger's where it's hard for me to organize my thoughts.

Mavis identified she was lacking information about college, especially from a parent or older sibling, and how that can make the process more stressful to navigate.

The structure of class schedules at the college level was also identified as unanticipated by most participants. Percy commented on the variable nature of class schedules, saying "Your schedule changes so much. I have all my classes on Tuesday and Thursday and one class on Mondays, Wednesdays, and Fridays. It changes every day." Mavis described herself as a very scheduled person who likes to know when things are going to happen, so when she, like Percy, found her schedule changing day-to-day, it took a toll on her. "When I had schedule changes, it exhausted me," she said. "So, for the first month, I was just exhausted all the time. I was stressed out...new schedule, I'm stressed." Henry also commented on this area, mentioning being pleased with receiving a syllabus for each class, as being able to plan out assignments for the whole semester was something he had not been expecting.

Anticipated Events and Nonevents. As participants discussed their experiences transitioning into higher education, there were not many events that they had anticipated happening. They primarily were focused on being accepted and doing well in college. Gordon, who attended a community college after high school, talked about being prepared for the transition to a four-year institution, saying "I knew what I wanted to achieve, the opportunities I wanted to take. I already had it all planned out by the time I got here." Mavis spoke about anticipating having a good relationship with the students in her residence hall. "I had so many friends on my floor. We had floor parties, we called them hallway parties and we'd sit in the hallways, and we would talk to each other until like three in the morning," she said.

As they talked about what they thought college would be they described what that experience would be like. Henry, a member of his institution's autism support program, anticipated setting a high standard for himself as he entered college, wanting to make a good impression on his professors. Percy worried he would do or say something for which he would get a bad reputation from his peers, but "to my knowledge, that didn't happen," he said. Mavis expected to have interpersonal issues, most of all with her roommate.

I did not warn her before I moved in that I was on the spectrum. I walked in and I looked at her and I said, 'By the way, I'm on the spectrum'. And so I thought we were going to butt heads a lot more than we did.

Edward commented on the role he expected college to play in his career development:

I really thought the point of high school was to prepare you for college. And I thought that college was like, now we're going to help you figure out what your career is going to be...And that really didn't happen. I realize now that I could have figured that out, but I thought that was just going to be part of the process, that the faculty and staff are going to really guide you.

Self

Understanding how the participants saw themselves was also important. The participants were asked questions about themselves and identified the aspects of their identity that impacted their experiences. While discussing their transition from high school to higher education, participants discussed their identity and the influencer of that while transitioning. From these responses, four themes emerged: academic identity, family, connections, and sense of self.

Academic identity. Becoming a college student was important to the students' sense of self. Identifying what that meant to them led to them sharing perspectives about the type of

student they needed to be as well as how they approached their academics. The ability to take ownership of their academics was the most cited factor for participants in their decision to enroll in higher education. Gordon, a senior, discussed college being more engaging than high school “because you can take [classes] you want to take and, yeah, there’s going to be more work involved, but when you have your mind set on the degree you’re looking for, the work doesn’t really seem that bad.” Henry and Toby both stated that identifying their major was important in their decision to attend. Henry talked about realizing how in college he would need to be a different student than in high school. “It was in senior year of high school that I really started to get the desire to be in college and just get excited about learning things that would be beneficial for my career.”

Understanding the college environment was identified by the participants in understanding the difference between their major classes and their general studies courses and how this impacted their student identity. After beginning classes, participants found classwork in courses related to their major to be more engaging than in subjects they were not interested in. “Most of the time [my major classes] are challenging,” said Henry, “but by nature of being something I enjoy, I enjoy actually pushing through that challenge.” Toby also stated the impact of being in classes he was invested in:

I find it a lot easier to retain information related to my degree than I do with gen eds. And I think that’s very common [for students with ASD], is that we’re more likely to retain something that we’re interested in.

He also talked about his improved experiences with faculty in his degree program compared to those in other fields. Mavis, who was diagnosed with an ASD during her senior year of high school, discussed the differences in her classroom behavior depending on the subject matter,

stating that she was more engaged and interactive in her major courses than her general education classes.

Family influence. Family also had an influence on their sense of self as they transitioned to becoming a college student. Participants brought up family as being a factor in the decision to attend college and become a college student. Percy, Henry, and Gordon discussed how their parents going to college and then encouraging them to enroll had an impact. Gordon said that the institution he was currently attending was the same one his father had graduated from, a tradition he wanted to continue. Percy revealed that both of his parents were first-generation college students who encouraged him to continue his education after high school.

Proximity to family was also a factor in the decision to attend college and maintain their familial connections. Gordon discussed wanting to be at a college within a relatively short driving distance from his parents, saying “If I ever need to go home and help my family with anything I can do that.” Edward, who attended two four-year universities, utilized his parents’ college experience to determine the school he transferred to as an undergraduate student, choosing to enroll at an institution that was more similar to parents’ alma mater.

Services. As students talked about their student identity they recognized and were able to talk about how they had used services in high school and having to understand that they would need support services as college students. The participants in this study were looking for support as they selected their college, knowing they would need it as they transitioned. Henry and Percy, the two participants who were enrolled in their institution’s autism support program, both cited that program as a major factor in choosing to attend. Henry talked about searching with his father to determine schools that had the right balance of academics and autism support:

Some colleges had a good IT program but no autism support program beyond [what is legally required by] disability services. One college I went to had a really good autism support program with a plethora of supports, but their IT program wasn't really the best, so [this institution] just made sense because it had the best of both worlds.

“Without that program, I would sink,” Percy stated, adding that his institution's autism support program was the biggest factor in determining where to attend college.

In addition to autism support programs, Disability Services offices was described as a key institutional factor for participants. “It's got extremely amazing help services for students like me,” said Gordon. Mavis discussed her experience being diagnosed less than a year before college and doing research to find an institution that could offer her the supports that she was discovering she needed to succeed. Percy went deeper, sharing an experience he had meeting with the Disability Services office:

The disability services people here are amazing, every single one. I remember talking to [the director of Disability Services] and I remember she was just really impressed with me, and she acted in a way that my mom was just blown away. She was so happy to have people like this. My mom has had to deal with so many people in special ed programs that just didn't care about me or didn't understand how I worked because they weren't trained enough on autism. That's a huge problem in our school systems.

A few participants cited financial aid as a service that informed their decision to attend college. Mavis talked about her institution's affordability and scholarships offered by the Financial Aid office, and Toby discussed his decision to take a gap year after having community college fully paid for by financial aid.

Connections. The last main motivator participants stated in their decision to enroll in college were interpersonal connections, including preexisting and desired ones, and how those connections impacted the way they viewed themselves. Percy, when told he may have had to take a fifth year of high school, “was adamantly against that because all of my friends would have been gone.” Edward cited existing connections as a factor in choosing his undergraduate institution, stating “I wouldn’t have even transferred to that school if my neighbor from high school had not been there. Like, that was the main reason for me going there, honestly.”

The desire for new relationships was also a motivator. Percy stated, “[at college,] no one knew of my antics at previous schools...I had maybe one or two people that really accepted me for who I was.” According to Edward, finding the connections he desired was a major factor in his decision to transfer institutions:

I didn’t think that the kind of individual that would go to my first institution would be interested in getting wasted all the time. That was an image of college that I was aware of, but I wanted to avoid...I thought that if I go to a private school, I’m going to be able to avoid that and just be with students who are really focused on the academics. And that didn’t end up being the case, and so I think I was frustrated by my peers not being similar to me in that way. And so it did kind of suck because I was like, oh, maybe I’m not actually that similar to these people after all. And when I transferred, I was like, okay, at this school people actually aren’t drinking. So, I enjoyed that because it meant that people weren’t there for the reasons that really frustrated me.

Sense of Self. The participants were asked to talk about how their friends describe them, providing insight into their sense of their own identity. As the participants talked about their transition to college, they used lots of different words to describe themselves. They shared things

about being hard-working and determined. “I’m diligent, I care greatly about doing a good job in class,” said Henry, who has been a member of his institution’s autism support program for four years. Edward said that to challenge himself, he “only applied to schools that were high caliber” and his hard-working nature helped him succeed. Adaptable was another way participants described themselves. “I’m a pretty quick learner, always have been, so I just like picked up on things fast, and I went from there,” said Mavis. Percy, who is a member of his university’s honors program, talked about how meeting people that were similar to him helped him to adjust quickly:

The Honors College was amazing for me because it had a bunch of people that were like-minded, even some neurodivergent people like myself...and then when I ran into a problem, I actually got over it and not I’m a lot better at that sort of thing.

Participants also expressed being other focused. “I worry too much and sometimes I let little things get to my head...and [my friends] know if they ever need me to help with something, I would be there without a second hesitation,” Gordon stated. Henry shared that he believes his friends “would say I’m a pleasure to be around, that I’m funny...that I’m just really kind, and I look out for others.”

Supports and Resources for Students with ASD in Higher Education

Participants were asked questions about the supports and resources they have utilized at college. As they shared, participants discussed aspects of the higher education experience that cause them stress as well as the on- and off-campus supports they use. In addition, the participants who had disclosed their ASD diagnosis with their institution’s Disability Services office described the accommodations that they receive.

Stressors

As participants talked about what supports they utilize, they also spoke about the things that cause them the most stress in their college experience; this included self-concept and expectations, understanding the new environment they were in, and engaging with others in and out of the classroom.

As they spoke about above, many came in with perceptions and expectations for themselves of what kind of student they would be. Gordon discussed feeling the need to hold himself to a high standard, saying, “whenever I’m performing a job, I want to hit that standard every time. And when I don’t, I get super angry at myself because I’m better than this. I know how good I am and what I can accomplish.” Edward, who transferred between undergraduate institutions, described his experience feeling like an imposter:

I really get in my head and I’m like, I don’t feel like this is the right fit, even if I’m able to do it well. And other people are able to say, ‘Oh, you’re doing a good job’, but there’s this part of me that’s like, this isn’t right, saying I don’t fit here.

The participants also spoke about balance and prioritizing things. Henry cited an increased workload compared to high school to be his largest source of stress, feeling more pressure to perform well on assignments. Mavis, the sophomore who was diagnosed with an ASD during high school, stated that the amount schedules change in college caused her stress:

I’m very much a scheduled person. I like having a set schedule, and I like knowing when things are going to happen...So going from working all day to having like, two or three classes a day and then working was kind of hard because I was not used to it...So for the first month, I was just so exhausted all the time. I was stressed out.

As identified above, the participants did not anticipate the higher level of interaction with others. For some this was inside the classroom and others it was socially. Toby spoke about the types of classwork and assignments that stress him out:

Group projects cause me a lot of stress because I'm worried that if I misunderstand something and don't do a part of the assignment right, that I'm letting all of them down. Because it's not just my grade that's at stake, it's theirs too...Presenting in front of class can be very stressful, too, even though I'm fairly good at it. Normally, I'm not really nervous about communicating with people, but when it's for a grade, it stresses me out.

Percy discussed his experiences socializing with people, sometimes feeling out of the loop during conversations:

Not being able to talk can be irritating because I don't know when people are going to stop talking. Also, someone else might start talking as the other person is finishing the sentence and it's just like, how do you know that? It's kind of interesting how not knowing how socializing works just naturally is detrimental.

All of this created stress for the participants that caused them to identify ways to manage this by seeking support to manage this new experience of college.

Supports

Participants were asked questions about the types of support they drew from as they made their way through college. As participants spoke, they identified that it came from a variety of places. Common themes included family, friends, and the various on-campus supports they utilized. Additionally, participants who did not utilize on-campus resources discussed why they did not.

Family. When asked about their experience in college, the first support every participant discussed was their family. Henry stated that his parents are some of the first people he goes to when he needs to talk about something on his mind. Percy spoke about his mother being a school psychologist who not only assisted his development in high school but continues to be someone he turns to for advice. Edward, when deciding whether to transfer colleges, talked through the process with his parents and grandparents, “and I hadn’t ever seen my family so worried for me before.” Edward also discussed his second undergraduate institution being close to his family, saying “it was nice to have the safety net of, like, every weekend if I need to, I can just go home. That was a really helpful thing.” Gordon and Mavis both acknowledged that, despite being hard-working and independent, being able to talk to family was a necessary support. Toby discussed how his connection with his family helps to manage his stress:

I talk to my parents once or twice a week just about how things are going, and if I’m really overwhelmed with something, they can kind of, like, talk me down. Like, ‘Hey, you’re not doing as badly as you think you are.’ Because sometimes I just get in my head, and I stress myself out and put too much pressure on myself...I start forgetting about the things I’m doing right.

Friends. Another support that participants spoke about was their friends they made while in college. Gordon and Toby said that the friends they have made in classes for their major have been helpful, whether they “sit down and talk about why we like the [classes] so much and connect,” in Gordon’s case or “help each other out with projects,” for Toby. Henry discussed talking through his problems with the friends he made going to church in the local community. Mavis talked about how important having friends is to her, saying “when I meet someone and I

really like them, I focus on every single thing about them. So, I'll notice [my friend's] order at Taco Bell, so I'll order food for her. That's how I am."

Gordon and Percy also spoke about the impact of having other friends with an ASD as a support in maneuvering through their college experience. Gordon discussed how that similarity can foster understanding, stating "even one of my friends [is] on the spectrum as well...So he and I connect very well because we grew up with that same kind of life where it's like people wouldn't really take the time to understand us." Percy, a member of the ASD program, relied on the experiences and knowledge of his friends with an ASD when making decisions, saying "I was going to have a professor that was really bad and just went up and said autism didn't exist. But one of my [friends with an ASD] was like, 'Yeah don't take that professor ever.'"

On-campus supports. Participants also discussed the services they have utilized on-campus during their college experience. These included people in their living environment, disability services, faculty, writing center, and career services.

Most of the participants lived on campus, with two living in and participating in an ASD specific learning community. Thus, several cited various ways that Residence Life supported them. Mavis and Henry spoke about the connections they developed in their residence hall that they have relied on since to succeed. Edward stated that he talked to the residence director of his building when he was struggling with the decision to change schools.

Participants listed an array of supports they utilized outside of the residence hall, including disability services, career services, the writing center, and the counseling center. Gordon and Percy specifically highlighted the effect that having helpful Disability Services staff had on them. "[The staff in the Disability Service office] are amazing. Whenever I visit, they

make sure to tell me, like, ‘Listen, you’re doing an amazing job,’ and it’s nice to be reminded of that,” said Gordon.

Percy and Henry, members of the institution’s autism support program, discussed the impact that program has had on them. Percy cited the program as a useful support for developing interpersonal connections, and Henry discussed its more holistic benefits:

[The autism support program here] has been the biggest resource just because of the supports it can provide through having mentors to just talk to when you’re stuck on assignments and having some study times set aside for you and a study space.

Supports not utilized. In conducting this research, it was important to know why they may not utilize resources that have been specifically designated to help students. While the participants talked about the supports they utilized throughout their college experience and the effect those supports have had on them; they also identified that some they just did not and provided insight in to why that might be the case for them. Gordon highlighted this, saying, “It really helps me out mentally when I have a good support system and that I have friends that I know will help me no matter what.”

Several participants cited a lack of knowledge about, and access to, supports as a reason for not utilizing them. Toby, when speaking about his use of the on-campus counseling service, said “I don’t really know of any other services to support mental health. That’s pretty much the only one I know of. I’m sure there are some [others].” Mavis was vocal about the effect accessibility to services had on her use of supports:

Sadly, I don’t use resources on campus...I know there’s writing services on campus, but I don’t need those. I know they provide other services somewhere on campus, but that’s about all I know...if it’s not easy to access, I’m not going to do it because that’s just too

much work. I already spend enough time pretending to be normal around other people. I don't need to go out of my way to get something to make me feel better if it's hard to get it.

The participants also identified perception and timing as an influence for not reaching out. Mavis discussed the impact that others' perceptions had on her willingness to utilize supports, saying "it's nice having the help, but it's also nerve-wracking because I don't want people to think that I can't do things." Henry talked about reaching a point where he felt he could have been more supported by the autism support program he was enrolled in:

They placed me in a work-life social skills class, which is meant to teach you about social skills that you might need for the workplace. The spring semester, when the class started, I felt it was applicable and I enjoyed being in it. This semester, the class dealt with a lot of lower-level topics that I felt I was way ahead in, and so I just felt because I was ahead of the other students socially, that that really wasn't the best support to have.

Strategies

In addition to the supports they received, participants were also asked to discuss their strategies for navigating higher education and what they do to ensure their success. Common themes that emerged included positive self-talk, talking through problems, getting involved, and pursuing hobbies.

Several participants spoke about the importance of being positive and supporting yourself. Gordon talked about reminding himself be okay with mistakes:

I set myself to a really high standard and whenever I'm performing a job, I want to hit that standard every time, and when I don't, I get super angry at myself because I'm better than this. I know what I can accomplish, but I have to remember that I'm human. I'm not

going to be good every time. There's going to be mess-ups, that's just how we're designed, and I forget that sometimes.

Toby also recalled reassuring himself when feeling down:

When I'm having negative self-talk, when I'm starting to beat myself up, that's when I say okay, I know this isn't true. I might feel this way right now, but I know it's not true because other people remind me all the time it isn't true.

Mavis discussed the process of motivating herself to do things she doesn't want to:

I either ignore what I don't want to do, and I just let myself sit, or I just go, okay, it's five minutes. You can do it; five minutes and you're going to feel better. During those five minutes, you might suffer a little, but as soon as you get out, you know you're going to feel better.

Talking through their problems was another strategy that participants discussed being helpful. Edward said that it was helpful for him to talk about the struggles he faced at his first institution with a counselor who was unaffiliated with that college. Toby discussed talking to his parents when feeling overwhelmed, saying, "they can kind of talk me down. Just like, 'Hey, you're not doing as badly as you think you are.'" Percy added that talking through his problems with himself was just as important as talking to others. "I talk to myself all the time, which sometimes feels like an interpersonal relationship," he said.

Getting involved and finding things to do were also strategies utilized by participants. Edward found a leadership position in his residence hall, saying "I really made the most out of the Residence Life programs, I was very involved as a sophomore. That program was just very strong there, so I was inevitably going to get a lot out of that." Percy and Toby discussed taking breaks to play video games when feeling overwhelmed and Henry said that going for walks and

journaling helps him when he is over-stimulated. The participants also identified that importance of getting involved in extracurricular activities related to majors. Gordon and Toby, students in the same degree program, discussed getting real-world experience to supplement their classes. “The news and radio stations are encouraging students to go and participate because you’re getting the hands-on experience with things you’re learning in class,” said Gordon. Toby identified a similar situation, saying “I’m a very hands-on learner, so what I’ve found to be helpful here is doing an activity on campus that supplements the degree you’re going into. That helps me a lot because I’m able to get the hands-on experience.” Finding strategies to get engaged helped them connect personally and academically.

Accommodations

Four of the participants, Percy, Gordon, Henry, Mavis had disclosed their diagnosis of an ASD to their institution’s Disability Services office. In the interviews they discussed the accommodations that that office had provided them, with nearly every accommodation being related to test-taking.

Testing-related accommodations fell under the categories of receiving extended time, testing in an alternate location, and receiving alternate testing materials. Receiving extended time and testing in an alternate location were useful for participants who found themselves getting distracted repeatedly, or “squirreling,” as Mavis described the phenomenon. Mavis and Henry were the participants with the accommodation to receive alternate materials, but only Henry made use of them. “I just found that trying to read by myself was just hopelessly inefficient. So, I ended up with the suggestion of my professors providing alternate media, which I can upload into a text-to-speech software,” he said.

Percy was the only participant who received an accommodation not related to test-taking. He was afforded the guarantee of being able to take notes electronically during class, even when the professor might not otherwise allow it. “Teachers will complain to no end, saying that writing helps with memory,” he said, “but I need to actually be able to see my notes and my handwriting is terrible.”

Disclosure Decision

Participants were asked to discuss their experiences disclosing their diagnoses of an ASD, specifically with the disability services office but also with instructors and peers. As they shared these experiences, they shared both their motivations to disclose as well as their reasons for not, or the decision to delay disclosing their diagnoses. They also shared their experiences with the disclosure process prior to and during college.

Experience Before College

In discussing their decision to disclose their ASD diagnosis at college, participants shared their experiences prior to attending their institutions. Participants felt that in high school they were not understood because of their ASD. Toby felt that his classmates in high school saw his diagnosis of ASD as his defining characteristic, saying “My peers were very unforgiving about social quirks...If I ever said something that came out wrong, not intending it to, they would just say, ‘Well, that’s who he is.’” Toby also felt that his teachers didn’t understand who he was because of his diagnosis:

I have ADHD, and from time to time in high school, I would zone out in class. I sent emails to teachers saying, like, ‘Hey I kind of zoned out during this portion of class, but this is what we were talking about before and after. What did I miss?’ And they would

just say like ‘Well, you should have just paid attention.’ I was trying to [pay attention], that’s how I know what else happened, they just didn’t understand what I was saying.

Percy also discussed his experiences with teachers in high school:

I was bullied by the teachers even more than the other students, who just ignored me. The teachers actively put me down for being the person I was because I was a little slower in conversations and I got put in the [lower-level] classes academically.

Other participants talked about how this lack of understanding led to them feeling like outsiders in high school. “As someone with autism, I didn’t have a whole lot of friends,” Gordon said, “Everybody looked at me like I was the outcast because of who I was. I knew what I wanted, and I dressed the way I wanted to, and it wasn’t like everybody else.” Mavis, who received her diagnosis while in high school, was concerned during the process of receiving it:

A fear was that people are going to think I can’t do things because I have autism, and that’s not the case. I can do things. It might be a little bit more of a struggle, but I can do everything.

Edward, while speaking about his IEP, said that even though he could have skipped a grade, he chose not to because he wanted to avoid feeling like an outcast:

My cousin skipped a grade and socially he had even more problems. He was ostracized by his new class because he was the little young kid and then his former class didn’t like him because they were like, “Oh, you’re too good for us.”

Edward also did not speak about disclosure in college, and as the only participant in graduate school he identified making it all the way through undergraduate without disclosing, so he felt there was not a need to disclose now.

Experience at College

Given the opportunity throughout the interview, the participants spoke extensively about their experiences with disclosure at college, not just with the institution, but with peers and faculty as well. Participants felt that after getting to college, they were understood better by others than they had been in high school. Percy, now a sophomore, explained the most impactful change he experienced with others:

Not only have I grown, but everyone around me has grown. It's a lot easier to socialize with people that are like, "Hey, this person is different, that's not bad. I'm going to appreciate them for what they can bring to the table instead of forcing them to adapt."

As a senior in college, Gordon talked about how his friends now differed from those he had in high school, saying "My friends treat me the same as they would anyone else, and they look at me as a regular human. They're like, 'Okay, that's what you have, and it doesn't make me like you any less.'" This increased understanding did not fully prevent participants from feeling nervous to disclose, as Mavis discussed, but after talking to one person about her diagnosis, she found it easier telling more people as she progressed.

After participants disclosed their ASD diagnosis to the institution through the admissions process, if they wanted to seek accommodations, they met with the Disability Services office to determine what they could be afforded. None of the participants who had disclosed with the institution discussed their interactions with the office in a negative way and each described their relationship with the Disability Services staff as being friendly and helpful, with some participants being on a first-name basis with the Director. They did provide an outline of the steps taken and it was fairly similar from participant to participant. After receiving accommodations from the Disability Services office, to utilize them, participants were required

to send a letter to their professors notifying them of the accommodation, at which point the professor scheduled a meeting with the student to talk about what accommodations would look like for the specific class. Participants described an array of experiences with faculty in this regard. Most had positive experiences, like Henry, who said, “They feel welcoming. I’m just glad that the faculty here are willing to work with students with disabilities.” Percy described a situation where he made a mistake and was helped by a professor:

One time last semester I forgot to send my accommodations letter to one teacher, and I had to come in and talk to them a little later. But even then, they were like, “Oh yeah, I’ll get that set up for you right away.”

Some participants described what they found to be odd experiences with faculty, as with Mavis, who said, “I don’t think my physics teacher realized why I needed accommodations. I think she just thought I wanted them, not that I needed them.” Henry talked about a situation after he sent a professor his accommodations letter, who reached out to other professors to understand how to incorporate the accommodations. “It just felt different. It sort of made me wonder, like, did they get the proper training on this?”

Few participants had negative experiences with faculty. Henry found one of his professors to be impatient with his accommodation for extended time on tests. Mavis shared an experience with a professor who made the necessary accommodations for her, but not to the specifications of her letter:

They had me start the exams in the department office and then when class would start, they would come and get me and bring me to the classroom and have me finish the exam in there. I didn’t like how I had to get up and move, sit down, and get back into the

mindset of taking an exam. I also didn't like going into the classroom to finish the exam because it was a regular class, so there were, like, 30 people in there and it got loud.

Overall, their experiences with disclosing to others on their college campus appears to have helped them as they pursued their education.

Factors Impacting the Decision to Disclose in College

Participants spoke about the factors that weighed in their decision to disclose. First, those that had disclosed their diagnosis discussed the reasons they had to make that disclosure.

Multiple participants said that overcoming stereotypes was a major factor for disclosure. "People on the spectrum are not all the same," said Toby, talking about how sharing his diagnosis with others could lead to them understanding him better, "Two people could have autism and be completely different...But I really think that we all want to be treated as normally as possible."

Percy, who had to disclose his diagnosis to his institution to enroll in the autism support program, discussed the impact that him disclosing could have on others:

[Sharing my diagnosis with someone] might cause them to become more involved and more passionate about the subject because of how different everyone with autism is. That can cause people to reconsider their views on autism because a lot of people still think autism is completely nonverbal, and if that's the only person with autism you know, I suppose it makes sense that you'd have a limited viewpoint.

Gordon spoke broadly about his motivations not just to disclose his diagnosis, but also to participate in studies about autism:

I feel like a lot of people have a stereotype of how people [with autism] look and sound. And I want to, as much as I possibly can, show people that there's a lot more to it than you think.

Participants also felt comfortable disclosing because they didn't see their diagnosis as a negative. Mavis, who received her diagnosis less than a year before attending college, said "It's nothing to hide, it's not anything bad. It just makes me different, and that's it." Percy felt that there are usually no major reasons to avoid disclosing his diagnosis, adding "I am really open about it. Other students might be more conservative about who they tell, but I just don't care. I think it's important."

While discussing their reasons for disclosing their diagnosis of an ASD, participants also shared the reasons they may not have, or may have hesitated to make the disclosure. While combating stereotypes was a reason for many participants to disclose, the existence of stereotypes, and how others perceive ASD was also a reason for most to be reluctant. Edward, the graduate student, talked about why he chooses not to disclose his diagnosis to others:

I think with the stigma of it, it's not something that the average person necessarily understands. So, it's like, if I disclose, I might have to educate you about what that actually means, and even then, you might misunderstand and treat me differently unnecessarily.

Toby also discussed the perceptions that others have of ASD:

I don't want people to look at me differently because I think that when people know you are diagnosed with anything on the spectrum, I just think that people immediately put you in a box, like, "Oh, you have Asperger's, so you don't know how to talk to people at all." They compare you to something out of a movie, and it's like I don't want people to do that.

Mavis, who was diagnosed in her senior year of college, felt she was still in the somewhat early stages of identifying with ASD, was worried that disclosing her diagnosis to others would make

them think differently about her. Percy was worried that sharing his diagnosis would prevent others from seeing him as an individual, concerned that “people [without ASD] will judge me based on the actions of others until I prove myself, or they might not even give me an opportunity to prove myself.” Edward shared that not seeing the effects of disclosing as helpful was a factor in him deciding to not disclose. The IEP he had in K-12 was put in place to allow him to take advanced classes, but once he reached college, he was able to take whatever difficulty of classes he wanted. He also felt that his ASD affected him socially more than academically, so because he saw his institution’s disability services office as being primarily to assist students academically, he never felt that it would be worthwhile to make the disclosure.

Summary

This chapter analyzed participant responses in relation to the research questions guiding this study. Through these responses, one can gain a better understanding of the experiences of students with ASD as they transition from high school to higher education, including how they view the situation of their transition, but also how their experiences are impacted by their sense of self. The supports that higher education students with ASD utilize while at college can also be seen, as well as the strategies they use to support themselves. In addition, the decision-making process that college students with ASD go through when deciding whether to disclose their diagnosis can also be seen through the participants’ responses. Chapter five will discuss this analysis, as well as providing recommendations for higher education professionals and future research.

CHAPTER V

Discussion

Chapter five presents the discussions of the findings from the study on the experiences of higher education students with autism spectrum disorders. The purpose of this study was to examine the experiences of students with autism spectrum disorders in the transition into higher education, the decision to disclose their diagnoses, and the supports that are offered to them. Understanding the experiences of college students with ASD is crucial in recognizing the best ways these individuals can be supported and set up for success. The chapter begins with a discussion of the findings. A theoretical model was developed and is presented to aid in the understanding the participants' responses. Implications of the results will be provided, followed by recommendations for future research.

Discussion

This discussion is broken up into three sections, each addressing one of the study's main research questions; the transition from high school to higher education, the supports and resources higher education offers to students with ASD, and the process that students with ASD go through when deciding whether to disclose their diagnosis.

Transitioning from high school to higher education

Discussion of the transition into higher education will be conducted within the *situation* and *self* aspects of Schlossberg's (1984) Transition Theory. These ideas provide an effective theoretical framework for understanding the ways students with ASD view the systems and individuals that surround them, as well as the ways they perceive themselves interacting with those systems.

Situation. It was clear from interviews with the participants that there was much more about the college experience that they did not anticipate than what they had anticipated. Students with ASD have previously discussed that while they may need to put forth a greater level of effort in the classroom than their peers without ASD (MacLeod, et. al., 2018), these students who have enrolled in higher education also frequently possess an “I’ll show you” mentality, bringing with it an increased level of motivation. This motivation commonly comes from being dismissed or underestimated by faculty who expect them to fail (MacLeod, et. al., 2018). The majority of the participants said that they thought the academic rigor of college was going to be more challenging than it ended up being. This was evidenced as participants spoke about how they overestimated the challenge of college work shared that their high school teachers, who insisted that, for them, the hardest change from high school to college would be inside the classroom. It can be easy for those in educational settings to assume that students with ASD may not be able to function at the same academic level as those without ASD, especially for those individuals without experience with that population. Individuals with authority play an integral role in preparing students for what to expect in college, especially those high school teachers.

It is commonly known that high school is set up to be routine for students and while college has its routines, they are less structured and more varied than students may have experienced previously. While students with ASD are typically detail-oriented and able to identify patterns within larger systems, removing or altering those patterns can create a point of stress (Anderson, et. al., 2019; Gaus, 2011). This was identified by participants who were surprised by how often aspects of college life stray from routine, or how much effort they have to put devote to develop that structure and routine. Some participants found their schedules differing every day and others were overwhelmed by how much “room for error” there was with

the process of class registration. Other participants were pleased with receiving syllabi for classes because it gave them that sense of structure, but then became stressed when professors strayed from those syllabi. Learning the processes of college is important for students with ASD to avoid unnecessary stress (Sefotho & Onyishi, 2021). The participants in this study certainly identified that the more structure that they have, the better they will do. This means that those working with this population should be willing to help students in that first year identify how to structure and manage their time because they will benefit from it.

The only aspect of college that participants consistently discussed anticipating was doing well academically, a characteristic that is typical for higher education students with ASD (Anderson, et. al., 2019). However, it has also been shown that students with ASD may be more likely to struggle with goal-setting, planning, and self-regulation, leading to issues academically (Azano & Tuckwiller, 2011; Hill, 2004). In this study, several of the participants felt more prepared for academics than other areas. Because of that preparation, and then finding that the academic components were not that bad, they were more likely to feel successful. This supports the idea that if students with ASD are aware of the difficulties they may face and accept that they may have to work harder than their peers, they will likely be better equipped to handle the challenges faced in academics.

It has been identified that in transitioning to higher education, it is important for students with ASD to receive social support from peers (Carrington, et. al., 2003), a need that is often magnified by the fact that students with ASD may lack the social skills needed to build relationships (Müller, et. al., 2008). The development of interpersonal relationships, or “a social life,” as it was deemed, was another unanticipated aspect of the college experience for participants of this study. As they spoke, they highlighted that they found their peers to be more

patient and understanding than they had anticipated. The participants stated that in college, others are more likely to take the time to get to know them than their high school classmates were, leading to more caring and meaningful interpersonal connections. Overall, participants had not anticipated having so many new relationships. This may be in part because they lacked friends in high school or because no one directly spoke to them about the social aspects of college. Because social activities can be among the most positive, yet most stressful, moments for students with ASD (Carrington, et. al., 2003; Glennon, 2001), it is important for them to develop relationships they can rely on for support. This highlights the importance of providing support and guidance to individuals with ASD as they transition to college, so they are able to make and maintain those social connections.

It was also clear from the participants' interviews that they cared about the social aspect of college. While participants did not talk about having social interactions in high school, it was clear through the interviews that this may have been lacking as they were pleasantly surprised by the number of friends they had and how patient those friends were with them. This, however, did cause some anxiety in anticipation of the process of developing relationships as well as how they would disclose to peers and how that might influence their interactions and others' perceptions of them. Müller, et. al., (2008) identified that students with ASD often do want those social interactions and seek to develop relationships with their peers, even though it may be a source of stress. Exposing these students to social situations they may otherwise not experience can help begin the friend-making process and lead to the development of relationships for a population that needs it.

Self. The ways that participants viewed themselves, and how their identity relates to others, proved to be an important factor in their experience in higher education. Most participants

cited the ability to take ownership of their academics as the most impactful consideration in the decision to enroll in college. Through their research on higher education students with ASD, Anderson and colleagues (2019) found that these students are typically driven academically by passion in their field of study. This idea was directly shown by the participants of this study who found that material in courses related to their major proved to be more engaging, easier to understand, and easier to retain than material from courses in other disciplines. Additionally, participants also found that they had an easier time connecting with, and understanding, faculty in their degree program compared to those in other fields. ASD students typically come into college having a better idea of their career interest than other students. Knowing this means that if those early connections to faculty are made, whether through coursework or otherwise, can help them feel more connected and self-assured in the academic arena.

Many participants also discussed the influence that their family had on their decision to attend college. For most, their parents had previously attended a higher education institution and encouraged them to enroll, citing the importance of continuing their education. A few participants talked about the proximity of their family to the institution they wished to attend as being a decision-making factor. Some stated that they wanted to be within driving distance of their family, should they or their family need any help, and one participant even transferred schools to attend an institution that was more similar to their parents' alma mater, which highlights just how important family can be as a factor in the decision to enroll in college. As individuals with ASD have maneuvered through life prior to college they have relied on family for their main support. Thus, it makes sense that they would want to maintain close ties to those individuals who are their greatest source because they may play a larger role in their lives and decision-making processes than students without an ASD.

All of the participants felt confident in their ability to recognize the supports they would need as a college student, and a majority stated that the types of services offered by their institution was a factor in their decision to attend. The institution attended by the participants hosts an autism support program for students with ASD. The services offered by this program, including mentoring, specialized courses, and a non-restrictive learning environment, have been previously shown to contribute to the success of students with ASD (Daughtry, et. al., 2009; Getzel, 2014; Law, 2020; Strauss & Sales, 2010; Wei, et. al., 2016). For the participants who were enrolled in this program, it was both a major factor influencing them to attend the institution, as well as a large contributor to their success. Most participants discussed their institution's disability services office as a motivation to enroll in the institution. These responses show that the kinds of services an institution provides plays an influential role in the process of choosing a college for students who have disclosed their ASD.

Interpersonal relationships have been shown to be a vital resource for higher education students with ASD (Carrington, et. al., 2003; Glennon, 2001; Müller, et. al., 2008). Responses from the participants of this study support this point, as a majority also discussed their connections with others as a motivation to attend college. Edward, who transferred undergraduate institutions, stated that finding the connections he wanted to make was a major factor in making the decision to leave his previous institution and that the connections made at his new institutions impacted his ability to stay. Other participants appreciated that college presented an opportunity to develop new connections with students who did not know them previously. Providing opportunities and experiences that help students interact in various areas and in various ways is important because these connections and relationships will help them to succeed.

As participants identified having friend groups in and out of the classroom it was interesting to hear them speak about the ways in which they have connected with others and how this differed from their experiences in high school. Students with ASD have been shown to have passion and motivation for topics they are interested in as well as strong skills for picking up on patterns and details (Anderson, et. al., 2019; Gaus, 2011; MacLeod, et. al., 2018), all traits that participants of this study described possessing. Many participants discussed being diligent, hard-working, and determined in their classes. Beyond this, though, nearly every participant also described themselves as thoughtful of others in some way, and this was connected to their academic interactions with peers. Some spoke about looking out for their friends and standing up for them, while others discussed remembering small details about others and acting on those to make them feel cared for. This becomes interesting as most research has provided little about the experiences of individuals with ASD socially in college; for example, Jaswal and Akhtar (2019) found that researchers are more likely to assume that study participants with ASD are more disconnected and uninterested socially than participants without ASD. Assuming that a student does not desire social interaction simply because they may not know how to engage in the same way as others could prevent them from establishing those connections that can help set them up for success in college. It was clear in this study that the participants were surprised to have as many social interactions as they did and how this impacted their collegiate experience overall.

Supports and resources for students with ASD in higher education

Discussion of the supports and resources of higher education will be conducted primarily within the *strategies* and *support* aspects of Schlossberg's (1984) Transition Theory, as well as examining major sources of stress for students with ASD. Schlossberg provides a useful basis for understanding where these students feel supported, in addition to how they manage their stress.

Stressors. Participants were able to reflect on and articulate the aspects of college that caused them stress. Higher education students with ASD have previously reported feeling stressed from the changes in self-perception, structural differences, and social interaction that college can necessitate (Adreon & Durocher, 2007; Carrington, et. al., 2003; Sefotho & Onyishi, 2021), all of which were themes discussed by participants of this study. Some participants highlighted that they set high expectations for themselves, which led to stress from both a fear of falling short of those expectations as well as feeling like an imposter, that they don't actually belong in higher education.

Participants struggled to find a balance between the social and academic aspects of college, as well as coping with an increased load than what they were used to in high school. The flexibility of schedules in college proved to be a major stressor for several participants, especially when attempting to develop a routine that involves attending classes, working a job, extracurricular activities, managing social relationships, and everything else. The participants in this study identified that this was not anticipated because they had developed strong routines in high school and now, they had to learn to do the same thing college; some did this on their own while others were supported in learning how to do it.

It has been shown that individuals with ASD are more likely to exhibit unconventional forms of communication and social relating than others without ASD and are therefore more likely to be misunderstood by their peers, which can lead to stress (Heasman & Gillespie, 2019). Participants of this study also talked about being more anxious when interacting socially with others. Many of their experiences were centered around the idea of conventional forms of communication, something a number of them struggled with. It is clear that, like with any student, those with ASD encounter stress from a wide variety of sources and understanding that

can help in identifying ways to help make their transition smoother. While their peers may vocalize similar stressors, students with ASD may find themselves uniquely stressed by situations that pose no issue to others, as well as the inability to articulate that stress. The participants in this study were able to identify the causes of their stress, they just may not have told staff at the institution. Professionals who engage in conversation with these students about where their stress is coming from can help them work through those situations and find good coping or management strategies.

Supports. As participants spoke during interviews, it was clear that they were aware of the supports, both institutional and otherwise, that were helpful to them during their college experience. While participants cited their family as motivational in the decision to enroll in higher education, every participant also listed their family first as they discussed the supports they rely on. Some participants stated that their parents were who they went to first for advice in making big decisions, while others felt like they simply needed to talk to their parents when they were feeling overwhelmed by the stress of college. As identified above, these students are more likely to choose institutions that are closer to family members so incorporating them into the college community may be beneficial. Even though the goal of higher education is often to empower students to be self-sufficient, it is important to balance that while still allowing students the access to the support systems they have utilized their entire lives.

As students progress through high school and into higher education, their support systems begin to shift, as they start to rely less on their families and more on their friends and peers in college (Barclay, 2017). This theme was echoed by participants, who also talked about their friends being supports they utilized. Many participants discussed finding friends through academic means, commonly finding connection with others in their degree fields. Having at least

one area of interest in common was beneficial for participants when communicating with peers, as it gave them something to talk about that they knew the other person would understand. In addition, participants enjoyed being able to assist their classmates with assignments and projects, as it made them feel useful and helped to build interpersonal relationships. Participants also discussed the importance of making friends through extracurricular endeavors. For some this may mean getting involved in the residence halls, academic program groups, social interest groups (such as fraternity or gaming group), as well as religiously-affiliated groups off campus, which was evidenced by different participants in this study. Some participants also talked about the impact that having other friends with an ASD, and the positive influence that had on them in maneuvering through college. Having this similarity with someone else helped the participants, as it gave them at least one relationship in which the other person understood that they were different. Even though participants first discussed their family when asked to talk about the supports they utilize on college, they always spoke about their friends, often more positively and at greater length. This mirrors what Barclay (2017) found, and when thinking about where these students are in their developmental journey it makes sense. Many students with ASD in high school feel misunderstood by their peers, and are often removed from those without ASD; and therefore rely more heavily on support from their family. As they move into college, however, they may find peers to be more accepting of them, likely finding it easier to build connection, and thus rely more heavily on support from their peers. The fact that participants discussed their friendships in this way highlights the importance of encouraging students with ASD to engage, and develop relationships with, other students.

If not supported institutionally, students with disabilities are at an increased risk of falling behind their peers (Strauss & Sales, 2010). As participants spoke about the supports they have

utilized through college, they each discussed on-campus services. Most of the participants who either currently or previously lived on campus talked about their living environment as a resource. They emphasized that the connections they made in the residence halls set them up for success in other areas of college life. Outside of the residence halls, participants named several institutional services they utilized, such as disability services, career services, the writing center, and the counseling center. Nearly every participant who had disclosed their ASD diagnosis to the institution spoke specifically, and positively, about disability services and the connections they made with that office. The participants who were members of the institution's autism support program also cited it as an important support. These programs have been proven to improve interpersonal relationships and social skills, as well as contribute to academic and professional success (Daughtry, et. al., 2009; Getzel, 2014; Law, 2020). Responses from the two who participated in the program reflected these benefits, specifically highlighting the relationships they developed. Because of the impact these services can have, it is important to make sure students with ASD are aware of them, and in some cases directly connected.

While participants were able to identify the services and people that they had relied on throughout their college experience, there were still institutional supports that had been specifically designed to help students that were not being utilized. Several participants simply had no knowledge of many of the supports that were available to them, while others felt that some of the supports they did know about were too difficult to access. When asked to name services on campus that were available to them, but that they did not utilize, most participants were not able to think of more than one. One participant, who was able to identify several support services on campus but stated that she did not use them because they were too confusing to access. A few participants also discussed the perceptions of others as reasons they did not

utilize on-campus resources. One participant was worried that if other students found out that they needed extra support, they may be looked down on. Seeing how important utilizing services on campus can be, it is also clear what the impact of not taking advantage of these supports can be. Extra efforts can be made to educate students and spread knowledge about the supports that have been created for them as well as minimizing the stigma that may be associated with using them.

Strategies. Participants also identified strategies they employed to navigate their higher education experience. Individuals with ASD, when compared to others without ASD, are at an increased risk of loneliness, suicidal ideation, depression, anxiety, and stress, and are also more likely to possess another diagnosis, including depression, generalized anxiety disorder, and obsessive-compulsive disorder (Hedley, et. al., 2018; Jackson, et. al., 2018). However, self-acceptance has been shown to be related to decreases in depression and anxiety and increases in self-esteem and student success (Chamberlain & Haaga, 2001; Flett et. al., 2003; MacCauley et. al., 2019). Therefore, while it is important for students with ASD to feel accepted socially, being accepted personally is just as important. Participants shared this sentiment, with many of them speaking about positive self-talk. One discussed the benefits of staying positive and reminding himself that it is okay to make mistakes, while others focused on reassuring, motivating, and supporting themselves when faced with challenging situations. Being aware of the benefits of these strategies is important in being able to recommend them to other students with ASD.

Participants spoke about the impact of talking through their problems with others, finding that getting someone else's opinion or advice helped prevent them from feeling overwhelmed. In a sense, what happens is that they learn that it's not just happening to them, or that they are not the only one feeling this way, and it normalizes the experience but also connects them to others

from whom they can gain support. Participants also discussed getting involved in other areas and finding hobbies. Some participants took on leadership positions in student organizations, while others began playing video games, going on walks, and journaling. No matter what specific activity they participated in, what the participants found was that their extracurricular activities helped them regulate their levels of stress and connect to others around them.

Accommodations. A majority of the participants had disclosed their ASD diagnosis to their institution's Disability Services office and, through the interviews, discussed the accommodations the office had provided them. Nearly every accommodation afforded to the participants was related to test-taking, either receiving extra time, testing in an alternate location, or receiving alternate testing materials. Participants reported that receiving some combination of these accommodations was beneficial in avoiding unnecessary distractions and better understanding the material. In addition to educating students with disabilities on the services that are provided for them, it is important to make sure that students are aware of the accommodations they may be able to receive and the benefits those may provide.

Disclosure Decision

Discussion on the decision for students with ASD to disclose their diagnosis will be divided into sections detailing the participants' experiences before and during college, as well as the factors they feel have most influenced them in the disclosure decision.

Experience before college. When discussing their experiences in education before starting college, participants mostly shared negative experiences. However, one participant did share that they had a number of positive experiences in high school, and while the rest of the participants likely had similarly positive experiences throughout high school, the fact that the majority of participants only shared negatives highlights what a significant impact these negative

experiences can have, and how different they were from their collegiate experience. Multiple participants talked about feeling misunderstood by their peers in high school, and thus being treated as an outsider, which can be difficult at a time when students have an increased need for social support from peers (Carrington, et. al., 2003). Participants also discussed feeling misunderstood by their teachers in high school, including feeling harassed by teachers for being in lower-level classes, which can cause students to not seek help, even if they need it. The participants in this study provided several examples of how they were mistreated by those in their high school, especially teachers. High school is clearly a difficult time for students with ASD and this may be due to the fact that they are not always in control of navigating their disclosure an ASD diagnosis. However, when they come to college, they are then put in the position to take control of their disclosure, and this new responsibility may make them hesitant to share. It would likely prove beneficial if these students were talked to about disclosure in college by those in a position to best explain it. It would also be beneficial to incorporate this into the admission and orientation process of the college.

Experience at college. Largely, participants had a more positive experience with ASD disclosure at college than they previously had, discussing their disclosure with their institution, with peers, and with faculty. Participants, regardless of whether they had disclosed their ASD diagnosis, reported feeling more understood by others than in high school. They stated that, in higher education, other students and teachers treated them the same as students without ASD, being appreciated for bringing their differences to the table instead of being forced to adapt to everyone else. According to the institution the participants attended, after they disclosed their ASD diagnosis to the school, if they wanted to receive accommodations, they were required to meet with the disability services office. None of the participants who went through this process

described their experience in a negative way and each one of them cited the disability services staff as a support in their overall college experience.

The disability services office proved beneficial to the students who utilized it through the provision of academic accommodations. If students with ASD are given accommodations, they are required to contact their professors to discuss the accommodations for each specific class. Most participants who had had these discussions with faculty shared either positive or neutral experiences, with very few sharing anything negative. Overall, participants described their professors as welcoming, understanding, and eager to tailor the accommodations to their classes in whatever way the participants needed. Some shared neutral or confusing experiences with some faculty when setting up accommodations, with participants sharing that professors were either hesitant to allow accommodations or did not fully understand the process for implementing them. Through the combination of these experiences, the question could be raised as to how much training instructors receive related to disability services, and perhaps more is needed regarding accepting of accommodations. Few participants shared negative experiences with faculty in relation to disclosure for the purpose of acquiring accommodations.

Factors impacting the decision to disclose in college. After discussing their experiences before and after entering higher education, participants discussed their process for deciding to disclose their ASD diagnosis and the factors that weighed in that decision. Disclosure is a crucial first step towards receiving support for students with ASD, but many of these students are reluctant to make that disclosure (Adreon & Durocher, 2007; Anderson, et. al., 2018; Rocco, 2011; Shattuck, 2014). This study, along with previous studies, shows that the decision to disclose a disability can include a fear of being stigmatized due to the diagnosis and a belief that the accommodations brought on by disclosure are not necessary (Anderson et. al., 2018;

Anderson et. al., 2019). Nearly every participant shared that the stigmas associated with ASD and the perceptions of others was either a motivator or a source of reluctance in the decision to disclose. Several participants discussed wanting to combat stereotypes of ASD, stating that while there may be similarities between individuals with ASD, each person is unique and there is no way to predict what someone with ASD is going to look, sound, or act like. Multiple participants talked about simply wanting to be seen as treated the same as everyone else, and they believed that being open about, and disclosing, their diagnosis was a way to achieve that. The fact that the participants understood the risks that could come from disclosing and still decided to go through with it shows how strong their motivations were, and how wrong they were in their assumptions about how they would be treated.

Stigmas and stereotypes also played a part in a few participants' reluctance to disclose their diagnosis. A few participants discussed worrying that they would be viewed differently by others after making their diagnosis, an experience that those who made the disclosure stated did not occur. Another factor in the decision to disclose was the perceived benefits of disclosing, and that some of these are negative and may mean they have to educate someone else about their own ASD. Sometimes they do not need academic support, but more social support, something that they identified disability services is less equipped to support. Overall, participants' experiences in higher education were much more positive than in high school, but they had to learn by experiencing it as no one really prepared them. Because their experience in college was more positive, it allowed them to feel more comfortable disclosing their ASD diagnosis to a variety of people, leading to improved social interactions, better mental health, and stronger academic performance.

The participants who made the decision to disclose their ASD diagnosis did so to combat stereotypes with the intention of being treated the same as those without an ASD. Those who had not disclosed their diagnosis did so for the same reason, the desire to be treated the same as others. Inclusion, connection, being understood, and “fitting in” have proven to be central to the experience for students with ASD transitioning from high school to higher education in how they interact with their surroundings, how they view themselves, and how they disclose their diagnoses to others.

Model of Support for College Students with ASD

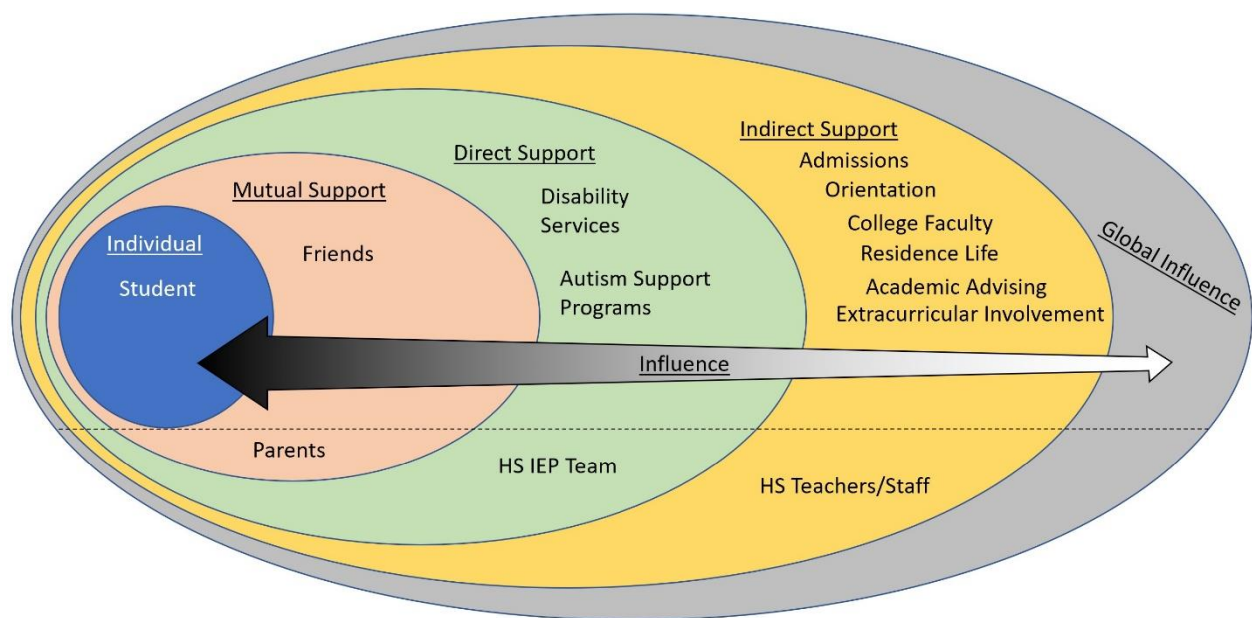
Participant responses indicate that the amount and types of support they received was the most influential factor in determining their success in college. Even if they were not consciously aware of it, their statements suggest that they were constantly being influenced by internal and external factors. In analyzing the data toward understanding the student experiences, a theoretical model was created in order to look more visually at the implications that can be derived from the results, as well as the findings of prior research. An explanation and breakdown of the model will be provided in this section, followed by suggestions for real world implications in the next section, as well as justifications for the placements of supports based on participant responses.

Inspiration for this model was drawn from Urie Bronfenbrenner’s (1979) ecological model of human development. He identified that an individual’s development is influenced by their environment, which is made up of a series of nested systems, with the systems closest to the person having the most impact and influence on them. In contrast to Bronfenbrenner’s model, which seeks to address every system which may impact any individual's entire life, this model is much narrower in scope, focusing only on college students with ASD. Additionally, this model concentrates solely on how these students navigate their transition out of high school into higher

education and the various factors that support and influence them. One significant aspect of this model is a dashed line that runs horizontally through the model. The purpose of this line is to identify that there may be aspects of a student with ASD's college experience that no longer play a direct role in their life but may still be affecting them, and anything that fits this definition is placed below the line. For instance, even though a student is in college and their education is no longer governed by their IEP, the fact that they had an IEP at all may influence the way they interact with systems of support in college.

Figure 1

Model of Support for College Students with ASD



A similar idea to Bronfenbrenner's nested systems was utilized in the development of this model, with the *Individual* resting at the center. This layer typically will only include the student and the internal strategies they employ to support themselves. As identified in this study, many of the students work hard to live like a normal college student. They spoke about working hard in

their classes, balancing relationships, and seeking support all to maintain this persona of a traditional college student; a persona that they held in their own minds.

In the next layer, *Mutual Support* are those systems which support the student on a deep, personal level and are often informal supports, such as friends and family. It is also common at this level for the feelings of support to be reciprocal, with the student able to offer support and influence in return. For students with ASD, parental support has been much more intentional than for the general population throughout their K-12 experience and coming to college many students seek to maintain that. This was seen in how the participants spoke about their relationship to their parents, and even their decision of where to go to college, which was at most two hours away from home for the participants. This stronger connection to family needs to be maintained for the students to be successful. The parents appear under a dotted line in this model because as the students move through college, the influence of the parent decreases; however, they are still seen as a source of mutual support and direction. The friends appear above the line because this is a new source of support for many of the students with ASD as indicated by the participants in this study. Many of them articulated learning how to manage these newfound relationships that were different from their friendships in high school.

The next layer of this model is *Direct Support*, which includes systems that offer support directly related to ASD. This layer will likely contain the fewest supports, since most colleges do not possess systems that directly assist students with their ASD aside from a disability services office or the occasional autism support program. The direct support of the student with ASD during high school comes in the form of an IEP which provides a student with a team of advocates and support individuals, including parents, throughout their experience. However, that goes away in after high school as there are rarely IEPs in college. This is why that support also

appears under the dotted line as it provides a bit of influence on the transition but quickly fades as they make their way through college. What these students identified, however, was the resource of the disability services office and how that staff helped direct them and offer guidance through their college experience. Some of that support included helping them disclose, connecting them with other resources, and being a safe space to go to when they were struggling or even before they struggled.

The final formal layer is *Indirect Support*, including the higher education systems that offer support, but not directly related to ASD. Unlike the Direct Support level, this layer will likely be the most expansive. As it is in the nature of higher education to support students, it should therefore be expected that nearly every aspect of these institutions will be able to offer support to a student with ASD in some way. What is important to consider here is the influence and not the direct support that might impact this population of students. This suggests that these areas need to be aware of the needs of this population and educated on the best ways to support and guide them. In this study, the participants identified that high school teachers, who appear below that dotted line, had a huge influence on their perception of the academic rigor they would experience in college. This impacted how they prepared themselves for college classes and actually over-prepared them and set them up to be more successful because it was not as bad as they had anticipated. Those areas on campus above the dotted line in this model need to be connected to the disability services office so that they know what to anticipate, how to support, and make themselves aware of resources for this population. By doing so, more direct supports and attention can be provided from the beginning, helping to create a seamless entry to college.

All of these layers of support are in turn contained within a sphere of *Global Influence*. This level of the model is unlike the prior layers in that it does not contain specific people or

systems. Rather, this sphere is made up by the prevailing attitudes and preconceptions about individuals with ASD that are possessed by greater society.

The final piece that makes up this model is an arrow labeled *Influence*. This arrow represents that there is bidirectional influence between each layer of the model, in that any layer is capable of influencing any other layer. In this way, though, each layer of support must also be viewed as a sort of lens. For instance, the way a student feels supported by a disability services office will be viewed through the lens of how their family and college friends have made them feel supported. Furthermore, the way a student feels supported by residence life or academic advising will not just be viewed through the multiple lenses of their friends, family, and their institution's disability services office. This highlights the vital role *Indirect Supports* play, being in the position with the greatest level of influence on the outside world. Additionally, the side of the arrow pointing toward the Individual is weighted more heavily to indicate that it is easier for each layer to influence the layers it contains than the ones containing it. For instance, it is much less likely for an individual student with ASD to influence the general attitudes of society than it is for them to be influenced by society.

It is important to understand that the words “support” and “influence” were carefully and particularly chosen in their placement within the model. The specific layers labeled “Support” were done so because the systems included in these layers have the underlying goal of helping the student. Even though they may occasionally fall short, it is believed that the ambitions of these systems are inherently positive for the student. Influence, however, has been used in any instance where one system is affecting another, but the intentions of that effect are not inherently positive. This is not to say that the influence is inherently negative, either, just that “influence” as a label is being used to signify where change can occur.

It is also important to note that the supports included in this model can move between layers, however it is most likely that oscillations will occur between the layers of *Mutual* and *Indirect Support*. This change can be expected when an individual's involvement with a particular system becomes so personal that they begin to have a strong outward influence. For example, a student who becomes deeply involved in an extracurricular activity will likely develop relationships that allow them to have an effect on the attitudes of the larger group.

This model helps explain how college students with ASD perceive and are impacted by the supports they receive, and how those working with this population can work to improve the ways these students are being supported.

Implications

Based on the analysis and discussion of this research along with the definitions laid out in the model above, the implications garnered from this research will be split into separate sections, each addressing the individuals, offices, and systems that make up the respective layers of support.

Indirect Supporters

Supporting all students, including those with ASD, is at the heart of education. Because of this, all higher education practitioners, whether faculty, staff, or otherwise, are working to support students, even if there is no clear connection to disability in one's work. Those who are in these areas of higher education can play a powerful role that is indirect in supporting students with ASD. As established above, those at the level of *Indirect Support* have the greatest potential to influence society and serve as the first lens through which society views college students with ASD. Because of this, it is important for these practitioners to remain aware of how they are working with students with ASD.

Before even getting to college, students with ASD are being shaped and developed through the education system. These individuals, whether part of a student's IEP team or not, are seen as influential in their lives. Understanding resources that are afforded to students in college and speaking about them is helpful. High school teachers and staff need to be aware of how they conduct themselves and what they say, because the way they talk about college can have a profound and lasting impact on the way those students view what is to come. While students without ASD may be more challenged by the academic rigor of college than high school, there exists a plethora of information suggesting that this is not the situation for their classmates with ASD, due in large part to being able to focus on one area of study (Jansen et al., 2017; Sefotho & Onyishi, 2021). In the case of this study, the participants identified that the academic rigor they anticipated based on comments from high school teachers was not as difficult as anticipated, thus setting them up to do better than expected in the classroom. However, the participants identified struggling with other aspects of college that high school teachers and staff can also address, perhaps even in workshops or as part of classroom conversations. These could include such topics as life outside the classroom, rapidly-changing schedules, and increased social interaction. It is important for high school teachers and staff to make this distinction so that students with ASD have a better understanding of what college is really going to be like for them. Turning as many unanticipated events as possible into anticipated ones could significantly diminish the amount of stress that new college students with ASD encounter.

The admissions process can also be daunting for most students, but for students with ASD, that can be even further heightened. These students have to determine whether or not they disclose their ASD during the application and interview processes. This is an idea they have carried with them for most of their lives and there may be some anxiety toward disclosing their

diagnosis and having that impact their opportunity for admission. What staff in these offices need to do is normalize disclosure as much as possible in the admissions process. They can do this by talking about resources on campus for all students and special populations. For example, they could invite disability services to talk with groups who are visiting campus and during that session they can talk about resources, supports for students with different disabilities, and show students where services are located on campus while on tours. This also means that the staff in these offices need to have training on how to also be advocates for students with ASD and provide appropriate direction to not just the students, but to their parents as well.

Many individuals with ASD feel misunderstood as they enter into college. One of their first official experiences comes in the way of their orientation and these offices are typically some of the best-informed, as it is their job to help students connect with many different areas of campus. This level of indirect support is critical in helping students with ASD begin to find their way around campus. It helps when the staff in the orientation office is educated on and aware of the unique opportunities and support mechanisms in place when working with the ASD population. In doing so, they also help to normalize the support and resources provided to all students without calling out a specific population. This office can help in setting a firm foundation for the students as they begin college.

As was learned in this study the participants did not anticipate having so many social interactions and making friends so easily. Those in charge of orientation need to offer information and educational opportunities for student leaders to learn about ASD and how they can engage with others who may be on the spectrum. Developing these options for learning and then creating experiences where students can connect with each other are beneficial toward creating community on campus, especially one that is supportive of all members. Orientation

sessions should also be provided for the parents of students with ASD to ensure that those in their closest layer of support are informed and equipped to support them. This means providing insight and resources to the parents during orientation and beyond. Thus, when the student turns to their parents with questions the parent may feel better equipped to help their child.

College faculty need to be educated themselves about this population of students and challenging themselves to conduct their work with accessibility and equity in mind. Principles of universal design can be employed in developing curriculum that is accessible to the majority of students rather than waiting to adopt material when required. Finding those sources for learning more can be difficult; thus, faculty can help advocate for this training on their own campuses, and over time perhaps they can become some of the educators to peers and other professionals. The following paragraphs provide insight and direction for some specific areas.

Outside of the classroom, those in the residence halls are likely to spend the most time with students with ASD. This is important because most students find their friend groups where they live, in large part because of the vast number of interaction experiences that are provided. This also means that their needs to be some education done with the residential staff. Starting with providing training for resident assistants who live on the floors as well as the residence hall professional staff. These individuals can ensure that programming is accessible and that students with ASD are being engaged in ways that work for them. They also need to review their policies and procedures to identify if they are developed to best serve all students, but especially this population.

This study has shown that there is also a noticeable lack of knowledge of institutional supports like disability services, writing centers, career services, and student success centers that are available for students with ASD. On top of a lack of knowledge, many students with ASD are

afraid to seek out these services either because they do not want to be a burden to those offices or because they do not want to be seen differently by their peers. This is an issue that every office on campus is capable of addressing. Academic advisors need to be aware of these resources and ensure that these students are being connected with the services they need and are being told directly that the services are there to help them and that they are not inconveniencing anyone by utilizing them. Similar approaches should be taken by residence life and orientation, who are both responsible for ensuring student success. Both departments need to be creating programming to provide students with ASD the information about on-campus resources. Residence life in particular, due to the closeness with which they work with students, can physically walk with students to these offices if that is what it takes to connect the students with support. While universities cannot require that students disclose any disabilities they may possess, those working in admissions should include optional opportunities for disability disclosure during the admissions process, that accentuates the benefits of disclosure. Not only will this help reduce stigmas related to ASD by showing students that they are accepted no matter what, gaining this information will allow disability services, faculty, and others on campus to reach out personally to students and offer support.

Additionally, stereotypes related to ASD are a major factor in the decision for students with ASD to disclose their diagnosis, which can impact students' social interactions, mental health, and academic performance. Individuals at the *Indirect Support* level should actively be working to remove these stigmas, and one of the most effective ways to accomplish this is by encouraging conversations on inclusivity and accessibility. The more that information about ASD is spread, and the more educated people are about these students, the more welcome and understood they will feel.

Direct Supporters

A college student with ASD may be influenced by their IEP and the team they worked with to implement it while in high school, even after they no longer utilize it. If they had a positive experience in high school in this regard, they may be more active and willing to engage with college disability services offices, and if they had a negative experience in high school, they may not. In these cases, it is also important for higher education professionals with disability experience to understand why these students may be hesitant to seek support and to articulate the benefits they will receive from disclosure. Students who did not have an IEP prior to college will also be affected by this experience, as they may not see the benefit of working with a disability services office or autism support program. Similarly, it is important for professionals in these areas to encourage these students to look for support.

Those in Direct Support of students with ASD should already be aware of how their work affects these students since their positions are specifically tailored for this assistance. When working with this population, it would be beneficial for offices like disability services or those working in an autism support program to remember that the way they are viewed by students with ASD is through the lens of the people closest to them, and this may take different forms. In some cases, a student may have been told something positive or negative about disability services by a friend that will affect the extent they seek assistance from that office. Other times, a student may hear about an institution's autism support program and speak with their parents to help decide whether to enroll there. Understanding this dynamic will allow professionals to communicate with and support these students more effectively. Raising awareness of disability services will help students without disabilities better understand the supports that are offered to

their classmates who need them, which will then make it easier for those students to seek those supports.

Those who work directly with students with ASD should similarly remember that they are also a lens through which these students view the rest of college. Before attending a program that their resident assistant planned, a student with ASD may think about what they have learned from their autism support program about time management and the importance of building relationships. Professionals in this area are also the ones who are best equipped to advocate for these students, as they possess more knowledge about these students than others on campus and likely have the most consistent interaction with them. These professionals should be working with other departments on campus, whether admissions, orientation, advising, residence life, or anything else, to ensure not only that these areas have the knowledge they need to support students with ASD, but that they are advocating for these students just as much. Other offices that do not directly deal with disabilities may struggle with tailoring their operations for students with ASD. Disability support offices are the ones who have this information and know what kind of programming would be most effective for targeting this population.

Working with the admissions orientation staffs should be a priority for the professionals in disability services. Their job should be to help this staff understand their role, purpose on campus as well as educate the admissions representative on students with ASD. And this can include developing the proper terminology used throughout their process to help newly admitted students see the benefits of disclosing their ASD diagnosis. Once these students are on campus, disability services can work with orientation to plan specific informational sessions for students with ASD to become familiar with the supports that are available for them. Part of the orientation experience is engaging with academic advising, another area that needs to be educated on these

students by disability services. When students with ASD are assigned to their particular advisor, that employee should make sure they are educated enough to support this student and make sure they are getting what they need. This ideally should be an area of training that every university employee receives from a disability services office.

Disability services offices can also work to create resources targeted at students with ASD and their families. Providing print materials such as pamphlets, brochures, and flyers that can be given out to students about campus resources, how to interact with others to build community, or even general student tips about studying or getting involved in extracurriculars can give them a level of ownership in their college experience and set them up for success. These resources could also be directed towards parents as well, focusing information on how to support their child while letting them take control of their experience. Parents could also receive a calendar from disability services that includes important academic dates, as well as social opportunities that they can encourage their students to get involved in.

Disability services offices, as well as autism support programs, have an incredibly amount of influence and insight in terms of the collaboration that could be done with areas like residence life. This department, along with others like campus activities and student life, not only have access to a large number of students, but also a great capacity for programming. Working with these areas is an opportunity that disability services offices should be seeking. This partnership could create programs focused on raising awareness, educating the student body on what ASD is and fighting the stereotypes associated with it. It also influences their ability to think about concepts of universal design and how that might be applied in their work. Doing so would not only lead to a greater acceptance of these students by their peers, but also help minimize the stigmas that they may feel when seeking the supports they need.

Disability services offices are not large when compared to other departments on a college campus. Implementing everything that has been discussed here may seem like an impossible task for these offices to accomplish alone, and that might be true. Most of the time, the effort and resources that these disability services offices and autism support programs possess gets redirected almost entirely back to the students who benefit from it, leaving little left to impact the rest of campus. However, if other departments take the initiative to work with these offices and aid in the support of students with ASD, the workload and stress on disability services offices will be decreased. If all other offices on campus work together to address the support of students with ASD, each would only need to make relatively small contributions to create impactful, widespread change.

Mutual Supporters

Individuals at this level are closer to the students with ASD than anyone else. College students with ASD typically receive and offer personal, unfiltered thoughts, questions, and opinions freely with those in this layer. These individuals are the ones who most greatly shape the experiences of students with ASD and are the first lens through which they view the world. For students with ASD, in their entire life before college, the only people who may have inhabited this level are their parents. As the student enters college, however, they begin to interact with their parents on a less regular basis and they start to develop deeper and more meaningful relationships than they may have ever before, and it is common for friends to take a closer spot in this layer than their parents.

This shift can be challenging for all involved to work through. It can be hard for the parents of a student with ASD to fully allow their child to work towards the autonomy that college provides when they likely have been deeply invested in their student their entire life. It

may also be difficult for the friends of a student with ASD to move into that role, as they may have never with this type of student before and could feel that they lack the knowledge necessary to fully support their new friend. It will also likely be challenging for the student to navigate the new social dynamics of college.

Parents of students with ASD need to find a balance in supporting their student and maintaining an influential role in their life while also giving their child the freedom and autonomy to develop the new systems of support they will find at college. These two ideas do not need to be mutually exclusive, either. In fact, parents who utilize the resources colleges offer will be more prepared to aid their student through the transition. Parents of these students may already possess some amount of ASD from their experiences working with an IEP team, but all parents of students with ASD should reach out to the disability services office at their child's institution to learn more about how ASD specifically impacts students in the college environment. Different offices on campus could provide information as well as one office collectively developing resources for parents of students with ASD. If the institution provides informational material, parents should be reading everything they can to develop a relationship with their student that balances support and autonomy. Even though they will likely not interact with their parents as much as in high school, or even at all, students with ASD are still affected by their experiences with their parents. Like the way that high school teachers and staff need to be more accurate in their depictions of college, parents of these students should also have honest, realistic conversations with their children about what college is going to be like. Maximizing what students with ASD can anticipate about college will make them more comfortable and successful once they get there and will make their transition much easier.

Friends of students with ASD should remember that they are a major influencer in how these students interact with everything else in their lives. Being encouraging and supportive is the most important thing these individuals can do for students with ASD. When they hear their friends speaking positively about disability services or faculty, students with ASD will be more likely to engage with these supports in meaningful ways. On the other hand, if they hear their friends putting down those same supports, they may be discouraged from reaching out, cutting them off from services that are crucial to their educational success. Institutions need to find ways to reach out to all students and present information that will help them learn about this population and about the positive impacts they can have on their peers.

Students with ASD should also engage with institutional supports and develop interpersonal relationships, because even though it may be challenging, it will greatly improve their college experience. Identifying sources of stress and utilizing strategies to mitigate that stress is also something that this population may not have thought about before but will help them achieve personal success. Seeking out other students with similar experiences is a tool that cannot be understated, whether that is peers who have the same major as them, those with similar hobbies, or even other students with ASD. Having other people to relate to on a personal level can spur deeper conversation and connection that will improve the way students with ASD interact with every other aspect of higher education.

Global Influences

The sphere of Global Influence is not made up by specific individuals or services, but rather by the general attitudes of society about individuals with ASD. These ideas, which at their worst may take the form of stereotypes or outright prejudice, are so pervasive that they influence every level of support for a student with ASD, even down to their view of themselves. At their

best, however, these societal views of ASD promote a sense of understanding and accommodation. Because of this, it is the responsibility of anyone who interacts with a student with ASD to learn as much as they can about how to support them as an individual. Everyone should be looking to disability services offices for information and improving their procedures to support these students. Beyond this, though, it is also everyone's responsibility to spread that knowledge so that everyone can understand not only how to support students with ASD, but the impact and importance of doing so. Spreading this knowledge will help in the fight against stigmas and stereotypes, two of the biggest obstacles standing between students with ASD and the support that will aid their success.

Overall, it will take collaboration at and between all levels to ensure that these things happen. College professionals should work with disability services and autism support programs to find ways to expand their knowledge as well as their practices to improve the experiences of students with ASD. Those who work directly with students with ASD should remember that the way they are viewed will be impacted by the personal connections of those students. Friends of students with ASD should be aware of the impact that they can have on how these friends' view the various aspects of college. Colleges that do not have a dedicated autism support program should either create one, hire a specialist to work in disability services, or look to develop relationships with other institutions that do. These programs are an incredible resource for students with ASD and as this college demographic continues to grow, if the number of these programs does not grow with it, there will exist an ever-increasing divide between the number of students who need support and the number of those who are receiving it. Lastly, individuals at all levels should be working to break down harmful societal preconceptions about ASD.

Further Research

It is impossible to fully understand this population's experience in college from one small study like this. Further research is still necessary to fully understand the experiences of college students with ASD, and what follows are recommendations for this future research.

One major limitation of this study was in the demographic makeup of the participants. Five of the six participants were male, and all six were white. Although this was not intended by the study, obtaining a more diverse sample of participants could allow for a better, more complete understanding of the transition experiences of students with ASD. A more diverse sample could also lead to the identification of how individual identity factors like race, sex, and gender affect the experience of students with ASD. This study could also be done by narrowing in on specific demographics as well, such as looking at only females, or only Black males to learn about those unique dynamics and how that impacts their experience.

The purpose of this study was to understand the transition experience from the student perspective. Interviewing higher education professionals, both those that work with students with ASD and those who do not, might share a unique perspective and improve the understanding of how professionals can effectively work with these students. Also, interviewing the parents of students with ASD about the ways they support their children could offer better insight into the long-term factors that specifically influence these students transition to higher education.

Conducting a similar study, but with a larger number of participants could also prove to be beneficial in understanding the intricacies of how students with ASD navigate the transition to college. A larger sample size could also help improve the model that was created in this study. Being that the goal of this model was to understand how college students with ASD are supported, determining how this model could be improved could also lead to an improvement in

the supports that these students receive. This study should also be replicated at different types of institutions with different levels of support provided to students. Not every institution is able to have a specific program for students with ASD, while others may have more resources than students could even imagine. Size of institution can also play a role in this and looking at institutions with different sets of populations could provide new and further insights.

Interviewing higher education students who possess a diagnosis of ASD but have not disclosed their diagnosis to their institution could provide incredibly beneficial information regarding the decision to disclose. Only one participant of this study had not disclosed his diagnosis to his institution and the experiences he shared about his decision-making process was very useful in the development of the theoretical model created in this study. Obtaining a sample of 10-20 students who have not made this disclosure could significantly contribute to the larger conversation on disclosure and offer valuable insights into how institutions can encourage students to disclose in order to provide them with the supports they may need. On the other side, interviewing students who were diagnosed during or before elementary school could also provide greater perspective.

Most importantly, this research could be conducted through a longitudinal study of this population, starting with participants in high school and conducting interviews and observation through their time in college. This would provide some of the most interesting and intriguing perspectives that could truly change the way higher education provides support for this population.

Conclusion

This qualitative study explored the experiences of college students with ASD, including how they view themselves and the situation of their transition, where they find support while at

college, and the factors that impact their decision to disclose their diagnosis of ASD. This research found that students with ASD are influenced in many ways by the individuals and services they interact with in their transition to and once at college. These students greatly value the feelings and opinions of those closest to them and will use those connections as a lens through which they view the rest of their college experience.

This study also showed that each of a student with ASD's supports have an effect on each other and on the broader attitudes of society regarding individuals with ASD. A need was identified for college professionals to encourage students with ASD to build connections that they can rely on for support as well as a need for greater collaboration between departments at higher education institutions. Improving understanding and feelings of inclusion was central to many of the themes found in this study, highlighting the importance of building college environments that are effective in welcoming students of all backgrounds and abilities.

There are more students with ASD in higher education now than ever before, meaning it is now more important than ever before to ensure that these students are supported in ways that will guarantee their success. College students with ASD will likely face challenges that are different from those experienced by their peers, so acknowledging that higher education professionals will need to become more diverse in their approach to supporting students is vital. The mission of higher education is to support students and understanding the experiences of students with ASD will allow institutions to better support EVERY student.

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APPENDIX A**Invitation Email**

Dear [University A] Student,

My name is Tj Estabrook, and I am conducting research on the transition process that students with autism spectrum disorders go through when going from high school to college. Because you have disclosed a diagnosis of an autism spectrum disorder with your university's Student Disability Services office, I am interested in interviewing you about your experiences. I am currently a graduate student pursuing a master's degree in College Student Affairs at Eastern Illinois University and this topic is the subject of the thesis I am writing under the direction of Dr. Dianne Timm. If you are interested in participating in this study, please take a minute or so to fill out this form:

https://qfreeaccountssjc1.az1.qualtrics.com/jfe/form/SV_3Wqk1kXNEp4Die

If you are found to be a good fit for this study, you will be asked to complete an interview that will take roughly an hour in length. If you have any questions, please contact me via email (tjestabrook@eiu.edu).

Thank you,

Tj Estabrook

tjestabrook@eiu.edu

APPENDIX B**Demographic Form**

Name:

Age:

Did you start college right after high school: Yes No

Year in School: First Second Third Fourth Fifth+

Major:

Minor:

Where do you live: On campus residence hall On campus apartment Off campus

Have you been diagnosed with autism spectrum disorder? Yes No

At what age:

Did you have an Individualized Education Plan (IEP) in high school? Yes No

Are you a member of an autism support program Currently? Yes No

Have you been a member of an autism support program? Yes No

Have you used disability support services while in college? Yes No

Would you be interested in participating in an interview with a graduate student about your experiences in college: Yes No

APPENDIX C

Interview Protocol

Welcome participant and thank them for their participation. Collect participants' informed consent forms, providing them with a new copy if needed. Allow participants to ask questions about the study and interview process before beginning.

1. When did you know you wanted to go to college? Can you tell me about your process of selecting where to go?
 - a. Who influenced you in wanting to go to college?
 - b. How did you learn about college(s)?
 - c. Where did information come from? How did you obtain it?
 - d. Did anyone from your high school talk to you about going to college? Who?
2. What did you think college would be like?
 - a. How did you think it would be different from high school?
 - b. Where did this information come from?
 - c. Did you talk with people at colleges? Who?
 - i. What did those conversations look like?
3. How does your current view of college match up with what you thought it would be like?
 - a. What are the similarities?

What are the differences you have experienced?
4. Tell me about your experience in transitioning to college?
 - a. What was the orientation process like?
 - b. What was easy for you?
 - c. What caused you stress?

- d. Who did you get to know as you came here?
 - e. How did you spend your out-of-class time during those early periods.
5. Tell me about your life in college thus far?
 - a. What are your classes like?
 - b. How do you spend your time outside of class?
 - c. Do you have a daily routine?
6. What kind of a student are you?
 - a. What would your faculty tell me about you as a student?
 - b. What would your classmates tell me about you as a student?
 - c. What would your friends tell me about you as a student?
7. Tell me about your friend group(s)?
 - a. Who are in your friend groups? Classmates, Floormates/roommates, organization involvement friends?
 - b. How do you spend your time with these groups?
 - c. What would they tell me about you?
 - d. What role do you play in your friend group?
8. What resources on campus have you utilized as a student?
 - a. How did you learn about these resources?
 - b. In what way does this resource help you?
9. Tell me about the disclosure process you went through with disability services office.
 - a. When did you disclose.
 - b. What did you need to provide?
 - c. What did you learn through the process?

- d. Have you continued to meet with anyone in that office?
 - e. What sort of accommodations have they helped you with?
10. Have you disclosed your ASD diagnosis to any officials (Faculty, staff) on campus? If so, who?
- a. Can you describe the process of disclosing?
 - b. What influenced your decision to disclose?
 - c. Tell me about situations where you had to disclose or chose to intentionally not disclose your ASD diagnosis.
11. Have you disclosed your ASD diagnosis to classmates and friends?
- a. Which friends have you shared this with and what made you share?
 - b. What influenced your decision to share?
 - c. Are there friends/classmates you have intentionally not shared this with? Why?
12. What causes you stress and how do you manage it?
- a. Academics, friend groups, living situation, studying?
 - b. How do you manage the stress?
 - c. What do you do when you are stressed?
 - d. Are there people or a person you go to? Do you talk to anyone about your stressors?
 - e. What skills/attributes do you feel help you succeed? Cause difficulty?
13. What strategies have you learned to be a successful student?
- a. Where did you learn those strategies?
 - b. Who taught you those?
 - c. What do you do when they do not work?

14. What support do you need to help you be a successful student?
 - a. How did you learn about that support?
 - b. How has it helped support you?
 - c. Was there a time that it was not supportive?
15. How often do you find yourself needing support or resources?
 - a. How do you know when you need support?
 - b. Do you seek out input from others in finding support? What does this look like?
 - c. What supports have you utilized outside the institution?
 - d. What more would be helpful to you?
16. As you prepared for this interview were you expecting me to ask you something specific that I did not cover? If so, what was it?