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The Lived Experiences of Students with High Functioning Autism in Higher Education

by

Aida C. G. Miles

A dissertation submitted to the faculty of Bethel University  
in partial fulfillment of the requirements for the degree of  
Doctor of Education.

St. Paul, MN

2019

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## Abstract

A growing number of students with high functioning autism (HFA) are entering higher education; this number is expected to grow as the prevalence of autism continues to rise. Students with HFA face many challenges when entering higher education. These challenges produce an environment that impedes student success and potential degree completion. This study explored the lived experiences of 17 participants with HFA who were enrolled in private colleges and universities in a metropolitan area of the Midwest. Although disability services offices are mandated to provide accommodations to students with disabilities, some of the challenges faced by participants were not supported by the services provided at their institution. Social and communication challenges were common areas not fully covered through accommodations, which precluded many participants from requesting assistance from instructors when having difficulty in class. Many participants also indicated discomfort with meeting people in college and challenges establishing friendships. The prevalence of mental health disorders arose as a salient theme, with most participants experiencing significant anxiety, at times impeding some students' ability to attend class and succeed academically. Many research opportunities exist to ascertain the best support systems needed to assist students with HFA in navigating higher education with ease. Students with HFA attending college or university need to grow, not only academically, but also by learning social and communication skills that will be instrumental in their future lives as more independent adults.

## Dedication

Prior to the start of the semester Jane contacted her instructor to speak about the accommodations she needed for the course. They agreed on a place, date, and time to meet, a seemingly simple matter. However, Jane asked for very specific directions on how to get there and how to find the instructor's office. The level of detail that Jane requested seemed so extreme that the instructor wondered if she was visually impaired.

Jane was not visually impaired; she was an articulate, yet very anxious lady, who was also clearly intelligent. She took copious notes during their meeting and asked about every minute detail of how the course would progress, above and beyond what the syllabus included. Jane's requests included copies of Power Point presentations ahead of time (two slides per page), additional time for assignments and tests, a seat in the front row, and audio-recordings of lectures. The instructor and Jane worked together closely during the semester to meet Jane's needs.

This interaction was the beginning of a long journey between this pair. Upon graduation Jane entered a health professional graduate school. What ensued was four years of hearing and witnessing the challenges that Jane endured throughout her training. A program that was only two years long took her almost four years to complete, and the road was steep and littered with obstacles. The instructor described above served as an advocate for Jane at times; she saw the type of treatment that Jane received from professors and staff. She also heard about comments and complaints of fellow students, all related to the characteristics of Jane's disability which made her irritating to them. Jane was different; she was not like the other students in her program who had good social skills, learned quickly, efficiently produced excellent work, and

did not need extra help and guidance. It seemed that other professors and staff misunderstood Jane's behavior and might have resented her peculiarities.

Although Jane did not disclose her diagnosis to the instructor, she exhibited attributes of someone with high functioning autism. This dissertation is dedicated to Jane and to all people with autism who enter higher education. While college life is a challenge to most students, the experience is especially difficult to those with a disability, particularly when this disability is invisible, as is the case for many people with autism who are higher functioning.

## Acknowledgments

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## List of Abbreviations

ADHD – Attention Deficit Hyperactivity Disorder

APA – American Psychiatric Association

ASD – Autism Spectrum Disorder

CDC – Center for Disease Control and Prevention

CD – Conduct Disorder

CGAS – Children’s Global Assessment Scale

DOSS – Disability Office for Support Services

ER – Emergency Room

GPA – Grade Point Average

HFA – High Functioning Autism

IEP – Individualized Education Plan

ILS – Independent Living Support

IPA – Interpretative Phenomenological Analysis

IQ – Intellectual Quotient

MIS – Management Information System

MDD – Major Depressive Disorder

NIMH – National Institute of Mental Health

OCD – Obsessive-Compulsive Disorder

ODD – Oppositional Defiant Disorder

PCA – Personal Care Assistant

PTSD – Post-Traumatic Stress Disorder

SAD – Seasonal Affective Disorder

SOR – Sensory Over-responsivity

TEACCH – Treatment and Education of Autistic and Communication Handicapped Children

PECS – Picture Exchange Communication System

## **Chapter One: Introduction**

### **Introduction to the Problem**

Autism Spectrum Disorder (ASD) is a developmental disability that can cause difficulties in socialization, communication, and behavior (Centers for Disease Control and Prevention [CDC], 2016a). Autism is an increasingly prevalent diagnosis among children in the U.S. with one in 59 children currently affected by the disorder (CDC, 2016b). With the rising prevalence of autism, experts anticipate that more youth with this disorder will enter higher education in the years to come; however, colleges and universities may not be equipped to provide the services these students could need (Gelbar, Smith, & Reichow, 2014).

Autism is found in people of all racial, ethnic, and socioeconomic groups in the U.S.; the disorder is also reported in Asia, Europe, and other parts of North America with an average prevalence of one to two percent. For reasons that are not clear, ASD is four times more common in boys than in girls (CDC, 2016b). People with ASD do not have physical features that distinguish them from others; rather they have problems with social interactions, expressing emotions, adjusting to changes, and communicating (CDC, 2016c). Their cognitive ability (how they learn, think, and problem solve) varies widely; some people with ASD are intellectually gifted while others suffer from intellectual disabilities (CDC, 2015). Autism is typically identified in early childhood (CDC, 2016a), although many who are higher functioning are identified later in life (Mazurek et al., 2014). Because no cure exists, the disorder typically lasts a lifetime (CDC, 2016a); however, some children can achieve a normal range of cognitive social and adaptive skills (Blumberg et al., 2016).

## **Background of the Study**

Given the projections that employment in the U.S. requires some type of college training, higher education is a goal for many youth (Carnevale, Smith, & Strohl, 2010). With the rise in the number of youth being identified as having autism, increasing numbers of people with ASD are entering higher education (Gardiner & Iarocci, 2014); however, they enroll at lower rates compared to youth with other disabilities (Shattuck et al., 2012). According to a longitudinal study conducted by the U.S. Department of Education (Sanford et al., 2011), approximately 47% of people with autism enroll in higher education within six years of high school graduation, and of these, only 35% earn a degree. This graduation rate is lower than that of students with disabilities in general, who have a completion rate of 38%, and lower than the completion rate of the general population, estimated at 51%.

Low rates of employment among adults with autism have also been found; these studies did not differentiate between individuals who completed any higher education and those who did not. Some studies indicate that only 25-50% of adults with ASD have some type of paid employment, and of those employed, many are underemployed (Hendricks, 2010). Sanford et al. (2011) found that only 45% of adults with autism were employed at the time of their interview, which was lower than the rate for people with learning disabilities (79%), mental retardation (46%), and multiple disabilities (46%). Even among people with autism who are high functioning (possessing an average intellectual quotient), rates of higher education completion and employment are low, with researchers finding that approximately 25% of those who began higher education or pursued employment completed their studies or maintained their jobs over time (Taylor, Henninger, & Mailick, 2015). The low graduation rates and attainment of employment are surprising given the intellectual ability of people with high functioning autism.



Transitioning from high school to higher education is difficult for all youth; students need to acquire and then apply new skills such as advocating for themselves, developing self-efficacy skills, adjusting to changing social contexts, and acquiring social independence (Girelli & Fisher, 2013). People with high functioning autism (HFA), largely due to the characteristics of their disorder, find these changes particularly difficult to maneuver. Characteristics of people with HFA include a need for routines and a resistance to change, heightened sensitivity to sensory input (light and/or noise), impaired ability to interact socially, difficulty engaging in conversations, impaired ability to build and maintain relationships, and lack of emotional reciprocity (Girelli & Fisher, 2013). Additional characteristics exhibited by people with HFA may include engaging in repetitive behaviors or having restrictive interests. People with HFA might have normal language and cognitive abilities as well as an above-average intellectual capacity (Girelli & Fisher, 2013). Despite this, many characteristics of their disorder greatly interfere with their ability to function, particularly during times of change such as entering higher education.

### **Statement of the Problem**

More people with ASD are finishing high school and enrolling in higher education, yet not enough is known about their experiences and support needs to succeed in college (Gardiner & Iarocci, 2014; Gelbar, Smith, & Reichow, 2014). People with HFA are typically regarded as not having academic challenges. Therefore, they are considered capable of pursuing higher education effectively. However, their difficulty with communication, social interactions, organizational skills, and adjusting to changes pose significant challenges (Matthews, Ly, & Goldberg, 2015). Performing well academically in high school may mask barriers that can interfere with the overall school success of individuals with HFA, as many of their impairments

are not evident to others (Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012). College students with HFA have been described as needing support in daily activities, not just academics (Fleischer, 2012). Sadly, the scant literature described their college experience as marked by anxiety, loneliness, depression, isolation, and marginalization (Gelbar et al., 2014).

Many of the challenges people with ASD face, including those with HFA, pertain to social interactions. For example, difficulties with living away from home for the first time, living in dormitories, having roommates, taking care of themselves, and dating have all proven to be challenging for people with ASD (Gobbo & Shmulsky, 2014). Other difficulties encountered involve aspects that impact their academic performance, such as challenges understanding the big picture, organizing time, setting long-range plans, working in groups, and interacting with others in the classroom (Gobbo & Shmulsky, 2014). In a qualitative study of 18 college faculty who participated in focus groups, Gobbo and Shmulsky discovered that the challenges that faculty observed among students with ASD in the classroom could be categorized into three groups: having deficits in social skills, exhibiting difficulty thinking critically, and showing high anxiety that precluded learning.

Social skill deficits described by faculty included not understanding nonverbal social cues, lacking perception when discussions moved to other topics, and portraying a poor ability to contribute in group settings (Gobbo & Shmulsky, 2014). Other social challenges included lack of physical boundaries (getting too close or not close enough to people), lack of discussion boundaries (talking too much, interrupting others, or not talking), and lack of eye contact. These challenges often caused difficulties as students with ASD did not want to work with others, and peers did not want to work with them.

Faculty described difficulties with critical thinking in students with ASD as having trouble recognizing who the audience was, or could be, during writing and other assignments (Gobbo & Shmulsky, 2014). Seeing the big picture was also regarded as a challenge, with students able to see the parts but not the whole, having difficulty generalizing ideas, and having trouble with abstract thinking. Faculty also regarded students as lacking flexibility and seeing things as either right or wrong. Students with autism exhibited a lack of tolerance for ambiguity, the need to be right, and the need to know what the right answer was (Gobbo & Shmulsky, 2014).

Faculty also noted escalating anxiety among students with ASD, commenting that social situations, including group work, tended to increase anxiety (Gobbo & Shmulsky, 2014). This anxiety had the propensity to escalate, and if not managed, could interfere with their classwork. The way in which anxiety was exhibited oftentimes involved disengaging and becoming more rigid, and sometimes included leaving class.

Although students with HFA have some characteristics that could be interpreted as ideal for college success, such as their diligence, passion for certain topics, and high intellectual ability, their social and communication difficulties often encumber their success (Gobbo & Shmulsky, 2014). Given their unique challenges, high drop-out and failure rates, as well as low graduation and employment rates among students with HFA (Roux, Shattuck, Rast, Rava, & Anderson, 2015), are not surprising. With the estimate that about 48,500 people with autism in the U.S. turn 18 each year (Shattuck et al., 2012), exploring the college experiences that impact their likelihood of success or failure as they embark in their higher education journey is essential.

Therefore, the problem addressed in this study is the limited success rate of people with HFA when enrolled in institutions of higher education. If these individuals are unable to manage

the higher education environment, their chances at future employment could be compromised. As such, their long-term ability to be independent and contribute as productive members of society may be limited.

### **Purpose of the Study**

This study intended to expand what is known about people with ASD entering higher education and elucidate areas that may be related to increased retention, degree completion, and increased chances of success in becoming productive members of society. The focus was on individuals with high functioning autism (HFA), using the definition of HFA by Bockler, Timmermans, Sebanz, Vogeley, and Schilbach (2014), which included individuals previously diagnosed with Asperger's syndrome and childhood autism who have average or above average intellectual quotient (IQ). Because these students do not have an intellectual disability, the expectation is that they can be academically successful. However, they encounter many challenges when entering higher education. The purpose of this phenomenological study was to explore the lived experiences of students with high functioning autism when enrolled in a four-year institution of higher education.

### **Research Questions**

The main research question was: What are the lived experiences of students with high functioning autism who are enrolled in institutions of higher education?

Research sub-questions were:

1. How do students with high-functioning autism describe their lived experience while attending an institution of higher education?
2. How do students with high-functioning autism describe their lived experience as they interact with the higher education system?

## **Significance of the Study in the Education Field**

Although ample research exists focused on early educational practices for children with autism, the literature on higher education experiences and practices for this population is limited (Matthews et al., 2015). The lack of sufficient research is concerning because people with autism will spend most of their lifetime in adulthood (Shattuck et al., 2012). This gap in the literature is also alarming given that the number of people diagnosed with autism is rising (CDC, 2016b) and more of these individuals are expected to enter higher education institutions in the future (Gelbar et al., 2014). Given the high number of students with autism that may pursue a college degree, the need to focus on this segment of the population and their future is important.

## **Rationale**

For higher education professionals, the challenge is no longer *if* they will meet a student with autism, but *when* they do. College faculty, administrators, support staff, and peers need to have knowledge of the unique challenges that these individuals face to provide the support systems needed to succeed (Barnhill, 2016). Because of their academic achievements, students with HFA may not have difficulty gaining college admission. However, the college retention rate of students with HFA is low (Siew, Mazzucchelli, Rooney, & Girdler, 2017). Institutions have provided services for students with HFA in the same way that they have provided services for students with other disabilities. However, people with HFA have significantly different needs compared to other students with disabilities and thus require a unique set of support systems that may not be in existence (Barnhill, 2016).

Differences exist between the accommodations students with disabilities receive in public elementary, middle-, and high-school, versus accommodations received in higher education (Gil, 2007). Public schools in the U.S. provide services to students with disabilities as mandated by

the Individuals with Disabilities Act (IDEA) of 2004 (IDEA, n.d.). Under IDEA, public schools provide services to students with disabilities that focus on the individual's success in the educational environment. Individualized goals are designed for each student, which may include curricular modifications to achieve the student's success. Therefore, by law, public schools provide regular or special education, in addition to any additional services or aids, to meet the individual educational needs of the student with a disability (U.S. Department of Education Office of Civil Rights, 2018a). Public schools must prepare an individualized education plan (IEP) for each student with disabilities, with input from parents/guardians, teachers, and students. Schools must provide any services deemed necessary, which may include personal attendants and assistive technology devices (Gil, 2007).

Post-secondary institutions are mandated to provide services to students with disabilities under Section 504 of the Rehabilitation Act of 1973 (U.S. Department of Education, Office of Civil Rights, 2010), and under the American with Disabilities act of 1990 (United States Department of Justice, n.d.). Higher education institutions must provide appropriate academic adjustments and additional services to students with disabilities as to allow an equal opportunity to participate in the school's programs. Post-secondary institutions are not required, however, to make changes or provide services that would constitute significant changes to the program or produce increased burden (U.S. Department of Education Office of Civil Rights, 2018b).

Additional differences exist between services in elementary and high-school, compared to those provided in higher education for students with disabilities based on federal law. In college, students who need accommodations must register with the disabilities office at the institution and provide documentation attesting to the disability and needed academic adjustments. Accommodations provided may include additional testing time, allowing the

audio-recording of courses, providing priority class registration, and securing interpreters (sign language). However, higher education institutions do not need to make modifications that would substantially change the nature of a service or program. In addition, colleges are not required to make changes that would be financially or administratively burdensome. For example, the provision of personal attendants, tutoring, or personal devices are not required (U.S. Department of Education Office of Civil Rights, 2018b).

Barnhill (2016) conducted a search to identify higher education institutions that claimed to provide specific support systems for students with ASD and HFA. The author found that 45 colleges and universities stated they provided specific supports for this student population. Although the author did not specify how the search was conducted, this number is less than one percent of the total number of post-secondary institutions (two- and four-year) in the United States, which is 4,726 (U.S. Department of Education, 2016). Upon surveying these institutions, Barnhill (2016) found that the most common accommodations provided to students with autism included additional time to take exams, alternative testing sites, note-taking assistance, academic technology supports, job-seeking resources, reduced course loads, copies of instructor's notes, life skills supports (budgeting, hygiene, doing own laundry, dating), social skill development assistance, peer mentors, and priority registration (Barnhill, 2016).

This list exemplifies the variety of support systems and accommodations that students with ASD and HFA need to navigate college life. Barnhill (2016) also found that most programs for these students relied on parent support and kept parents informed of student progress (with students' permission). The survey findings also indicated that few programs had been in existence long enough to have data on graduation and post-graduation employment rates. Most

respondents estimated that these students completed a four-year degree in approximately five years.

Barnhill (2016) stated that many issues remain unsolved regarding support systems for students with ASD and HFA in college. Issues needing additional research included balancing student integration with peers while providing additional support systems, and whether summer transition programs were instrumental for students with ASD and HFA. Another area that needed investigation was determining which students with ASD and HFA benefitted the most from special support systems geared specifically for students with autism. Barnhill (2016) also found that one third of the institutions claiming on their websites to have structured support systems in place for students with ASD and HFA did not actually have them. In addition, Barnhill (2016) found that existing support programs for students with autism were operating without prior student needs assessment or outcome tracking; thus, further research is needed.

The ability to complete a higher education degree is important for many people with disabilities, including those with HFA. For several decades, students with disabilities have lagged in their ability to succeed after high school graduation, both in obtaining employment and/or a higher education degree (Kohler & Field, 2003). The area of transition planning for youth with disabilities has matured over time, to ensure greater success for people with disabilities. In a review paper, Kohler and Field (2003) highlighted the complexity of transition planning for people with disabilities. The authors stated that transition for youth into adult roles is a complex process and multiple factors affect students' lives after finishing high school. Additionally, the authors indicated that transition success relied heavily on the characteristics of both the student and the family, as well as their economic condition, community supports, and services available to them.



Kohler and Field (2003) also highlighted the need for collaboration among various stakeholders, and an individualized approach, as central to transition planning. Their literature review reinforced that transition planning included the involvement of various stakeholders assisting the student with continued skill development. These stakeholders included educators, service providers, and families. Additionally, Kohler and Field (2003) emphasized the need for service provision beyond high school for skill development and to continue to enhance students' abilities. These authors reiterated the importance of individualized services, stating that “‘one size fits all’ and ‘check the box’” (p. 181) strategies cannot meet the unique needs of students with disabilities.

Although Kohler and Field (2003) examined the literature on students with disabilities in general, their findings apply to people with HFA as well. As students with HFA transition from high school to higher education they encounter various changes, including increasing levels of independence, self-directing their learning, managing their time within schedules that lack the structure to which they are accustomed, encountering new peer groups, facing different social situations, and for many it also entails living away from home for the first time, sometimes in a different geographical area (Mitchell & Beresford, 2014). The distinguishing uniqueness between youth with HFA entering college and other youth with disabilities is that their intellectual ability and their past educational success may mask their struggles and needs for support systems (Mitchell & Beresford, 2014). Additionally, college students with invisible disabilities have found it more challenging to obtain needed accommodations when compared to the needs of students with visible disabilities, which schools more readily meet (Magnus & Tøssebro, 2014).

Given the increased number of students with HFA entering higher education institutions (Gardiner & Iarocci, 2014; Gelbar et al., 2014) and the lack of research pertaining to their specific needs (Matthews et al., 2015), an exploration is warranted of what these students described as their lived experiences navigating the higher education environment. This study will help fill this knowledge gap through documenting the lived experiences of students with HFA enrolled in higher education institutions. By reading about their lived experiences, including challenges faced that may differ from those of other students with disabilities, transition planning and higher education professionals can gain knowledge on supportive systems that may assist these students in succeeding in their higher education endeavors.

### **Definition of Terms**

**Autism Spectrum Disorder:** According to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) (Livanis, Almodovar, & Skolnik, 2017), Autism Spectrum Disorder is a neurodevelopmental disorder that is evident when a child's development portrays areas of low functioning. Two sets of characteristics must be present for a child to receive this diagnosis. First, the child should show deficits in social and communication interactions in various contexts. Second, the child should exhibit restrictive and repetitive behavioral patterns.

The term Autism Spectrum Disorder, as defined above, has been in effect since 2013 when the DSM-5 was published. Prior to this publication, the term utilized was Autism Spectrum Disorders (plural), as an umbrella term that included individuals with deficits in socialization, communication, and who exhibited repetitive stereotypical behaviors (Livanis et al., 2017). An individual could be diagnosed with autism (lower functioning), Asperger disorder

(high functioning, no intellectual disability), childhood disintegrative disorder, Rett's disorder, and pervasive developmental disability—not otherwise specified.

With the publication of the DSM-5 in 2013, the sub-categorization of autism was removed. Instead, an individual could be diagnosed with an Autism Spectrum Disorder, with the understanding that the severity varied widely (Livanis et al., 2017). Thus, the term Asperger disorder (also known as Asperger's syndrome) was removed as a diagnosis.

The term *high functioning autism* encompasses individuals who had a diagnosis of Asperger's syndrome prior to the publication of the DSM-5. It includes people who meet the definition criteria for Autism Spectrum Disorder who do not have intellectual disability, thus are higher functioning (Bockler, Timmermans, Sebanz, Vogeley, & Schilbach, 2014).

### **Assumptions and Limitations**

Several assumptions were made when planning the study. The assumption that disability services offices at various private schools would be willing to assist the researcher with participant recruitment was made. An additional assumption was that a number of students with HFA who were informed about the study would agree to be interviewed. The researcher also assumed that students would be more willing to participate in the study if they received an incentive in the form of a gift card. Lastly, the assumption that participants would feel comfortable expressing themselves and sharing their lived experiences with the interviewer was made.

This study had several limitations. Only private schools were approached to solicit assistance with student recruitment. Students with HFA who enroll in a private school may differ from students attending public institutions of higher education. The number of participants interviewed, although within the parameters recommended for a phenomenological research

study, was still low at 17 students. The findings, therefore, are not generalizable to wider populations of college students with HFA. Lastly, because of the social and communication difficulties that people with autism exhibit, the possibility exists that participants were unable to accurately relay to the interviewer certain nuances of their lived experiences, which could have been hard to describe verbally.

### **Nature of the Study**

The present study was a qualitative phenomenological investigation exploring the lived experiences of individuals with HFA enrolled in higher education. A qualitative study was pursued as to give voice to students with HFA, allowing them to express themselves freely and provide the audience with a window into their lived experiences.

### **Organization of the Remainder of the Study**

The remaining chapters in this dissertation are organized as follows. First, the literature review provides an overview of what autism is, how the disorder is identified, and what treatment options are available. It also differentiates between Autism Spectrum Disorder (ASD) and high functioning autism (HFA). The literature review also summarizes research articles pertaining to youth with ASD and HFA who may enroll in higher education, including what is currently known about potential challenges and outcomes. Chapter Three provides a detailed account of the methodology followed in this study, explaining the type of phenomenology utilized, which was Interpretative Phenomenological Analysis. Following this information, Chapter Four outlines the results gathered through the 17 participant interviews. Because this is a phenomenological research study with an aim of giving voice to students with HFA, quotes from participants were included throughout as to give the reader an opportunity to hear participants' accounts. Quotes of participants were not edited to give the reader an idea how

difficult communication can be; participants paused often, repeated words frequently, and struggled, at times, to find the words to express their thoughts. Chapter Five includes a description of the themes identified through the interviews and compares these findings with existing literature. Recommendations for higher education personnel and academicians were made, based on study findings. A summary of findings is included at the end of this dissertation.

## **Chapter Two: Review of the Literature**

### **General Information about Autism**

Autism Spectrum Disorder (ASD) encompasses a range of developmental disorders broadly characterized by having impaired social communication skills and restrictive areas of interest (American Psychiatric Association [APA], 2013). The most recent estimate is that autism occurs in one in 68 people in the U.S. (Christensen et al., 2016). Having a child with autism is also more common, at a rate of 10-19%, in families who already have a son or daughter with the diagnosis (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010; Grenborg, Schendel, & Parmer, 2013; Ozonoff et al., 2011). People with ASD have symptoms, skill sets, and levels of disability that range widely, from mild to severe. They have distinctive characteristics that include having social difficulties (challenges with communication and social interactions), having a narrow set of interests, engaging in repetitive behaviors, and exhibiting other symptoms that impact their ability to function in various areas of life. The severity of signs and symptoms varies among individuals; some people will exhibit more behaviors associated with autism than others, and to various levels of intensity (National Institute of Mental Health [NIMH], 2016).

Early identification of ASD is encouraged because of evidence that outcome improves with early intervention in young children (Zwaigenbaum et al., 2015). One reason is that a significant amount of brain development occurs in the first two years of life, thus early diagnosis with immediate intervention can positively affect these children. Recent research has facilitated the detection of ASD characteristics in children before the age of two (Zwaigenbaum et al., 2015). Because of the benefit of early identification, the American Academy of Pediatrics recommends that pediatricians screen all children for autism at the 18- and 24-month visits, or earlier if there is a concern expressed by the parent, the physician, or others (Johnson & Myers,

2007). The current median age of diagnosis of autism is 52 months, thus efforts toward early diagnosis are important (Baio et al., 2018).

**Diagnosis of autism.** Autism is diagnosed based on signs and symptoms, which may be seen by parents or health professionals in preschoolers, since symptoms are present at an early age (NIMH, 2016). If not identified earlier, school personnel may notice behaviors characteristic of autism in school-age children and adolescents (NIHM, 2016). This delay in diagnosis may be due to a child's high intellect and compensation masking challenges, a strong family and social support system, symptoms being mild, or other disorders and psychiatric conditions obscuring the presence of autism (Bastiaansen et al., 2011).

Signs and symptoms of autism are divided into two main categories, exhibiting restrictive or repetitive behaviors, and having difficulty with social communication and interactions (NIHM, 2016). Restrictive and repetitive behaviors may include engaging in a behavior multiple times or exhibiting unusual behaviors, like hand flapping. Repetitive behaviors may also manifest as having an intense focus on certain objects or activities, for instance spinning a toy-car's wheels for long periods of time. Another type of repetitive or restrictive behavior includes having a very strong interest in specific topics, for example focusing intensely on numbers or train schedules (NIHM, 2016).

Social communication and social interactions challenges may be numerous. Children with autism may portray great anxiety, including crying and screaming, if a routine is disrupted or upon entering an environment that they find excessively stimulating (too noisy, for instance) (NIHM, 2016). Children with autism may fail to make eye contact and do not typically share attention to an object with others; for instance, failing to point at an airplane to show a parent. Other communication challenges include seeming inattentiveness when others are speaking to

them, or not responding when called. If verbal, people with autism may have trouble carrying on a conversation. Children with autism may also have difficulty interpreting facial or verbal cues that show other people's feelings. Due to their difficulty with interpreting social cues, some people with autism may dominate a conversation by speaking excessively about their own interests. The tone of voice of people with autism is sometimes described as robot-like. Some children with autism also repeat phrases verbatim, often out of context, which is called echolalia (NIHM, 2016). For example, they may repeat what someone is saying at the time, or they may quote verbatim a marketing phrase they have heard on television. Another characteristic of autism is difficulty understanding other people's perspective, in addition to having trouble understanding or predicting other people's action (NIHM, 2016).

In addition to the signs and symptoms related to repetitive behaviors or communication challenges, people with autism may also have other difficulties, including gastrointestinal problems, sleep problems, irritability, and heightened sensitivity to tastes, smells, light, clothing, or temperature (NIHM, 2016). Another characteristic is that some have above-average abilities in certain areas, despite other challenging symptoms. For example, some have above-average intelligence, are able to memorize and remember a considerable amount of information and have superior abilities in certain areas, such as math or science (NIHM, 2016).

Because autism is diagnosed based on symptoms, and every individual with autism differs in terms of symptom severity, arriving at a diagnosis is challenging. Diagnosis is also complicated because no marker or test exists to conclusively ascertain that a person has the disorder (CDC, 2015b). Diagnosis in early childhood involves conducting a developmental screening, typically done by a primary care provider, and a subsequent comprehensive evaluation by an autism specialist, such as a trained psychologist or developmental pediatrician (CDC,



2015b). Experts recommend that every child be screened for autism during the 18- and 24-month visit to the pediatrician. If a child has a sibling or a parent with autism, or if symptoms of autism are identified, screening for autism should be done earlier than 18 months (CDC, 2016d).

If an infant or young child is thought to potentially have autism, the child is referred for additional testing by a developmental pediatrician or another trained professional (CDC, 2016d).

For adolescents and adults, diagnosis may be more difficult. School personnel may notice a child's behaviors and suggest that additional testing be done. The tool that has been shown to be reliable among older children is the Autism Diagnostic Observation Schedule (ADOS) module four (Lord et al., 2000). ADOS is a standardized instrument that evaluates a person's social interactions, level of imagination, and communication skills during a semi-structured interaction with a trained clinician (Bastiaansen et al., 2011). Adults who have concerns about potentially having autism are referred to specialists who conduct interviews about various behaviors and review the person's developmental history (NIHM, 2016).

Some people are at greater risk of having autism. Boys are more likely to have a diagnosis of autism than girls. Children who have siblings with autism have a greater likelihood of having this disorder. Offspring of older parents (mother over 35 years, father over 40 years) are also more likely to have this diagnosis. In addition, people with some genetic conditions have a higher likelihood of having a diagnosis of autism; these conditions include Fragile X, Down syndrome, and tuberous sclerosis (NIHM, 2016).

**Treatment of autism.** Just as no one test exists to conclusively diagnose autism, no single treatment for the disorder is available. Intervening early can help alleviate symptoms and assist individuals in capitalizing on their strengths (NIHM, 2016). According to the Centers for

Disease Control and Prevention (2015c), four broad approaches to treatment exist: behavioral and communication, dietary, medication, and complementary/alternative approaches.

Behavioral and communication approaches include applied behavior analysis (reinforcing positive behaviors and discouraging negative ones), Floortime (focusing on the development of emotions and relationships, as well as dealing with sensory input), Treatment and Education of Autistic and Communication handicapped Children (TEACCH) (utilizing visual cues to learn skills), occupational therapy (focusing on skill development), sensory integration therapy (assisting with managing sensory input), speech therapy (working on communication skills), and Picture Exchange Communication System (PECS) (using picture symbols as a communication tool) (CDC, 2015c). Parents are advised to speak with the pediatrician or another health provider to assist them in selecting the therapy that might best assist their child (NIHM, 2016).

Dietary treatment approaches focus on removing certain food types that are believed to contribute to negative behaviors, and/or providing nutrient supplements (CDC, 2015c). These approaches have not been scientifically proven to be effective, thus they may not be of benefit to all children with autism (CDC, 2015c). Some medications are used to decrease symptoms of autism or co-existing conditions, for example depression, seizures, high activity levels, and lack of focus (CDC, 2015c). Families also utilize complementary and alternative treatments to ameliorate their child's symptoms. These treatment modalities have not been scientifically proven to be effective, however they are popular and often used by families of children with autism (CDC, 2015c).

**Characteristics of people with autism.** As mentioned in the discussion about diagnosis, behaviors associated with autism can be categorized into those that pertain to restrictive interests and repetitive behaviors, and those that pertain to social interactions and communication (NIHM,

2016). In terms of exhibiting unusual interests and behaviors, these behaviors may include needing to follow routines, having obsessive interests, being highly organized about certain aspects of life, becoming upset with minor changes due to a need for routines and sameness, and exhibiting repetitive motions such as rocking the body or hand flapping (CDC, 2015a).

Challenges with social skills may include avoiding eye-contact, having trouble understanding other's feelings, difficulty talking about their own feelings, not understanding personal space boundaries, not sharing common interests with others, interacting socially only to pursue a personal goal, avoiding physical contact, exhibiting flat or inappropriate facial expressions, and preferring to be alone (CDC, 2015a).

Some people with autism are nonverbal, while others are verbal but have communication challenges. Communication difficulties might include talking in a flat or robot-like voice, not understanding jokes, sarcasm, or teasing, having difficulty understanding nonverbal communication such as gestures or facial expressions, talking excessively about their interests without engaging in back-and-forth conversations, and using facial expressions that do not match their dialogue (CDC, 2015a).

Each person with autism exhibits a unique combination of the above characteristics and to different degrees of intensity. Characteristics of autism also change as the child grows and develops. Because of this, parents of people with autism and those who work with them often state "If you know one person with autism, you know one person with autism" (O'Leary, 2015, para. 1). This highlights the fact that no two people with autism have identical symptoms or characteristics.

**Classification and prevalence of autism.** Before the 2013 publication of the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental

Disorders (DSM-5) (APA, 2013), autism was a sub-category of pervasive developmental disorders. This category also included Asperger's syndrome, which described people with autism who were higher functioning. This subcategorization has been removed with the latest DSM-5 publication (NIMH, 2016), thus the term Asperger's syndrome no longer exists as a diagnosis. Instead, autism spectrum disorder (ASD) is one disorder with various levels of severity.

This study focused on individuals who were formerly categorized as having Asperger's syndrome. These individuals have average or above-average intellectual quotient (IQ) (70 or above) (Bockler et al., 2014), and the term used in this study is high-functioning autism (HFA). Despite their IQ, people with HFA are also a heterogeneous group and individuals display a wide range of disability and severity of problems (White, Ollendick, & Bray, 2011). For this study, the literature about ASD in general was reviewed, as well as that which pertains only to HFA. Much less literature specific to HFA exists, therefore both terms will be used according to the population on which each reference is focused.

The prevalence of autism in the United States has risen considerably over the past few years and thus this disorder has garnered much attention. The prevalence has risen from one in 150 children in the year 2000, to one in 68 children in the year 2012, which encompasses the latest year of surveillance data; this constitutes a 220% increase in only 12 years (Christensen, et al., 2016). Autism occurs in people of all racial, ethnic, and socioeconomic statuses, and the diagnosis is about 4.5 times more common in boys than in girls (CDC, 2016c). The prevalence of HFA (which used to be called Asperger's syndrome) is unknown. Some have estimated it to be between 0.03 to 6 per 1,000 children (Mattila et al., 2007). One study in Japan found it to be 25.3% among a cohort of 95 children with an autism diagnosis (Honda, Shimizu, Imai, & Nitto,

2005). White et al. (2011) noted that between 0.7 and 1.9% had a diagnosis of HFA among a group of 667 students attending a technology-oriented university in the U.S.

**Outcome of people with autism.** The long-term outcome of people with ASD, including those with HFA, is largely unknown. Researchers have used scales that include scores for independent living, friendships, and occupation to categorize the outcome of people with autism. These scales utilize a point system for different outcome expectations; based on this system, the outcome of people with ASD can be categorized into groups, ranging from very poor to very good outcome (Steinhausen, Jensen, & Lauritsen 2016). In a meta-analysis that included 828 teens and adults with autism, Steinhausen, et al. (2016) found that 19.7% of individuals had a good outcome, 31.1% had a fair outcome, and 47.7% had a poor outcome related to global measures of adjustment. A good outcome was defined as having a high level of independence or requiring minimum support for daily living. A fair outcome was defined as having a level of independence, requiring some support but not needing residential assistance. A poor outcome was defined as needing a high level of supervision and support. The authors stated that studies that had included only people with more severe autism showed higher proportions of poor outcomes, when compared to studies that included people with autism with a higher range of functioning, including those with HFA.

Billstedt, Gillberg, and Gillberg (2011) also investigated the outcome of Swedish people with autism who were diagnosed in childhood. They described this group as including low- to middle-functioning people with autism, not Asperger's or high functioning autism. The authors reported on measures of quality of life of 108 adults who had been followed for 13 to 22 years since their autism diagnosis. Only 18% of the participants had near-average or average IQ. Of those with a higher IQ, three participants had attended a mainstream high school without

accommodations, and of these, two had experienced difficulties finding a job and were classified as having poor quality of life. One of the three had been successful and no longer held a diagnosis of autism, although still exhibited autism traits. One female had also attended a mainstream high school and had completed a bachelor's degree.

Billstedt et al. (2011) also found that most of the individuals with autism who they followed were not living independently; 38% were living at home, 49% were in group homes, 8% lived in apartments with some assistance, 4% lived on their own with some help, and one individual lived with a significant other. Regarding employment, 27% of participants were still in high school, 6% had a job with support systems in place, 48% worked at centers for people with disabilities, and one individual had a regular factory job (no longer classified as having autism); 18% of participants did not have employment. The authors found a correlation between IQ and living situation, with those with the highest IQs being more likely to live in apartments. In addition, those with the highest IQs were also more likely to have a daily occupation.

Billstedt et al. (2011) also reported on friendships of people with autism, as described by their caregivers. Only 12% of individuals were reported to have a friend or friends, with 11% described as desiring friendships but not having them; 68% were portrayed by caregivers as not understanding the concept of friendship.

Although the participants in the study by Billstedt et al. (2011) were not classified as having HFA or Asperger's syndrome, the findings are relevant to understand the challenges faced by individuals with autism as they transition to adulthood. Many of them do not live independently, continue to need support systems, and are unable to hold paid employment. One would expect that people with HFA or Asperger's syndrome would exhibit more positive outcomes, although data is lacking.

Gray et al. (2014) studied the outcomes of Australian adults with autism in terms of their level of community inclusion (living arrangement, daily schedule, and employment) and living skills. They followed a set of people with autism from childhood and adolescence into adulthood, conducting assessments every few years through interviews with parents/care providers and individuals. Their report of adult outcomes was based on their fifth assessment, with 89 participants (out of the initial cohort of 119 participants at the onset of the study in 1991). They found that 61% of individuals with autism still lived at home as adults, with only 9% living independently. Those participants with more severe intellectual disability were more likely to live at home. Of the participants, 27% were involved in daytime activities for less than 20 hours a week, and these included day programs, workshops, studying, or paid employment on few occasions. Of the 14 participants who had paying jobs, five had mild intellectual disability and six had borderline intellectual disability, with the remainder having greater intellectual disability.

Gray et al. (2014) concluded that although people with autism without intellectual disability (or with milder disability) were more likely to have better outcomes (live independently, be employed, or pursue higher education), many of them still lacked a positive outcome. Their findings reiterated the need for continued research and support programs for youth with autism to improve their adult outcomes.

Mazurek (2014) investigated outcomes of adults with autism by exploring their well-being, friendships, and degrees of loneliness. The study involved conducting assessments on 108 adults with autism (64% had Asperger syndrome or HFA) between the ages of 18 and 62 years. About 40% of the respondents did not have a close or best friend and 58% were single. He found that people who had higher levels of loneliness were also more likely to have depression and

anxiety, as well as lower self-esteem and satisfaction with life. The author concluded that these findings confirmed that people with autism do feel loneliness, and hypothesized that this feeling is a result of their difficulties with socialization, an area that needs further research.

**Mental health and autism.** Mental health disorders are increasingly common among the general population of college students. According to the Association for University and College Counseling Center Directors (Reetz, Bershad, LeVines, & Whitlock, 2016), the most common mental health problems among college students who seek help are anxiety (50%), depression (41%), relationship concerns (34%), suicidal ideation (20%), self-injury (14%), and alcohol abuse (9%). Mental health disorders are also common in autism. Zager, Alpern, McKeon, Maxan and Mulvey (2013) stated that comorbid mental health disorders common in people with ASD include anxiety, disorders with attention and thinking, and depression. These conditions aggravate the symptoms and difficulties that already challenge people with ASD.

Mental health disorders described in the literature are typically clustered within various categories. Anxiety disorders include panic disorder, phobias (MentalHealth.gov, 2017), and obsessive-compulsive disorder (OCD) (American Psychiatric Association, 2017). Behavior disorders include attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), and conduct disorder. Mood disorders include depression, bipolar disorder, seasonal affective disorder (SAD), and self-harm. Personality disorders include antisocial personality disorder and borderline personality disorder. Psychotic disorders include schizophrenia. Trauma and stress-related disorders include post-traumatic stress disorder (PTSD) (MentalHealth.gov, 2017).

Hofvander et al. (2009) examined the prevalence of psychosocial and psychiatric problems in a group of 122 adults (age range from 16 to 60 years) with autism and normal



intelligence who were referred for assessment at two European clinics (in France and Sweden). They found that 43% of the individuals had a diagnosis of ADHD. A mood disorder was present in 53% of individuals; 34% of these individuals had received treatment for depression and 8% had been diagnosed with bipolar disorder; 12% of subjects had a psychotic disorder that included psychotic disorder not otherwise specified, schizophrenia, brief psychotic episode, and delusional disorder. The study also found 16% of individuals had a substance use disorder, most involving alcohol and some including cannabis, amphetamine, opiates, or analgesics. Anxiety disorders were also common, with 15% having generalized anxiety disorder, 13% social phobia, 11% panic disorder and/or agoraphobia, 6% a specific phobia, and two (1.6%) individuals having post-traumatic stress disorder (PTSD).

Hofvander et al. (2009) also found that some individuals were affected by impulse control disorders, including intermittent explosive disorder in 6% of subjects. In addition, kleptomania, pyromania, pathological gambling, trichotillomania, and impulse control disorder not-otherwise-specified were found in one individual each. Personality disorders were also seen in 62% of subjects, with obsessive compulsive personality disorder being the most prevalent, present in 32% of individuals studied.

In terms of psychosocial findings, Hofvander et al. (2009) found that most individuals reported having been bullied in school (56%), with females reporting more bullying than males. Among the participants, 65% had graduated from secondary school, and 24% had completed college. A total of 43% of individuals were employed or were students at the time. The remainder were not engaged in organized daily activities, were on sick leave, had a medical pension, or were unemployed. Half (50%) of those 23 years and older lived independently, and 16% had experienced a long-term relationship. A full 40% of individuals were still living with

parents or in community group homes. The authors noted these were poor outcomes for these adults given their high intellectual ability.

Mattila et al. (2010) reported on comorbid psychiatric conditions found in a group of 50 youth (ages 9-16 years) with Asperger's syndrome or HFA in Finland. They found that most individuals (84%) had experienced comorbid psychiatric conditions in their lifetime, the most common being behavioral (50%), anxiety (56%), and tic disorders (38%). At the time of the study, 8% of the subjects had four or more disorders, 14% had three or more disorders, 20% had two or more disorders, and 32% had one disorder. The authors also found that psychiatric disorders were more common in elementary students than in secondary students, with no students in secondary school having a tic disorder at the time; however, four recalled having had the disorder in elementary school.

Mattila et al. (2010) also found that ADHD was a common (44% of the subjects) lifelong comorbid disorder in this population, with the type of ADHD having changed over time in 21% of the subjects. The most common anxiety disorders being experienced by participants at the time included phobias (28% of the subjects), followed by OCD (22% of the subjects); 14% of participants exhibited two or more anxiety disorders. The authors also found that of the subjects with oppositional defiant disorder (ODD), none had reported recovering from it (having had that diagnosis but no longer having it). In addition, no subject with ODD had experienced a change from that diagnosis to conduct disorder (CD). This transition from ODD to CD is common in people without autism, but it had not been experienced by the group studied. The authors hypothesized that ODD may have more permanence in ASD than in typically developing groups. Another finding was the high level of insomnia in this study, with 34% of subjects having experienced it.

Mattila et al. (2010) also measured the Children's Global Assessment Scale (CGAS) to determine the level of functioning of the children studied. The CGAS is a tool used to evaluate the lowest level of functioning of a child or adolescent at a given time on a scale of 1 to 100, with 1 being the most impairment, and 100 being the healthiest state (Shaffer et al., 1983). Mattila and colleagues found that the more comorbid psychiatric disorders an individual had, the lower the CGAS score. They found significantly lower CGAS scores in those with anxiety or behavioral disorders who also had ODD or major depressive disorder (MDD). They also found lower CGAS scores among girls compared to boys.

Joshi et al. (2013) investigated the frequency and severity of psychiatric disorders among adults with ASD referred to a university hospital that specialized in treating people with autism and behavioral and emotional problems. They compared 63 individuals with ASD to individuals referred to another psychiatry program who served people with behavioral and emotional problems who did not have a specific disorder. They found that adults with ASD had more lifetime and current comorbidities compared to those without ASD. These comorbidities included major depressive disorder, ADHD, and multiple anxiety disorders (agoraphobia, obsessive-compulsive disorder, and social phobia). Most of the adults in the ASD group had a normal IQ (>85). Reasons for referral to the clinic among those with ASD included mood dysregulation and anxiety. The authors noted that all the adults with a history of social anxiety had HFA, speculating that people with higher functioning autism desire social interactions, but have difficulties in engaging socially, thus experiencing anxiety.

Lever and Geurts (2016) examined the prevalence of psychiatric comorbidities in young, middle-aged, and older adults with ASD without intellectual disability. Their group included 247 adults between 19 and 79 years of age who lived in the Netherlands and compared them to a

control group without ASD. The authors found that people with ASD had a higher prevalence of one or more lifetime psychiatric diagnoses (79%) compared to the control group (48.8%). However, a difference between age groups existed. Older adults with ASD had less psychiatric diseases compared to younger groups of people with ASD; this age difference was not seen in the control group. Within the ASD groups, mood disorders were the most common diagnoses, particularly among middle-age adults; 57.2% of adults with ASD exhibited these diagnoses (major depression in 53.6% of individuals, and dysthymia in 18.1%). Anxiety disorders comprised the second most common diagnoses among the ASD group, present in 53.6% of the participants (OCD in 21.7% of individuals, and agoraphobia in 21%). No significant difference in the prevalence of mood disorders with varying ages of the ASD individuals was found. Social anxiety was more prevalent in young and middle-aged individuals with ASD, but not in older adults with ASD. Anxiety disorders were more prevalent in the group with ASD than in the control group, and no age difference was found in the control group.

Lever and Geurts (2016) also found that depression and anxiety symptoms were positively associated with the severity of ASD. In addition, a positive association was found between being female and having any mood disorder. The severity of ASD and being younger was also positively associated with having any anxiety disorder.

Matson and Cervantes (2014) conducted a literature review of research about comorbid psychiatric conditions often seen in people with ASD. They found that most research had focused on children and adolescents, with ADHD being the most frequently studied psychiatric condition in childhood, followed by oppositional defiant disorder and conduct disorder. They also found that most studies had focused on people with ASD who had normal intelligence.

In summary, mental health disorders appear to be common in people with ASD, although information on mental health disorders among those with HFA is lacking. In addition, information specific to mental health disorders among college students with HFA is also lacking. This study provided insights into the lived experiences of college students with HFA and can shed light onto their depiction of their mental health while enrolled in college.

**Executive function.** People with autism typically have impairments in executive function (Hill, 2004). Executive functions are a group of mental processes that allow people to connect past experiences with current actions. These functions are utilized when individuals plan, organize, strategize, pay attention, and recall facts (National Center for Learning Disabilities, 2017). A person with difficulties with executive function has trouble making plans, tracking time, managing more than one thing at a time, participating in groups, evaluating and reflecting on ideas or work, sticking to a decision, requesting help, finishing tasks on time, and not speaking out of turn. Because of these challenges, people with executive function problems would have difficulty planning a project and anticipating how long tasks might take, telling a story in an organized and sequential manner, memorizing information, producing ideas, and starting tasks.

Examples of how executive function challenges are exhibited in autism include their perseverative behaviors and tendency toward inflexibility (Pellicano, 2012). Students with ASD may have difficulty staying engaged in lectures, may be easily distracted, may start doing unrelated tasks during class times, and may have trouble transitioning from one task to another in laboratories, all of which can be due to executive dysfunction (Zager, Alpern, McKeon, Maxam & Mulvey, 2013). These challenges can be worsened by having too many conflicting stimuli (such as noise) and conflicting activities. Students with ASD therefore exhibit difficulty

organizing themselves, managing their time, pacing themselves, meeting deadlines, and being punctual (Zager et al., 2013). Executive functioning deficits in autism may affect their long-term outcomes, including their social abilities, how they adapt to everyday life, and how they achieve academically (Pellicano, 2012).

**Sensory issues.** Sensory over-responsivity (SOR) has been defined as exhibiting an exaggerated response to one or more types of sensory stimuli; these responses are automatic and unconscious, and can produce emotional reactions like moodiness, irritability, or poor social skills (Miller, Anzalone, Lane, Cermak, & Osten, 2007). This over-responsivity to sensory input is commonly found in people with ASD (Zager, Alpern, McKeon, Maxam, & Mulvey, 2013). Tavassoli, Miller, Schoen, Nielsen, and Baron-Cohen (2014) conducted a study comparing the response to sensory input between 221 adults with ASD and 181 adults without ASD. The researchers measured sensory responsiveness for each sensory modality (vision, hearing, touch, smell, taste, proprioception) and in general. They found that adults with ASD had higher SOR for each of the individual senses and for all senses in general. Investigators also found that adults who reported more autistic traits also exhibited higher degrees of SOR.

Sensory over-responsiveness is concerning since it has been associated with anxiety in children with ASD, and this experience is felt to be an impairing condition (Green & Ben-Sasson, 2010). Sensory over-responsiveness has also been associated with anxiety and depression in adults with ASD, negatively affecting their quality of life (Kinnealey, Moya, Koenig, Patten, & Sinclair, 2011). Students with autism in higher education may have difficulty adjusting to the many sensory inputs experienced in college; this area warrants investigation.

## **College student retention and success in the United States**

In a report of college student retention and persistence in the United States for the 2014-2015 academic year, the National Student Clearinghouse Research Center (2016) found a 60.6% retention rate (number of students who returned to the same school) and a persistence rate of 72.1% (students who returned to college, with some transferring to a different school). The U.S. Department of Education's National Center for Education Statistics (2018a) reported somewhat different statistics, with an estimated retention rate of 81% for students enrolled in a four-year institution in 2014. Differences existed based on how selective schools were, with higher retention rates in schools that were more selective, regardless of their status as public, private-for-profit, or private not-for-profit. Retention rates among private non-profit schools were 82% overall, with a range from 96% for those schools that were more selective in admitting students, down to 62% for schools with open admissions.

The U.S. Department of Education's National Center for Education Statistics (2018) also examined six-year graduation rates of college students. They found a 59% graduation rate overall, with varying rates depending on the type of school: public institutions had a graduation rate of 59%, private non-profit schools had a rate of 62%, and private for-profit had a graduation rate of 23%. Graduation rates also varied based on the selectivity that the school exercised with admissions: Schools with open admissions, regardless of type of school, had a six-year graduation rate of 32%, and those with a more selective acceptance rate (admitting less than 25% of applicants), had a six-year graduation rate of 88%.

The retention and persistence rates of college students with ASD, or specifically HFA, is not known. Given the many challenges people with autism face as part of their disorders, it would not be surprising if retention and persistence rates were lower in this population.

Additional research is needed in this area. The following section will summarize the literature pertaining individuals with ASD in higher education.

### **Autism in Higher Education**

With the increased prevalence of ASD, more individuals with autism are entering higher education (Gardiner & Iarocci, 2014). Because people with HFA typically have the intellectual capacity to do well academically in mainstream high schools, the assumption is made that they can navigate higher education successfully (MacLeod & Green, 2009). Their academic success can mask the everyday challenges they encounter as part of their disorder. Those around them, including some school teachers in general education classrooms, may be unaware of their struggles (Sciutto, Richwine, Mentrikoski, & Niedzwiecki, 2012).

Researchers have attempted to measure the higher education success rate of those with autism. Shattuck et al. (2012) investigated participation in postsecondary education and employment among 500 individuals with autism who had recently graduated from high school. These students were part of a longitudinal study of youth with autism who were receiving special education services at their schools. People at all levels of capability within the autism spectrum were included, not only high-functioning students. Of note is that students not receiving services were not part of the cohort, which could have excluded some with HFA. Shattuck et al. (2012) investigated their rate of participation in higher education and employment post-high school and compared these rates with those of other recent high school graduates who had learning disabilities, mental retardation, or speech/language impairment. According to findings, people with autism had lower rates of participation in higher education than other people with disabilities, except for people with intellectual disability (mental retardation). Rates were lower



among Hispanic and African American youth with autism; rates were also lower among those with autism from low socioeconomic backgrounds or severe comorbid conditions.

The findings of Shattuck et al. (2012) are significant as they underscore the challenges people with autism face in their pursuit of higher education attainment. However, it does not distinguish among students with more severe autism disability from those who are higher functioning, which this study focused on. Research on outcomes specific to those with HFA, particularly studies with large numbers of participants, is lacking.

Roux et al. (2015) also shed light on issues faced by youth with autism as they transition to adulthood. They compiled the National Autism Indicators Report and the executive summary highlighted the following findings:

Young adults with autism have a difficult time following high school for almost any outcome you choose – working, continuing school, living independently, socializing and participating in the community, and staying healthy and safe. To complicate matters, many of these youth begin their journey into adulthood by stepping off a services cliff. Access to needed supports and services drops off dramatically after high school – with too many having no help at all. (Roux et al., 2015, p. 8)

Although this conclusion refers to all young adults with autism, not just those with HFA, the statement is concerning because people with autism who enroll in higher education face many obstacles that affect their ability to succeed.

In a systematic literature review about experiences of people with autism in higher education, Gelbar et al. (2014) noted that most of the publications reviewed mentioned depression, loneliness, and anxiety as being common among people with ASD in college. Similarly, White et al. (2011) found that students identified as having HFA at a technology-

oriented university were also more likely to test positively for depression, social anxiety, aggression, and hostility. These students also expressed lower levels of satisfaction with both college life and life in general, even though their self-reported Grade Point Averages (GPAs) were higher compared to peers. If many college students with HFA exhibit these symptoms, their ability to successfully complete their higher education goals might be limited.

**Transition planning.** Enrolling and succeeding in postsecondary education is challenging for people with autism. Whereas K-12 schools provide many support systems for students with autism as part of federal mandates (VanBergeijk & Cavanagh, 2012), the same support systems may not exist after high school because higher education institutions are not mandated to provide the same level of supports (U.S. Department of Education Office of Civil Rights, 2018b). Shattuck et al. (2012) found that more than 50% of the high school graduates with autism who they followed were unengaged with work or school two years post-graduation; they hypothesized that gaps may exist in transition planning from high school for this specific population of youth. Their cohort included people with autism as a diagnosis, not only those with HFA.

Alverson, Lindstrom, and Hirano (2015) conducted a qualitative phenomenological study of five males with autism who transitioned from high school to college, interviewing the students, family members, high school teachers or transition specialists, and rehabilitation counselors (if they were engaged in vocational rehabilitation). Five predominant themes were identified as facilitating a better transition from high school to college for these students: (1) being aware of their own disability, (2) being motivated to be in college, (3) having a high level of family involvement, (4) having a clear transition plan, (5) and having a plan post college graduation.

Alverson et al. (2015) found that the challenges that these five males with autism encountered in high school persisted into higher education. Students continued to have problems with social skills, communication, and executive functions. The authors recommended better coordination of transition plans in high school for people with ASD, including assisting them with understanding their disability. Facilitating more experiences in the community to address social and communication challenges was another identified need. In addition, heightened attention to executive functioning skills such as goal setting, taking care of selves, and fulfilling commitments were recommended. The researchers also suggested helping students identify possible anxiety sources in college, teaching coping strategies, and identifying support systems. Including the family during the transition planning and process also seemed to be important.

**Characteristics and college life.** Students with autism face unique challenges when entering college due to their difficulty with communication, socialization, sensory overload, difficulties adapting to change, and other characteristics of the disorder (Van Hees, Moyson, & Roeyers, 2015). They often have difficulty with activities that are common in college, including tackling competing priorities, working in groups, speaking in public, getting less individual attention from instructors, living away from home, and integrating socially. Many of them have heightened sensitivity to sounds, sights, and crowds, all of which are common on college campuses (Madriaga, 2010). Given that college students' meeting and socializing spaces are typically loud and crowded, meeting fellow college students and engaging socially becomes challenging for students with autism.

Despite the notion that people with ASD are not interested in having friends, the opposite may be true. Some people with autism express that their social challenges are more concerning to them than their academic difficulties. They seem concerned with having a network of friends,

which produces a sense of belonging in college (Van Hees, Moyson, & Roeyers, 2012). Some of the fears students with ASD expressed related to socialization included being aware of their social inadequacies and concern about expressing selves inappropriately. Coupled with other challenges they face, these fears discourage them from attempts at socialization, which increases loneliness.

Madriaga (2010) followed eight students with Asperger syndrome enrolled in their first year of college in the United Kingdom, conducting interviews over a span of one year. This research study focused on the places these students frequented or avoided within their colleges, and the reasons for their behaviors. Two students reported not attending the week-long orientation to college due to their heightened sensitivity to noise and crowds. These students knew that the week of orientation offered opportunities to meet fellow students, however their sensitivities precluded them from participating.

Half of the students studied by Madriaga (2010) reported not going to the student pub (bar) because of their sensitivity to noise, crowds, and/or smoke. These students acknowledged that not going to the pub with fellow students precluded them from forming friendships outside of the classroom. They also reported feelings of loneliness and isolation.

Madriaga (2010) inquired about the perspectives that students with Asperger's had about their college library. Most of the eight students regarded the library as too noisy or crowded, and thus not a space that they frequented. One student reported finding the library to be a place of refuge, where he could isolate himself. Because students attended different higher education institutions, libraries likely differed in terms of noise level and the number of students who frequented them.

Students in this study (Madriaga, 2010) regarded their dormitory room as their safe space because the room was quiet and they could be alone. However, they recognized that they spent a significant amount of time alone in their room, which added to their loneliness and feelings of isolation. One student did not find comfort in his room due to being next to the front door, in which case the noise from the door closing was frustrating to him.

Empirical research focusing on the perceptions and difficulties of students with ASD living in campus housing is lacking. Based on observations at the Rochester Institute of Technology, Ackles, Fields, and Skinner (2013) described the challenges students with ASD face in higher education when living in student housing and offered suggestions to address the challenges. Given that these students were often living away from home for the first time, their challenges included not knowing how to secure assistance from professionals or from fellow students, having difficulty in their social communication and developing friendships and relationships, as well as needing to share living spaces, managing self-care activities, and managing sensory input they found overstimulating.

Ackles et al. (2013) suggested training college staff, including those in housing and dining services, about the characteristics of people with autism. They recommended using vignettes as examples to help staff recognize autistic-like behaviors and teaching them strategies for working with these individuals. The authors also recommended conducting small-group meetings with staff as they began to interact with students with autistic characteristics, discussing their experiences and providing feedback and support.

For students who had disclosed their autism diagnosis, Ackles et.al (2013) discussed the advantages and disadvantages of assigning them a single room. Because these students have difficulty with social interactions, and are oftentimes misunderstood and teased by peers,

assigning them their own room might minimize their social concerns. However, the authors emphasized that students with autism might feel isolated if having a single room. A suggestion made by the authors was to consider placing students with autism in a suite-like room, where they had their own sleeping space, but shared other spaces.

**Support systems.** Although various academic challenges encountered by people with ASD can be addressed through accommodations, many students with HFA do not consider themselves to have a disability when entering college or choose not to disclose their disability (Newman & Madaus, 2015). For instance, in a study involving 23 college students with ASD and 15 family members, Van Hees et al. (2012) found many students being reluctant to disclose their disabilities and only did so when the stress of their difficulties became intolerable. By not disclosing, they were attempting to continually hide their challenges, which also added to their level of anxiety and thus worsened their mental state. Family members and students spoke often about feelings of anxiety, obsessive compulsive behavior tendencies, as well as depression, all of which are common occurrences in this population. Without adequate support systems and referrals to address the students' mental health, the likelihood that they would drop out of college increased (Van Hees et al., 2012).

Due to the unique challenges faced by students with autism, they need additional support systems that differ from those that other students with disabilities might need (MacLeod & Green, 2009). Lack of understanding of autism on the part of faculty, staff, and fellow students is common (Gillespie-Lynch et al., 2015). Through interviews with six students with autism enrolled in college, MacLeod, Lewis, and Robertson (2013) found that these individuals did not feel similar to other students who had visible disabilities. Despite the differences, disability services at their higher education institutions provided the same services to students with autism

as provided to other students with different disabilities. Through a survey of disability services offered at various universities, Smith (2007) found that most of the schools that responded were providing similar types of accommodations to students with autism as they did for any other student with a disability. This finding may be due to a combination of lack of understanding of autism, as well as the fact that autism is an invisible disability and the level to which it negatively affects an individual varies significantly (Van Hees et al., 2015).

**Importance of higher education.** Obtaining a college degree is advantageous to today's youth as it increases their ability to obtain a job and attain higher earnings (Pew Research Center, 2014). However, it is not known if the same outcome can be anticipated by those with HFA who obtain a college degree. Taylor, Henninger, and Mailick (2015) reported on the employment status and postsecondary education achievement of 73 adults with HFA who were followed over a 12-year period. According to the research, 31 individuals had attained a college degree, and of these, only three were working in their field. More than half (57.9%) of the individuals who had a college degree were minimally employed or were unemployed for a period of time during the observation. The researchers found that many of these adults who had completed a college degree, as well as those who had not received a degree, were employed in entry-level, non-skilled types of jobs.

Yokotani (2010) conducted a study of 22 Japanese adults with HFA, all of whom had normal intelligence and verbal ability. Eleven participants had graduated from a technical college and two from a university. Yokotani (2010) found that people with HFA who had attained more years of education had an advantage in obtaining a job, however this completion pattern did not apply to retaining a job. On average, employment duration was 7.5 months. These findings suggest that a college education provides academic skills to students, but not

social skills, which is the difficulty for people with HFA. Thus, a graduate may be hired based on perceived job-related skills, but may not be retained due to lack of social skills.

Müeller, Schuler, Burton, and Yates (2003) reported on the experiences of 18 adults with HFA; two were still in high school, three had completed some college, four had an associate's degree, three had a bachelor's degree, four had a master's degree, one was in a doctoral program, and one had completed a doctoral program. The researchers did not differentiate between results from participants who had achieved a higher education degree and those who did not, however most participants (16 out of 18) had pursued higher education. Most participants reported long periods of unemployment or underemployment, in addition to limited opportunities to advance in their career. Participants who had trained in professional careers reported being hired for lower-level types of jobs, often performing repetitive tasks. Because of frequent termination from jobs and having long periods of unemployment, participants reported added difficulties in securing future jobs and in career advancement.

Müeller et al. (2003) found that most of the 18 adults with HFA interviewed had a history of negative work experiences. These experiences included not receiving sufficient time to learn tasks, being placed in jobs that did not match their skills, and having difficulty interacting with supervisors and co-workers. These difficulties caused added financial stress, depression, poor self-esteem, and frustration at their inability to be self-sufficient. Those adults with HFA who reported positive work experiences were in jobs that capitalized on their skills, did not require significant social interaction, or had supervisors and co-workers who supported and assisted them with challenging tasks. The authors provided various recommendations for vocational support services for individuals with HFA to assist them in all areas of employment. Müeller et



al. (2003) recommended that vocational services assist individuals with HFA during the process of job searching, and that support continues during the initial weeks of employment.

Negative findings in the literature (Müeller et al., 2003; Taylor et al., 2015; Yokotani, 2010) regarding employment challenges for individuals with HFA, even those who received a college degree, are concerning. Additional research is needed to determine factors that preclude people with HFA from obtaining and maintaining employment, particularly those who have received a college degree. Programs and support systems can be implemented in college to improve the success rate of students with HFA and assist them in becoming productive members of society.

## **Chapter Three: Methodology**

### **Philosophy and Justification**

This dissertation is a qualitative phenomenological research study describing the lived experiences of students with HFA while enrolled in institutions of higher education. A number of qualitative studies about students with autism in higher education have been conducted (Gelbar et al., 2014), including surveys of parents, support personnel, and occasionally students with HFA about challenges encountered in college. Based on a literature review, a study that explores the lived experiences of college students with HFA in the U.S. has not been published, which is the goal of this study.

### **Research Questions and Objectives**

The purpose of this study was to expand the knowledge about students with HFA entering higher education and to elucidate areas that may be related to increased retention, degree completion, and improved chances of success in later employment. The intention of this study was to explore the lived experiences of students with high functioning autism when enrolled in an institution of higher education. To explore this topic, the main research question was: What are the lived experiences of students with high functioning autism who are enrolled in institutions of higher education? The two sub-questions were:

1. How do students with high-functioning autism describe their lived experience while attending an institution of higher education?
2. How do students with high-functioning autism describe their lived experience as they interact with the higher education system?

Utilizing the Theory of Self-Determination (Deci & Ryan, 2000) as the lens that drives this study, the areas of competence, relatedness, and autonomy was explored in relation to these questions. Therefore, the research objectives were:

1. To describe areas of the students' lived experience in higher education that support or hinder their sense of competence.
2. To describe aspects of the students' lived experience in higher education that facilitate or hinder their ability to develop socially.
3. To describe the students' perception of their level of autonomy while enrolled in an institution of higher education.

Appendix A outlines the interview questions that were utilized. Appendix B contains a table that outlines the connection between the research questions, the study's objectives, and the interview questions.

### **Theoretical Framework**

Special education professionals have applied principles from the Theory of Self-Determination in transition planning efforts for students with disabilities (Carter, Lane, Pierson, & Stang, 2008; Sayman, 2015). The use of this theory relates to policy mandates as well as research indicating that increased self-determination in youth with disabilities may improve outcomes such as performance, participation in higher education, future employment, independence, and overall quality of life (Carter, Lane, Pierson, & Glaeser, 2006; National Council on Disability, 2004). The authors postulate that special-education high school graduates who have developed the qualities of individuals with high levels of self-determination may have a better chance of future success. These qualities, as described by Carter et al. (2006), "assume more prominent roles in educational and life planning – understanding and communicating their

strengths and needs, setting and working toward self-selected goals, advocating for themselves, and self-assessing their own progress and outcomes” (p. 334). The Theory of Self-Determination appears to be an appropriate theoretical framework for this study given the challenges that youth with ASD encounter when transitioning from high school to college.

Examining the college experience of students with ASD by use of the Theory of Self-Determination includes exploring three areas proposed as basic psychological needs considered central to human motivation: competence, autonomy, and relatedness (Deci & Ryan, 2000). Competence includes attaining desired outcomes and performing tasks effectively; autonomy involves initiating tasks and regulating oneself; and relatedness includes making meaningful social connections with others. People with ASD, including those with HFA, exhibit various degrees of challenges that can interfere in these areas. Ascertaining which of these areas are challenging during their college life is therefore important, as motivation to stay in school and the desire to persevere and become a contributing member of society may be compromised if any of these characteristics are not being attained.

### **Research Design Strategy**

**Phenomenology.** This dissertation is a qualitative phenomenological research study. Phenomenology is a qualitative research approach that is rooted on the works of the German philosophers Edmund Husserl (1859-1938), Martin Heidegger (1889-1976), and other philosophers and psychologists who have ascribed to, and adapted, their teachings (Matua & Van Der Wal, 2015). Phenomenology explores the relationship between an experience (or phenomenon), the way the experience is expressed in the world (such as verbally, through art, through objects), and the understanding that is gained from the expression of the experience. Examples of phenomena include experiencing grief, having insomnia, being left out, having

cardiovascular disease, or experiencing anger (Creswell, 2013). A phenomenon could be explored using different qualitative research approaches, however phenomenology differs from other qualitative methods in that it attempts to answer questions such as “What is this experience like?” (van Manen, 2017, p. 812) and, “What is the nature or meaning of this phenomenon?” (Matua & Van Der Wal, 2015, p. 23). Phenomenology explores the phenomenon through the accounts of individuals who have lived through the experience first-hand and explores the common meaning of these experiences (Creswell, 2013; Matua & Van Der Wal, 2015).

Phenomenological inquiry uses the term *lived experience* to define the connection between the experience and the world (van Manen, 2017). The concept of lived experience can be difficult to comprehend. One description by van Manen (2017) is:

Any experience can be a subject for phenomenological inquiry: having a conversation, being bored . . . and so forth. Yet, phenomenology is not the study of the meaning of concepts, words, or texts, but of experience as lived. The problem of phenomenology is not how to get from text to meaning but how to get from meaning to text (p. 813).

Van Manen further explained that lived experiences are the equivalent of data in other types of research; he stated, “Phenomenology is concerned with meaning and meaningfulness rather than ‘informational’ content” (p. 814). The meanings of the lived experiences are termed the *essences* in phenomenological inquiry (Moustakas, 1994).

A qualitative phenomenological approach to research was appropriate for this study because of the desire to obtain detailed accounts of the lived experiences of students with HFA engaged in higher education. This study attempted to derive the essence of these lived experiences as students engaged with the higher education system. In addition to selecting

phenomenology as the research approach, the investigator selected the type of phenomenological methodology to be utilized. The following is a brief description of some of the methodological approaches that can be used when engaging in phenomenology.

The way phenomenological research is conducted has evolved over the years. Originally, phenomenology was used solely to describe experiences, according to the teachings of Husserl, the German philosopher who first described it (Davidson, 2004). Phenomenology today may also involve interpreting experiences, per the teachings of Heidegger, a student of Husserl who deviated from some of Husserl's premises (Matua & Van Der Wal, 2015). Investigators using phenomenological approaches will broadly use one of these two methods, descriptive or interpretive phenomenology.

***Descriptive phenomenology.*** This type of phenomenology (initially conceived by Husserl) involves exploring, analyzing, and describing a phenomenon to provide a picture in as pure a form as possible (Matua & Van Der Wal, 2015). It focuses on describing the way things appear to an individual as they live through a phenomenon. Descriptive phenomenology attempts to identify the essential parts of an experience and how people perceive that experience (or phenomenon).

Descriptive phenomenology does not attempt to compare people's perceptions with any predetermined system, criteria, or theory; no prior assumptions exist (Pietkiewicz & Smith, 2014). To practice descriptive phenomenology, the researcher must set aside any presuppositions and existing knowledge about the phenomenon and approach it with an attitude of discovery. In descriptive phenomenology, this is called *epoche*, *bracketing*, or *phenomenological reduction* (Matua & Van Der Wal, 2015; Vagle, 2014). Vagle (2009) explained: "Descriptive phenomenological researchers assume that when one tries to understand

phenomena one must *reduce* what one knows in order to *find* how the phenomenon shows itself in intentional consciousness” (p. 588). By practicing phenomenological reduction (also called epoche or bracketing), the researcher is said to be capable of tapping directly into the essence of that experience and can describe the experience as it is (Matua & Van Der Wal, 2015).

***Interpretive phenomenology.*** This type of phenomenology involves investigating the *meaning* of the phenomenon. This approach seeks to acquire a deeper understanding of the experience (Matua & Van Der Wal, 2015). The researcher imagines what the experience is like for the subject and attempts to give it meaning through interpreting that experience (Pietkiewicz & Smith, 2014). As stated above, interpretive phenomenology was a departure from Husserl’s descriptive phenomenological approach and was first conceived by Heddiger, a student of Husserl. Heddiger stated that human beings continually interpret the world, and therefore bracketing (removing all presuppositions) was not possible. In addition, unlike descriptive phenomenology which does not rely on any theoretical underpinning, interpretive phenomenology uses existing theories to interpret the phenomenon being studied (Vagle, 2014).

Pre-understandings and prior knowledge are not completely bracketed in interpretive phenomenology but are integrated into the research findings and are considered guides to achieve a deeper understanding of these findings (Matua & Van Der Wal, 2015). In interpretive phenomenology, the researcher is encouraged to make explicit any pre-understandings, pre-suppositions, biases, assumptions, beliefs, and theories about the phenomenon. These pre-understandings are to be held back during the research process as to not limit the participants’ experiences based on the researcher’s assumptions. The difference between this bracketing and the bracketing in descriptive phenomenology is that descriptive phenomenologists must assume an attitude of not having any prior understandings; whereas interpretive phenomenologists admit

to having prior knowledge, however they do not allow it to interfere with the process.

Interpretive phenomenologists will bring theoretical understandings to bear during the process of interpreting participants' accounts (Vagle, 2009).

***Interpretative phenomenological analysis.*** The current research study utilized an adaptation of interpretive phenomenology, called interpretative phenomenological analysis (IPA), to guide its methodology. IPA was first described as a qualitative research approach in the mid-1990s that was grounded in psychology (Eatough & Smith, 2011). Smith and Osborn (2004) stated that IPA “attempts to explore/understand/make sense of the subjective meanings of events/experiences/states of the individual participants themselves” (p. 229). Smith and Osborn also explained that although IPA attempts to understand the phenomenon from the participants' perspectives, the researcher must also interpret the participants' accounts to derive meaning from these lived experiences.

Interpretative phenomenological analysis is said to bring together phenomenology (uncovering meaning), hermeneutics (interpretation), and idiography (examining individual perspectives) (Pietkiewicz & Smith, 2014). Hermeneutics involves interpreting the meaning of experiences (Matua & Van Der Wal, 2015) and attempts to discover how individuals make sense of events, objects, and happenings in their lives (Pietkiewicz & Smith, 2014). IPA has been described as using a double-hermeneutic approach (also called the *shared meaning making* approach) because both the participants' and the investigator's perspectives of the phenomenon are explored as they ascribe meaning to the experience (Matua & Van Der Wal, 2015; Pietkiewicz & Smith, 2014). Smith, Flowers, and Osborn (2009) described the double-hermeneutic: “Although the primary concern of IPA is the lived experience of the participant and



the meaning which the participant makes of the lived experience, the end result is always an account of how the analyst thinks the participant is thinking” (p. 80).

Idiography is another characteristic of IPA. Idiography involves conducting an in-depth analysis of each participant’s account (case) in its unique context (Pietkiewicz & Smith, 2014). Idiography is an important component of IPA because this method is concerned with portraying an intimate account of each participant’s experience. Only after careful examination of each case individually does the researcher start grouping participants based on their accounts (Smith & Osborn, 2004).

In summary, this study utilized a qualitative phenomenological approach to investigate the lived experiences of study participants with HFA engaged in higher education. This research method was appropriate as to provide detailed accounts and descriptions utilizing participants’ own words, giving their experiences a voice. This research study applied IPA as a methodology, aimed at not only describing the essence of participants’ lived experiences, but also interpreting and comparing them against premises from the Theory of Self-Determination.

### **Sampling Design**

Participants in this study were students with HFA who were enrolled in a four-year college or university at the time of the study. The sample was a convenience and purposive sample in which students volunteered to participate. Purposive sampling is the typical modality used in IPA because this approach investigates one specific phenomenon from the perspective of a select group of individuals experiencing it (Smith & Osborn, 2004). In this case, students recruited needed to have HFA as a diagnosis and be enrolled in a higher education institution.

Because of the emphasis on idiography (individual perspectives) in IPA, sample size is an important aspect of conducting this type of research. Some authors stated that the number of

participants in IPA can range from one to 30, with most researchers agreeing on a small sample size as preferable in order to explore individual accounts more deeply. Experts stated that several factors should be considered when selecting a sample size. These factors included possible restrictions on accessing individuals, how rich each individual case might be, how the researcher planned to compare each case, and how committed to the case-by-case approach the investigator was (Eatough & Smith, 2011; Pietkiewicz & Smith, 2014). Given these recommendations, the researcher's intent was to recruit at least eight student participants. The researcher predicted that student recruitment might be difficult because people with HFA have social and communication challenges (National Institute of Mental Health [NIMH], 2016), and thus they could be reluctant to being interviewed.

The researcher decided to solicit assistance from disability services office directors to recruit students with HFA that might desire to participate in the project. In order to maintain a degree of homogeneity, only private colleges and universities in the Minneapolis and St. Paul (referred to as the Twin Cities) metro area of Minnesota were contacted. Smith, Flowers, and Larkin (2009) stated that IPA researchers typically recruit a "fairly homogeneous sample" (p. 49) to include participants to whom the research question will be meaningful. A total of 10 private higher education institutions were identified in the metro area and email communication was attempted with their disability office. Of these, no response was received from two schools after two attempts to establish communication; the attempts were three weeks apart. Of the remaining eight schools, two made additional inquiries via e-mail; one felt that they did not have time to assist, and the other did not respond to the additional information and subsequent follow-up emails. Of the remaining six schools, one disability director felt that too few students had registered with disability services with a diagnosis of autism (although he suspected that many

more students had this diagnosis, but had not disclosed it); thus he did not feel able to assist. The remaining five schools' directors of disability services agreed to assist. The investigator met with each to further explain the study. Four of these meetings were in person, which allowed the investigator to visit each school and familiarize herself with the school's environment. One meeting took place via a scheduled telephone meeting, and the investigator then visited the school to familiarize herself with the environment prior to the start of interviews. A brief description of each school is found in Table 1.

Table 1

*Description of Private Colleges and Universities that Assisted with Participant Recruitment.*

Assigned Name	School Size (number of students)	Student-to-Faculty Ratio	Brief Description of Mission Statement and Denominational Background
HEI-A	3,500	13:1	Prepares students for service in community and church. Lutheran.
HEI-B	6,000	11:1	Prepares students within an evangelical perspective and community. Non-denominational Christian.
HEI-C	1,500	17:1	Prepares students to be biblical models of leadership and ministry. Assemblies of God.
HEI-D	3,500	14:1	Prepares students in liberal arts degrees. Shared belief in Christ. Non-denominational Christian.
HEI-E	10,000	14:1	Prepares students to be morally responsible leaders and advance the common good. Catholic.

During the initial discussions of the study design with the dissertation committee chair, the investigator had decided to only recruit students with HFA who had completed at least two years of higher education. The researcher and committee chair felt that students in earlier years might have challenges with higher education that were common for underclassmen and did not

pertain to their HFA diagnosis. However, upon discussion with disability services' directors, the investigator decided to recruit students in college regardless of their academic standing, due to the perceived difficulty in recruiting participants; students with autism are often reluctant to participate in any activities. Because of the concern that too few students might be recruited, the investigator did not place a requirement of participants being upperclassmen (juniors or seniors).

The directors of disability services offices who agreed to assist with recruitment were provided information they could share with students via e-mail, including details about the study and the investigator's contact information (e-mail address and cell phone number). Students who expressed interest in the study were provided further information, including the criteria: being a current student in a four-year college or university, not having intellectual disability, having high-functioning autism (or Asperger's syndrome), and being able to meet with the investigator for at least one hour for an audio-recorded interview. Proof of diagnosis was not solicited; the researcher accepted the student's assertion of this diagnosis without further evidence. No proof of diagnosis was required because students with HFA may not be in possession of this documentation, and/or may choose not to share with their family that they are participating in a study. In addition, since the disability services offices only contacted students who were registered for their services, the assumption was that these offices had proof of diagnosis; they could not provide accommodations without such proof on file. An incentive of a \$40 Amazon gift card was offered to students who agreed to participate, which was sent to them electronically after completing the interview.

**Setting.** Students attending a private four-year college or university in the Minneapolis and St. Paul area were recruited. Students were given a choice of a meeting space: in a private room at their college or university, in their dorm room or residence, at the investigator's office,

or in a public place of their choice. Disability services staff at each college or university agreed to let the investigator use one of their meeting rooms for a private interview with the student, if that was the student's preference.

**Instrumentation and measures.** Semi-structured interviews are the preferred modality to obtain participant's accounts when using IPA. Through semi-structured interviews, the researcher has a set of questions to ask but uses these flexibly. Conducting more structured interviews or utilizing questionnaires are avoided because they typically elicit short responses from the participants and can pose questions that reflect the researcher's biases about the phenomenon (Smith & Osborn, 2004). Given this information, individual face-to-face interviews with students were conducted in this study. The interviews were semi-structured using open-ended questions. Questions were not read verbatim, and they were adjusted during the interview as needed. The interview questions are listed in Appendix A.

### **Data Collection Procedures**

When using IPA, experts recommended that participant interviews are audio recorded and then transcribed verbatim (Smith & Osborn, 2004). In this study, all interviews were audio-recorded and later transcribed. Data was collected using two audio recorders. Two recorders were used in case one failed; the reason for two recorders was explained to the participant. Prior to the interview, students were informed that the interview would be audio taped, and that confidentiality was assured. In addition to audio taping, the interviewer took brief notes about any salient observations that were not captured via the audio recorder. A printout of the questions and prompts provided notetaking space for the interviewer to use as needed.

Before the interview began participants were given time to read, ask questions, and sign the consent form. A copy of the Consent Form is found in Appendix C. These forms were

stored by the researcher in a locked file in her office. Before the interview the researcher asked the participant to create a pseudonym for himself/herself, which was the name used during the interview. This practice maintained confidentiality by not recording the participant's name digitally or electronically.

After the interview, the researcher wrote general comments about the interview, which included the setting, how the participant appeared (relaxed, anxious), if the participant's affect changed during the interview, and notes about what could be altered for future interviews. Merriam and Tisdell (2016) advised to write out observer comments as to stimulate critical thinking. In addition, the audio recording was downloaded to the researcher's computer, which is password protected. The audio files were then uploaded to another password protected and encrypted site that uses dual-authorization standards to provide additional security. The list of names with contact information, and pseudonyms, was kept in a separate file, also password protected and encrypted on the site that requires dual-authorization to access it. Audio files with no identifying participant information were sent to a transcriptionist via a secure server. When completed, each transcription was stored in the participant's folder, identified by the pseudonym. Participant were sent a copy of their transcript for review. They were asked to indicate if the transcript of the interview reflected their intentions, and to make any changes or add content if desired.

### **Data Analysis**

Data analysis was performed utilizing recommendations by Smith, Flowers, and Larkin (2009) regarding theme identification in an Interpretative Phenomenological Analysis (IPA) study. Once the data had been transcribed and participants had provided feedback, transcripts were uploaded to MaxQDA (version 10, Cleverbridge Inc., Cologne, Germany), a qualitative

research program, for ease of organization and coding. The investigator had created a preliminary list of possible codes during the writing of the dissertation proposal. These were entered into MaxQDA and utilized as preliminary codes to organize the data during analysis. These codes aligned with the Theory of Self-Determination: competence-classes, competence-system, relatedness-faculty/staff, relatedness-peers, autonomy, and suggestions.

Reviewing transcripts followed suggestion by Smith et al. (2009), starting with reading each individual transcript, line-by-line, to obtain a general understanding of each participant's lived experience. During the initial reading of each transcript, the investigator listened to the audio recording to be reminded of the participant's voice and better recall the session. During the first reading, the investigator did not attempt to categorize or code the transcript; the intent was to become familiar with the account before attempting to analyze the content. As suggested by Smith et al. (2009), the investigator kept notes about her feelings and personal thoughts regarding the participant during the transcript review. Keeping notes on a separate notebook was done as a way of focusing on the participant's account while removing the investigators emotions or pre-conceptions. In phenomenology, this process is called bracketing (Creswell, 2014).

After an individual transcript was meticulously read, the investigator reviewed the transcript again to identify major themes. Initially the investigator applied the predetermined broad code categories. With each subsequent reading of the interview the investigator added new codes as themes arose. When the investigator determined that a thorough review of a transcript had been done, the next transcript would be reviewed.

The same method was followed with each transcript, first conducting a line-by-line close review while listening to the interview recording, making annotations in a separate notebook to

bracket the investigator's ideas or feelings. After the initial transcript review, in which no coding or transcript notes were made, the investigator reviewed the transcript again, coding for themes, looking for patterns, commonalities among participants, and ways in which participants diverged. This practice was followed for each of the 17 interviews.

Through the process of reviewing each transcript, a series of themes developed. Most of the themes aligned with one of the three areas within Theory of Self-Determination (competence, relatedness, and autonomy), however emerging themes were also identified. Table 2 outlines the codes utilized during data analysis, including sub-codes.

Table 2

*Codes that Emerged through Transcript Review*



Primary Code	Description: Participant talks about or states:	Sub-Codes	Description: Participant talks about or states:
Competence	competence-related questions by sub-category	Self-care	self-care activities in school (cooking, laundry, cleaning, self-grooming)
		Difficult subjects	subjects/ classes that have been difficult in college
		Communication	challenges with communication – verbal and nonverbal
		Seeking help	ease or difficulty seeking help in college
		Concentration	challenges concentrating in college
		Organizing self	experience organizing self in college
		System	ease or difficulty navigating the college system
		Classes	how classes are going (well or not well), including past classes
Relatedness	relatedness (how he/she relates to faculty, staff, classmates, peers, friends)	College living arrangement	living in dorm or off-campus, including description of challenges with living arrangement and roommate(s)
		Significant other	having a boyfriend or girlfriend at time of interview or earlier
		Friends	having friends in college
		Peers	interactions with peers in college
		Classmates	interactions with classmates
		Staff	interactions with college staff, including disability services staff, advisors (anyone other than professors/instructors)
		Faculty	interactions with professors/ instructors
Autonomy	autonomy-related topics (including plans post college)	Parent support	how much parents are involved in college life, including parent assistance with courses, organization, self-care
		Job in college	having a job currently (while in college)
		Job post college	employment plans post-college
		Self-care	activities of daily living (eating, grooming), laundry, cooking
		Independent living	plans post-college: living with parents, living on his/her own
Suggestions	what he/she wants other people to know about autism	Administrators	what he/she wants administrators to know or keep in mind about people with autism

Primary Code	Description: Participant talks about or states:	Sub-Codes	Description: Participant talks about or states:
		Peers	what he/she wants peers (other college students) to know about people with autism
		Staff	what he/she wants staff (people that work in the college who are not their instructors/professors) to know about people with autism
		Faculty	what he/she wants faculty (instructors/professors) to know about people with autism
		Other	what he/she wants people in general to know about people with autism
Mental Health	having a mental health problem/diagnosis	Depression	having a diagnosis of depression, being depressed, having depression
		Anxiety	having a diagnosis of anxiety, being anxious, having anxiety
		Other	other mental health problems or disorders, aside from depression and anxiety

When all participant transcripts had been reviewed and coded, the investigator utilized a filtering tool in MaxQDA to separate data from multiple transcripts by theme. As suggested by Smith et al. (2009), the investigator created tables for each theme and sub-theme, including participant characteristics (pseudonym, year in school). The investigator subsequently reviewed each table carefully, making notations about insights gathered from the review of each theme individually. This practice also allowed the investigator to determine that some of the codes did not generate a true theme, as few or only one participant mentioned a particular experience; thus, these were not included in the results.

Participants' experiences and themes were described by using a narrative style, including several participants' quotes to illustrate the themes and interpretations of those themes. The

researcher postulated possible relationships between findings to the Theory of Self-Determination's components of competence, relatedness, and autonomy. Suggestions for practice and future research were also made based on this study's findings.

The validity of the data was ascertained using strategies described by Creswell (2014). Participants were provided transcripts of their interviews for review, giving them an opportunity to make any desired changes. Through the review of their interview transcripts, participants were able to provide additional insights about their lived experiences. In addition to allowing participants to revise their transcripts, the researcher reflected on the biases she had about the subject matter and documented these biases in a separate notebook. Beyond reflecting on possible biases, the researcher also made notations about emotions that arose during the interviews or transcription review process. Through this reflection, admission of bias, and documenting the researcher's emotions, the researcher was able to exercise caution when analyzing and interpreting findings.

Another strategy used to ascertain validity was to examine findings from this research study that differed from existing literature. Creswell (2014) explained that portraying information that is counter to other investigator's findings provides additional validity and realism to a study. To further validate data, the researcher explored the website of the school that each participant was attending, focusing on information regarding services for students with disabilities. The researcher also visited each school, exploring places where students gather, observing classroom set up, and witnessing how students (not participants) used various school environments. Visiting schools allowed the researcher to experience the environment that participants encountered and imagine how students with autism might perceive these spaces.

Merriam (2016) indicated that employing a variety of methods can add credibility to qualitative research, such as triangulation of data, which includes utilizing multiple methods of data collection, for instance, interviews, documents on the topic, and direct observations. In this study, triangulation of data was accomplished by soliciting participants' input about their transcribed interviews, reflecting and documenting the researcher's biases, exploring schools' offerings to students with disabilities, and visiting each school.

Reliability of the data was also ascertained. During the initial stages of transcript coding, a second coder reviewed transcripts and assigned codes based on pre-determined definitions. Inter-coder agreement (Creswell, 2014) was calculated by comparing the primary researcher's code assignment against that of the second coder. Inter-coder agreement was low at 67% during the first attempt. The researcher and second coder reviewed the transcripts, discussed code assignment, and identified differences. Most differences related to sub-codes, however major codes were consistent. After determining that the major codes (or categories) were the most important to identify, a second set of transcripts was reviewed, resulting in inter-coder agreement of 82%, which was above the recommended minimum level of 80% agreement.

### **Limitations of Methodology**

Several limitations to this study exist. Qualitative research seeks to understand an issue in depth, rather than breadth as quantitative research would (Creswell, 2014; Orcher, 2014). As such, findings of qualitative research are not meant to be generalizable to a broad population. This study describes the lived experiences of some students with HFA in higher education and does not imply that these experiences are the same as those of every student with autism in college. In addition, the sampling is a purposive and a convenience sample (Orcher, 2014), with particular schools agreeing to assist with participant recruitment, and students within those

schools agreeing to participate. Because the sites and students who agree to participate may be different from those who do not, the study has a bias and lack of generalizability. In addition, the study is utilizing participant's accounts of their experiences based on their insights. Whereas this is the goal of a phenomenological study, the reader should consider that these are individual perceptions and interpretations (Creswell, 2014).

The setting where the interview occurs could also be a limitation. Participants may have different levels of comfort based on the interview location, which ranged from a room at a disability office, to a coffee shop, the researcher's private office, the participant's dorm room, and the participant's home. In addition, being interviewed can be a source of anxiety to participants, and the desire to answer in a manner that the participant perceives as most appropriate could also affect the responses.

This study also has delimitations. It focuses on students who have HFA only, not on students with more severe forms of autism that include some degree of intellectual disability. In addition, only students enrolled in four-year institutions were included, not those enrolled in two-year technical programs or in community colleges. This delimitation is to describe the experiences of students who were admitted to a four-year institution and perceived to have the ability and skillset to perform at a college or university level.

The study focuses on students enrolled in higher education institutions in the Minneapolis and St. Paul metro area of Minnesota who volunteered to participate. This delimitation facilitated conducting in-person interviews, given that the researcher lived in this geographical region. In addition, only in-person interviews were conducted. Some demographic questions were asked (age, year in college, major), but no written or electronic survey was administered to maintain the nature of a qualitative phenomenological study. Students who participated were

asked to disclose their autism diagnosis (HFA or Asperger's syndrome), but no proof was required.

### **Ethical Considerations**

Several ethical considerations were considered through the research process (Creswell, 2014). Approval from the Institution Review Board (IRB) at Bethel University was solicited and acquired prior to initiating the study. The researcher communicated with individuals at colleges and universities who facilitated the recruitment of participants, to ensure they had no vested interest. Comments made by individual students might be perceived as reflecting negatively on their institutions; those comments were included in the narration. Maintaining confidentiality of participant information and assigning pseudonyms decreased the risk of participant identification; however, the schools may be discernible in the context of the narrative. Therefore, the researcher assured no vested interest on the parts of the individuals or schools that assisted with student recruitment.

Conducting research that benefits study participants is desirable. Because the current study was qualitative phenomenological research, the outcome may or may not directly benefit the participant; however, it may provide a better understanding of the lived experiences of some individuals with autism. With the increasing numbers of students with autism entering higher education, insights into their lived experiences can be beneficial to those students, their families, and to disability services staff at the schools they attend.

Participants were given an opportunity to read the study's informed consent form before agreeing to participate. Informed consent is required by the U.S. Office for Human Research Protections (U.S. Department of Health and Human Services, n.d.) to ensure that human subjects are protected in research through the disclosure by the investigator of all pertinent details of the

study. The informed consent form included a statement of the voluntary nature of participation, as well as assurance that participants could remove themselves from the study at any point (see Appendix C).

Prior to the start of interviews, the researcher requested that experts in the field and relatives of people with HFA review and comment on the interview questions. The purpose of this review was to prevent asking a question that could be perceived as biased or judgmental. During the interview, the researcher explained to the participant how the research would be utilized. The researcher also provided their interview transcript for the participants to review and edit. Participants were also provided with a gift card in appreciation of their time, not to coerce participation.

When analyzing the data, the researcher refrained from empathizing with participants or disclosing only positive results (Creswell, 2014). Instead, the researcher attempted to describe various perspectives, including unanticipated findings. All data obtained is being reported. Participants selected a pseudonym to maintain confidentiality; the researcher attempted to report the findings in a manner that precludes identifying the participant or the school. With the goal of transparency, participants and institutions who assisted with recruitment will be provided a copy of the dissertation.

Ensuring ethical practice through research is essential. The measures outlined above are intended to maintain high levels of ethical behavior throughout the study. By following these practices, the researcher attempted to minimize the potential for ethical issues to arise during or as a result of the study.

## **Chapter Four: Results**

The purpose of this phenomenological study was to explore the lived experiences of students with high functioning autism who were enrolled in a four-year institution of higher education. The main research question was as follows: What are the lived experiences of students with high functioning autism who are enrolled in institutions of higher education? The research sub-questions were: (1) How do students with high-functioning autism describe their lived experience while attending an institution of higher education? and (2) How do students with high-functioning autism describe their lived experience as they interact with the higher education system?

Ten private schools in the Minneapolis and St. Paul metro area of Minnesota were contacted to inquire about assisting with participant recruitment. Of these, five private schools aided with the recruitment of participants through their disability services offices.

### **Participant Description**

A total of 17 students, nine males and eight females, were recruited from the five schools: four students from HEI-A, one student from HEI-B, three students from HEI-C, four students from HEI-D, and five students from HEI-E. A description of the students is found in Table 3. The interviews started after students had identified a pseudonym to be used during the recording. The first set of questions asked demographic and background information, including age, year in school, major (if they had already declared), autism diagnosis (if they had a specific diagnosis within the spectrum), and the age of their autism diagnosis.

Table 3



*Description of Student Participants.*

Pseudonym	Gender	School	Age	School Year	Major	ASD Diagnosis	Age of ASD Diagnosis
Isaac	M	HEI-D	18	Freshman	Education	Asperger's	11
Susan	F	HEI-C	18	Freshman	Secondary Education	Asperger's	3
Carl	M	HEI-E	18	Freshman	Accounting	Asperger's	Entering high school
William	M	HEI-A	20	Sophomore	Computer Science and Math, Minor in Biology	Asperger's	High school
Kirk	M	HEI-B	20	Junior	Math and Economics	Asperger's	2
Megan	F	HEI-D	20	Junior	English and Writing	Pervasive Developmental Disability-Not Otherwise Specified	3
Riley	F	HEI-D	20	Junior	Studio Art	Asperger's	17 or 18, senior in high school
Jordan	M	HEI-C	20	Junior	Elementary Education	Asperger's	13
Allyn	F	HEI-A	21	Junior	Film Production and Creative Writing	high functioning autism	2
Marcus	M	HEI-E	21	Junior	Actuary Science	Unknown	"little kid"
Jackie	F	HEI-D	22	Sophomore	Psychology	ASD-mild	19
Elizabeth	F	HEI-E	22	Senior	Liturgical Music, minor in Catholic Studies	Asperger's, high functioning	13-14
James	M	HEI-E	22	Senior	Business	Asperger's	3
Mike	M	HEI-E	22	Senior	General Education, Secondary	Asperger's	6 <sup>th</sup> grade

Pseudonym	Gender	School	Age	School Year	Major	ASD Diagnosis	Age of ASD Diagnosis
					Education		
Chase	M	HEI-C	23	Senior	Intercultural Studies and Education	Asperger's	2
Speed Runner	F	HEI-A	27	Sophomore	Communications, minor in Special Education	Unknown	3
Frodo	F	HEI-A	42	Senior	Computer Science, minor in Geology	Asperger's	Late 20s

**Participant ages.** Most participants had ages typical of traditional college students.

Three were 18 years old and were freshmen. Five participants were 20 years old; one was a sophomore, and the remaining four were juniors. Two participants were 21 years old; both were juniors. Four participants were 22 years old; one was a sophomore and three were seniors. One participant was 23 years old and was a senior. One participant was 27 years old and was a sophomore. One participant was 42 years old and was a senior.

**Year in school.** During the initial discussions of the study design with the dissertation committee chair, the investigator had decided to only recruit students with HFA who had completed at least two years of higher education. The concern was that students in earlier years might be experiencing challenges that were common when transitioning to a college or university context and were unrelated to their HFA diagnosis. However, upon discussion with disability services' directors, the investigator decided to recruit students in college regardless of their academic standing due to the perceived difficulty in recruiting participants since people

with autism are often reluctant to volunteer for interviews. Because of the concern that too few students might be recruited, the investigator did not require participants to be juniors or seniors.

Of the 17 participants, three were freshman, two males and one female. Three students, one male and two females, were in their sophomore year. Six students, three males and three females, were in their junior year. Five students, three males and two females, were seniors. Thus, more than half (11) of the students interviewed were in their junior or senior year in college, and thus well acquainted with college life and its challenges.

**Age of diagnosis.** Of the 17 students interviewed, eight participants, four females and four males, had been diagnosed at two, three or four years of age (during the preschool years). No participants were diagnosed during elementary school, or between five and 10 years. Four participants, three males and one female, were diagnosed in middle school (ages 11 to 14 years). Three participants, three males and one female, were diagnosed in high school (ages 15 to 18 years). Two female participants were diagnosed after high school, one at age 19 during her first year in college and one in her late 20s.

**Autism Diagnosis.** When asked about their autism diagnosis, most participants, eight males and four females, stated they had a diagnosis of Asperger's syndrome. Two female participants stated their diagnosis was autism spectrum disorder with the addition of the term *mild* in one instance, and *high functioning* in the other. One female participant had a diagnosis of pervasive developmental disability, not otherwise specified. Two participants, one male and one female, did not know the name or classification of their autism diagnosis.

**Major in college.** Great variety was found in the participants' disciplines, their majors and minors. One major was common among six of the participants: education. Four males and two females had a declared major in education, although the area of focus varied, including

elementary, secondary, and special education. Computer science was mentioned as a major among two students, one male and one female. Math was mentioned as a major by two male participants who had a double major – one in computer science and math, and one in math and economics. Writing was mentioned as a major by two female participants, both of whom had a double major – one in English and writing, and one in film production and creative writing. The other majors mentioned were studio art, actuary science, liturgical music, and business.

**Introductory Questions**

At the beginning of the interview, students were asked what they liked most and least about being in college. These questions were intended to start a conversation and put participants at ease. Table 4 includes the questions asked of the participants.

Table 4

*Questions at the Start of the Interview*

Primary Question	Sub-Questions
Tell me about your experience in college so far.	What do you like most?
	What do you like least?

When asked what participants liked the most about being in college, a variety of responses emerged. One theme mentioned by three participants was that college provided them opportunities for future success. For example, Jackie (a sophomore) stated, “What I like the most is probably the promise that it holds.” Also, speaking about opportunities for the future, William (a sophomore) stated, “The fact that I can continue my learning past where a lot of people tend to stop . . . I can spend that time moving towards the goal – some of the stuff that I

really want to learn how to do.” Mike (a senior) expressed satisfaction with his ability to be in college and being able to graduate:

The experiences that I thought that I could never have. And I guess this is the progress from, well, just being in college. A lot of people when I was younger didn't think that I would go to college and I'm finishing college soon.

As highlighted by these participants' words, the theme of the ability to attend college, despite their disability, and to complete a degree held a hope for future success.

Three female participants stated that their favorite part about college was meeting fellow college students. Elizabeth (a senior) stated, “I- I have liked it that there are so many—well, there are so many good people on campus.” Megan (a junior) also referred to meeting students, although she met fellow college students through becoming involved; she expressed, “I guess getting involved helped a lot in order to get to like appreciate the college life. So, I'd joined band and got to know people in there.” Allyn (a junior) mentioned, “There are other people who have similar interests as me, so I have a few more people to talk with.” As these three female participants explained, meeting people was an aspect of college life that they particularly enjoyed.

Three male students noted that what they liked most was independence. Kirk (a junior) stated, “I think, just, I like being on my own. Developing some independence and learning important life skills.” Chase (a senior) described it as “being able to step out on my own.” Isaac (a freshman) described what he liked most about college in terms of his dislike of having to follow a routine, as he did in high school. He stated, “I -- my own pace, my own schedule, so I'm not like . . . I know it's really contradicting to what actually is mostly seen for ASD, but it's,

I hated a fixed routine.” Having more independence was the aspect of college life that these three male participants liked the most.

Two female students stated that what they liked most was their interaction with support staff. Speed Runner (a sophomore) stated:

That they're really good with students who have disabilities, or you can, you could go to a [disability] office, where they'll be willing to give you different things to help you succeed in class. If it means using your laptop to record your professors, or if it means, you know, having special times where you go to check in with somebody to say, "This is what I'm struggling with. Could you help me get a tutor or somebody?"

Susan (a freshman) also expressed satisfaction with support services. She stated, “The good things about college would definitely be that the staff are always really willing to help you. They have a lot of resources for you to get help.” Both participants had positive experiences with support staff, particularly disabilities office staff, and they appreciated this aspect of college life.

In summary, although this initial question was only intended to put people at ease, some similarities in responses emerged. Common themes regarding what participants liked most about college included the opportunity for future success, meeting fellow students, the availability of support services, and the ability to be more independent.

When asked about aspects they liked least about college life, a variety of responses were provided. Six students mentioned various stressors, particularly related to class loads. Susan (a freshman) described the stress of the heavy workload as “a negative is that it's like you have a million things to do in one class for the whole 10 million things to do in another and you just like have to figure that out, you . . . like better organization.” Elizabeth (a senior) stated, “A lot of the workloads, especially some of the classes that involve a lot of reading, or maybe writing – and a

lot of writing.” Chase (a senior) described it as “one stressor after another.” Mike (a senior) expressed “the stress from—the stress and anxiety from the tests and the social aspect, but mostly the tests.” All these students felt the heavy workload was an aspect of college they enjoyed the least, and many mentioned experiencing increased levels of stress as a result.

Two students mentioned isolation due to their college’s location as an aspect they disliked. Jackie (a sophomore) expressed:

I can’t drive because of my disability. I don’t respond well enough to a changing visual environment. Getting to the grocery store and back can be a real pain because I have to either walk there or have to fiddle with bus schedules or I just have to bum a ride off my sister.

Megan (a junior) stated, “Well, it feels kind of isolated here, especially here because the campus itself is like enclosed. So, it’s like at times, I kind of felt like kind of like trapped.”

Both students attended a college that was a distance away from any grocery or convenience stores. Megan’s dormitory was also adjacent to, but not within the confines of the college campus.

Two students mentioned that self-advocacy was challenging. Riley (a junior) described “getting used to actually advocating for myself and giving my professors the information they needed so that they could help me.” Mike (a senior) stated that self-advocacy was difficult “adjusting to being more of an advocate for yourself.” Both of these students found soliciting help for their disability to be more challenging in college than in high school because their family members were no longer involved.

Participants also mentioned other aspects of college they liked the least. Carl (a freshman) expressed that transitioning between classes was his least liked aspect of college life:

Maybe just transitioning between classes. Just always different people who are complete strangers to me, just walking in big groups, just maybe being stuck in the middle of them. Being uncomfortable like that. So, the shift between different periods of the day, just with so many different people walking around, I would say would—so far—would be my biggest dislike.

When clarification was sought, Carl expressed that the proximity of people around him in hallways between classes, and the perception of being surrounded by too many people, were both uncomfortable situations because of his need for more personal space.

Marcus (a junior) referenced group work as the aspect of college he disliked the most: It's like group work is like—I struggle with a group to begin with. It's just like whenever someone says that we're doing group work I just get really stressed out over it. Like I just don't like—it just makes me really worried.

Marcus was visibly uncomfortable when speaking about his difficulty with being asked to work in a group with fellow students. Allyn (a junior) expressed that public speaking was a college activity she disliked:

One of the aspects, I guess, is with I guess public speaking. And just talking in front of a class. I have always had a bit of—like sometimes I have had trouble with that. Where I just—just get a little shaky and I can't articulate, and I just speed up while I am talking.

Allyn also expressed that, even though public speaking was a common fear for people, she felt that speaking in front of a group of people was much worse for her due to having autism.

In summary, the second introductory question about what students disliked the most about college also provided shared and unique findings. Several students disliked the stress related to having a heavy load with multiple classes and deadlines. Some students disliked the



isolation due to their college's location. Two male students had difficulty with self-advocacy, and a few students mentioned other common college activities such as working in groups, speaking in public, and being surrounded by too many people in hallways.

The next set of questions asked during the interview was intended to elicit the experiences of participants in three areas: competence, relatedness and autonomy. According to the Theory of Self-Determination (Deci & Ryan, 2000), these basic psychological needs are central to human motivation. Results will be presented based on insights gathered in these three areas, followed by unexpected insights that arose during the interviews.

### **Theory of Self-Determination Themes**

**Competence.** Competence was the first area explored, in relation to the Theory of Self-Determination, as an essential skill that influences human motivation. The questions asked related to competence are listed in Table 5.

Table 5

*Interview Questions Pertaining Competence*

Primary Question	Sub-Questions
Tell me about your classes; what classes are you taking?	How are your classes going so far? How did you decide to register for these classes? Did you get the advice and support you needed to register for your classes?
Tell me about how you keep yourself organized for your classes and schoolwork.	How well is this system working for you?
If you needed help, how comfortable are you with getting help with your courses?	Who are you comfortable asking for help, if you needed it? <ul style="list-style-type: none"> <li>• For instance, are you comfortable asking an instructor for help?</li> <li>• Are you comfortable asking a teaching assistant for help?</li> <li>• Are you comfortable asking fellow students for help?</li> </ul>

**Classes.** After the first few interviews, the investigator determined that asking participants which classes they were currently enrolled in was not helpful. Participants struggled to remember the names of their classes. In subsequent interviews, the investigator asked how they were progressing in their classes. This change led participants to talk about the classes they were enrolled in and comment on their performance. Participants would typically list courses that were particularly challenging, and then explain why they were challenging. They would also speak about courses in which they were not having difficulty. By adjusting the interview questions, participants were better able to articulate their experiences with various classes.

Some participants changed their original major due to difficulty understanding core courses in their initial discipline. One example is Megan (a junior), who spent her first two years

in college as a management information systems (MIS) major; she changed her major to English and writing at the end of her sophomore year, after struggling in MIS. When asked about her experience in her first two years in college while majoring in MIS, she stated:

So, it was like I was very stressed out, and I was like “I don’t understand this, and if I’m going to be doing this later on, I need to be able to understand it.” And like my professor would try explaining it to me, and I’m just like “I don’t get this. Like why are we doing this?” And they’d just [say], “Oh you just do this.” And it’s like, “but why?” So, it was like stressful, frustrating, it was [pause] it was just hard. ‘Cause then I like had to try to ask for help but I’m just not the best at that yet.

Even though Megan sought help with her MIS classes, the subject matter was still too difficult for her to understand and rationalize, which prompted her to change majors. How Megan had initially decided to major in MIS was not further investigated. Megan did indicate that she was performing well in her current major.

Marcus (a junior) also changed majors and schools after a period of difficulty with his original major of engineering. Marcus started college at a large public state university (over 30,000 undergraduate students). From the beginning, he experienced challenges; he didn’t understand how registration worked so he sought assistance from his freshman orientation leader. During his first semester, he had difficulty in most of his classes, needing to drop a class with assistance from his father, because the system was too hard for him to understand. He described his difficulty with the class he dropped as follows:

I took the physics class, but I ended up having to drop it because I tried going to the tutoring. I went to see the professors and the—I don’t remember all of the names for everything, but like the assistant teachers because the physics class I had like—it was

more or less like an auditorium. . . . This was kind of like hundreds of students, so it was like after every lecture, we had to go to like a smaller, separate lecture of like a teaching assistant. So, we had to go to that, and it was like it didn't help. So, I couldn't really ever see my regular professor -- because there was too many people. And my teaching assistants, I tried getting help from, but I don't think I could understand it, and it was just so much I couldn't do.

In his second semester, Marcus enrolled in fewer courses at the large university and more courses at a community college. When asked how this experience differed from his first semester, he expressed that it went well. When asked why, he stated, "First off, there was 100 less students in the class." Thus, the class size appeared to be a factor in the perception of his ability to succeed in school and influenced his decision to switch schools.

In addition to these challenges, Marcus also realized he would be required to take several language classes at the large university, and he recognized that his ability to learn languages was limited. According to the participant, this requirement also contributed to his decision to leave the large university. He described:

I just thought like I was in like the—because in the engineers, at the [large university], they require you to have a language. Basically, at where I am now . . . I still have a language, but I only have to take a few courses. They wanted me to take more advanced courses at the [large university].

Therefore, another contributing factor to his decision to switch majors and transfer to another school was related to the required courses. Even though both schools had language requirements, the smaller school had fewer stipulations. Marcus spent his second year in college enrolled solely at a community college and then transferred to a small, private college with a

major in actuarial science. When asked why he had selected this major, Marcus stated that his father recommended it after Marcus expressed his enjoyment of a statistics class.

Difficulty learning a foreign language was also mentioned by James (a senior). He was able to waive the foreign language requirement at his university as one of his accommodations; instead of taking a foreign language, he was required to enroll in a global studies course. He described his experience when taking a Spanish class as follows:

I'm terrible at memorization. I think I have one of the worst memories ever, and maybe that's not even an Asperger's, maybe that's just me. But I can't learn the simplest phrase in any language. So, you know, I was barely getting by in the Spanish class and my professor urged me to drop it, because I wasn't going to pass, and by then, I was already very anxious about the class, because we'd have to talk to each other and you know, he'd tell us to have a conversation in the language. And everybody else was much better at it than I was, and it was very embarrassing. Like I was known in the class for being terrible at the language. And it wasn't from a lack of effort, either. I worked harder in that class than any of my other classes that semester, but I had to drop it.

These two students described their difficulty in learning a foreign language and how that challenge influenced them. One student changed his major and transferred to a different school, and the other student requested an accommodation to waive the language requirement. These were the only two participants who expressed difficulty with foreign languages, although no specific question asked regarding languages were asked.

The next set of interview questions inquired about how students had decided on their class schedule, and the selection process. These questions provided limited information. Most participants stated that once they declared a major, the schedule of classes was planned for them

and it was not difficult to determine which classes to take each semester or quarter. Participants also mentioned having an advisor with whom they met to determine their class schedule and progression. For most of the participants, this system was described as “easy to follow.”

**Organization.** Questions about how participants organized themselves provided insights into challenges with executive function skills. Challenges with organization was a recurring theme. Although most participants had found a strategy for organization, the researcher surmised that participants had experienced difficulties with organizational skills in the past. Based on the stories of two participants, learning organization skills had been a challenge. Jackie (a sophomore) had completed her freshman year at a public university in a neighboring state; she had failed all her classes and was expelled. As a result, her family investigated reasons for Jackie’s challenges, which led to a diagnosis of HFA. Upon diagnosis, Jackie underwent various therapies to learn to manage difficulties related to autism and to help prepare her for college. One of her therapists, a speech pathologist, mentored Jackie in organizational skills, including the use of a planner. Jackie described the process as follows:

Now I have a planner and I know how to use it. Before, I was very resistant to the idea of a planner because my only experience with them had been with weekly/monthly planners that I had in junior high which had not worked for me because I would cram them with information about when classes start and they just couldn’t accommodate all of that data. I didn’t know how to prioritize or how to plan multistep projects like papers that need to be written. My take away from that had been planners just don’t work for me. Then when I went through speech therapy I was given a series of tasks like you’re going to pretend that these are your assignments for the day, identify which ones are the most important, and think about what kinds of steps you might need to take in order to do that.

It always took me awhile to figure that out, but eventually it became so easy like I could almost do it in my sleep or without thinking about it.

In addition to using a planner, Jackie also described needing to set alarms on her phone to alert her of appointments.

Elizabeth (a senior) also described her initial difficulty with organization in college. During her sophomore year, she became overwhelmed with the workload, which was starting to become more challenging as she started taking classes within her major. She started to miss deadlines, received low grades in her classes, and she became increasingly anxious, but was not willing to share this with her support system (her mother, instructors, and support staff). When the stress became unbearable, she confided in her mom who encouraged her to meet with disability services staff; her mom accompanied her to the meeting. One of the strategies that helped her be more successful in college was meeting weekly with a disability staff member to organize her schedule. She described the assistance she received as follows:

They help me put together a kind of schedule of my—my upcoming week, and what assignments I have, based on the syllabus. And any other—any other types of events I have going on, and to kind of plot out when I do which assignment—and—when I have breaks, when I have lunch and—when I am done for the day.

Although these meetings started during Elizabeth's sophomore year, she continued meeting with a disability services staff member every week to work on her schedule until graduation.

Eight participants mentioned using a planner to organize themselves. Most stated that they reviewed the syllabus for each class and entered deadlines in their planner. One participant stated she used a planner in addition to a composition book to write out daily tasks. Two participants mentioned using alarms on their phone for reminders. Even when an activity had

been entered in their planner, they stated they would forget about it without having an additional alarm on their phone.

Four participants, three male and one female, admitted to not having an organizational system and having difficulty with organization. One of these participants was a freshman, one a sophomore, and two were seniors. For example, when asked about a system to organize herself, Frodo (a senior) stated, “Oh, that’s a nightmare.” James (a senior) described his challenge with organizing himself as: “Okay, so I’m terrible at keeping a schedule, which is not something good for somebody to do with a terrible memory. I mean, every time I’ve tried keeping a schedule, I kind of lose track of it and start keeping track of it in my mind, but then I don’t.” Even though both Frodo and James were seniors, they had not been able to identify an organizational system, and thus they both had difficulty in this area.

In summary, challenges with organizational skills arose as a theme during participant interviews. Several participants had found planners to be instrumental in organizing their schedules in college, some also utilizing alarms to alert them to appointments. Four respondents, however, two of whom were seniors, had not identified a system to remain organized and admitted that the lack of organizational tools was challenging.

***Soliciting help.*** When asked about their comfort level in asking for help with coursework, some participants reported reluctance in doing so; however, many did access support services often. As Kirk (a junior) stated, “Not something I’m terribly good with. I like to just figure stuff out myself.” When asked what he would do if he were having difficulty in a class, he mentioned that he was comfortable attending math lab. He stated:

[University name] has something called the Math Lab. It's every night, and basically you get to go there and they have tutors there to answer your questions. I have utilized that a



lot. . . . It's not my thing. That's definitely not what I would prefer to do, but I have done it before.

Thus, even though Kirk preferred not to seek help, he voiced that he had attended the math lab and had found benefit in doing so. Seeking help appeared to be uncomfortable for Kirk and the interviewer perceived that he did not want to continue to converse about this topic.

When asked about her comfort level seeking help with coursework, Frodo (a senior) stated she was “not at all” comfortable. The only person she was comfortable approaching was one professor. She stated, “I have a good relationship with professor [name] in the math department. And so I'll go, I'll eventually go to him. That's the only person I really ask for help.” While uncomfortable asking for help in general, Frodo was comfortable with one specific adult at her college. Familiarity with an individual appeared as a common theme when participants with HFA considered asking for help. On several occasions participants would indicate comfort speaking with an individual if they knew him/her, and great discomfort approaching a so-called stranger.

Speed Runner (a sophomore) expressed comfort with seeking help from her academic advisor. Speed Runner also had other support systems, and she stated:

Um, so, I have an ILS...that has helped me doing studying, and making sure that my appointments that I need to take care of are done. I have a PCA, who also, you know, helps me if I need like, about religion questions. I can also ask my brother who lives in Denver, but he's taken so many religion classes. So, he's, he could kind of help me figure out stuff.

Speed Runner was referring to an independent living support (ILS) program and having a personal care assistant (PCA). These individuals assisted her in organizing her school schedule,

studying, and deciding who to contact in college when she needed additional help. Speed Runner chose to be interviewed in her home. At the time of the interview, a PCA was with her assisting her with homework. Speed Runner lived with her mother, who also assisted her at times by reviewing her papers. Upon interacting with Speed Runner, the interviewer thought this participant may have some intellectual disability, although no inquiry was made and the suspicion was not confirmed.

When Chase (a senior) was asked about his comfort level for seeking assistance with coursework, he explained how he has taken advantage of the programs at his university:

It was relatively easy because [university name] has a student success—they have tutors and things like, and then as far as my last math class I ever took—I took full advantage—I need help because the stuff was the type of math we were taking just like ah.

Chase also described how he utilized other support programs at his university, he stated:

Normally I meet with an academic counselor and say this is where I'm at as far as my assignments go. She's like:

“did you get this assignment done?”

“Like, yeah.”

“This one?”

“Yeah.”

“This one?”

“Yeah.”

“That one?”

“No.”

Chase explained that he met with these people once a week and had needed to do that after failing two courses.

In summary, even though some students were reluctant to ask for help when having difficulty in a class or were only comfortable with an individual (such as Frodo was), several students reported taking advantage of academic support systems at their university. Therefore, acquiring help from academic support systems in college by students with HFA arose as another theme in this research study.

**Communication.** Although no interview questions were asked that addressed communication directly, difficulties with communicating arose as an additional theme pertaining competence. Difficulty expressing themselves verbally was mentioned by several participants. Kirk (a junior) stated:

'Cause a lot of times I might know I have a problem, but I don't, I don't really know what questions to ask . . . Because I feel like, I might, I might ask about something, and then I'll feel like my question really wasn't answered.

Elizabeth (a senior) also stated that she had trouble putting her thoughts into words. She explained that staff from the disabilities office occasionally assisted her in drafting emails. She stated:

They have helped me communicate to my professors if-if for-if I'm having trouble with a project or with an assignment. And I - I always have trouble with communicating, to-- to other people, especially people who I don't normally communicate that often to. And I just basically ask them oh, can you help me compose an email asking about this assignment?

Elizabeth was receiving assistance from the disability support staff. These staff met with her weekly to review Elizabeth's schedule, and they also assisted her in drafting e-mail communications to professors when needed.

Frodo (a senior) also expressed difficulty communicating and described her experience when speaking with the disabilities office staff, "But I don't, um, I don't know how to express what I need." Frodo cried at this time, and continued by stating, "It's really hard. Um, to put in words what I need is very difficult. And even when I can put it in words, sometimes they don't understand. And so there's a communication barrier. And it's huge." In Frodo's case, her difficulty communicating also extended to the people that worked in disability services, an issue that produced anxiety for her.

Frodo also expressed difficulty understanding directions or questions. She used tests as an example. She indicated that she read an exam's questions but did not understand what was expected of her. Frodo also described her thought process as contributing to communication difficulties. "Uh, and then there's the thing where my brain, I think in pictures and not . . . It's not verbal. It's hard to describe. It was more like a movie." She described herself as a visual learner and stated, "And so it's really hard for me with instructors who don't do the visual and . . . [Name of University] doesn't do a lot of visual stuff. And so that's hard."

In summary, communication challenges arose as a common theme among study participants. Difficulty communicating was mentioned in several interviews and caused significant anxiety for some participants (for example, Frodo cried as she relayed this information). Several other participants also expressed communication challenges, which are described in other sections of this paper.

**Relatedness.** According to the Theory of Self Determination, relatedness is the second area that influences human motivation. In this study, how participants interacted with others and established relationships in college was explored. The questions asked pertaining to relatedness are in Table 6.

Table 6

*Interview Questions Pertaining to Relatedness.*

Primary Question	Sub-questions
Tell me about the people you have met in school?	What has been your experience in talking to faculty or instructors?
	What has been your experience in talking to support staff (these could be people that work for the university, other than instructors)?
	What has been your experience with meeting other students in your classes?
	What has been your experience with making new friends in school?

**Talking to faculty.** When asked about their experience speaking with faculty or instructors, the responses were varied; however, the salient theme was reluctance to verbally speak with faculty when having difficulty in a course. Some participants reported preferring to contact professors via email instead of speaking with them in person. For example, Megan (a junior) had been having difficulty with classes, yet she was reluctant to speak with professors in person. She explained:

Well, I would get nervous, but that comes with like anxiety and stuff like that, but like I don't know. I usually preferred to email them, so I didn't have to talk to them . . . and

either they were like busy or if I was, I don't know what to say yet, like I hadn't like thought through my questions, and I would just leave and email them later.

When asked if she meant that she found it hard to put into words the difficulties she was having, Megan stated, "Yeah, that's accurate." Megan's difficulty with communication (a challenge common to many participants, as explained earlier) was interfering with her ability to approach a professor to ask questions in person. Megan's demeanor during the interview reflected nervousness. At the end of the interview she expressed that she had been worried about answering questions continuously since she had made an appointment. The interviewer could easily imagine that Megan felt anxious approaching her professors, since communication was a clear challenge.

Other students also expressed difficulty putting their questions or concerns into words. Mike (a senior) also mentioned reluctance to speak with a professor, and his concern also stemmed from communication challenges. He stated:

Or then I just get nervous, which can make me forget why I was there in the first place. So, it is sort of in that aspect, but for some reason I am just reluctant to go to the professor right away.

Mike also stated that he would more easily speak with a tutor if he had questions, however, speaking with a tutor was challenging as well:

I would say it's easier, but it is still something that I have to push myself to because it's—I mean, there's different challenges. It is a person that I may have never met before, so don't really know the person, so it makes it difficult to read them or know how to act in front of them, or you know.

Mike's communication challenge was highlighted by the above statement; he was concerned about his difficulty reading nonverbal communication and was troubled by how he might be perceived. His statement also exemplified a common finding that many participants felt uncomfortable approaching a person they did not personally know.

Marcus (a junior) also stated his reluctance to speak with professors stemmed from his difficulty communicating clearly. He described his experience going to office hours:

Well, I always worry. If I ask this, if it's going to make sense or not, because I have trouble explaining things. So, to me, it's like sometimes I'll just sit there and wait for—like, he might speak up before me. Because I just-- it is hard to just ask smaller questions because I might look like an idiot or something.

Marcus had also expressed that going to office hours had been challenging because, at times, other students were with the instructor asking questions. He did not know if he could walk in and join them, or if he should wait. He admitted to standing outside the office (out of view) and listening to the interactions between the instructor and other students for periods of time, and then walking away feeling too nervous to wait or go inside. Marcus' concerns also exemplified a level of social discomfort, not knowing what was socially appropriate, and feeling worried about how he might be perceived by others.

Allyn (a junior) also described difficulty expressing herself and speaking with professors. When she had difficulty with a class she explained, "It is kind of hard. Again, it is like, like—again, I just don't—I just can't really talk to people, sometimes, and like that kind of interaction always just makes me a little bit nervous." The interviewer witnessed that Allyn had difficulty communicating. Allyn seldom made eye contact during the interview and fidgeted with her

hands and clothes when speaking. Allyn explained that she was only comfortable interacting with people she knew well, or with people she perceived shared her same interests.

Mike (a senior) also expressed difficulty in approaching professors for help when he did not understand concepts or assignments in a class. He expressed:

I really don't like doing that. In fact, I think that was one of my IEP goals since middle school, to be more-- to advocate that more and open the conversations. And I really kind of refused to do that during the second semester, and it was just uncomfortable for me to do that.

Mike was referring to his individual education plan (IEP) during his pre-college school years, explaining how he had not met the goal of advocating more for himself then, and he continued to have difficulty with this skill in college.

Some participants expressed that they did verbally communicate with professors. These participants related that speaking with professors was an important aspect of advocating for their needs. For example, Jackie (a sophomore) stated that she learned to advocate for herself through therapy and counseling. In the past, she felt that disclosing her disability would hurt her academically or professionally, but her opinion on disclosing had changed. She stated:

I'm more comfortable now. Part of going through therapy, counseling as well, frankly, has been that I'm more comfortable initiating a discussion and saying I have this problem and feeling like I'm not going to be judged or that, if I am judged, that there are people—like DOSS [Disabilities Office for Support Services], like my counselor, like my parents, like my doctors – who can come in and advocate for me.



Unlike Mike, who had difficulty with self-advocacy, Jackie had learned the value of doing so. Jordan (a junior) also expressed that he had learned to advocate for his needs, which facilitated his comfort in approaching professors. He stated:

All through high school, my mom taught me to be and really advocate for myself. I learned that you get things is by, you know, going and talking to people. . . . I let my teachers know in advance, asked them for accommodations for that, was in very strong communication with them. Whenever I have a class that drops below like 85%, I immediately go to my professor and say, “Hey, is there something that I’m not understanding? Is there a way that you can help me understand this better so I can do better in your class, ‘cause I’d like to do as well as I can.”

Jordan had developed a comfort level with self-advocacy. Jordan had also made concerted efforts to overcome social-communication challenges common in autism, thus the interviewer could envision Jordan approaching professors for assistance.

Some participants stated they felt comfortable meeting with faculty during office hours. For example, Carl (a freshman) expressed that he learned when each professor’s office hours were and would meet with them during those times whenever he had questions about assignments. He stated:

There have been certain parts of assignments that I needed clarification on, because I didn’t fully-- really understand what was going on. They have no problem sitting down with me, whenever they have free time, to try explaining it differently, or just going over it to make sure I understand it. So, the professors were really accommodating, if I had any issues.

Carl, unlike some students who were reluctant to speak with professors, felt comfortable approaching professors during office hours. Carl appeared comfortable during the interview, although the investigator perceived that he was attempting to sound confident. However, observation was subjective and cannot be validated.

In summary, communicating with professors was difficult for some participants, but not for all. The participants who found it challenging had concerns about their communication skills and their ability to make themselves understood. These challenges precluded them from speaking with professors, and thus impeded their ability to form relationships with them. Some participants expressed more comfort communicating with professors, taking advantage of office hours, and being proactive in advocating for themselves.

***Talking to support staff.*** When asked about their experience speaking with college staff (college employees other than professors or instructors), most participants had a positive experience, stating that their academic advisors were helpful. A few participants expressed a negative or mixed experience with their advisors. Several advisors were also a professor or instructor, thus the researcher asked participants to talk about their comfort level interacting with them as an advisor. Frodo (a senior) was having a negative experience with her advisor. She stated, “And I don’t really care for my advisor, so . . . she’s a math department advisor and I, frankly, I have the same personality conflict with her as I did the pre-calculus [professor].” Frodo explained that her prior academic advisor, with whom she had developed a positive relationship, had left the school.

Jordan (a junior) expressed mixed feelings about his advisor:

My academic advisor is actually one of my professors, so we interacted quite frequently. . . . He was definitely my hardest teacher amongst all of them. He was—definitely pushed

me to go further. Sometimes that was awesome, 'cause I wanted to be pushed, but at other times, not so much.

Whereas Jordan had more interaction with his academic advisor, William and Jackie (both sophomores) indicated that academic advising was available, although they felt they did not need it as much, yet they attended meetings because they were required. They did not appear to see it as positive or negative and did not appear to have a relationship with their academic advisors.

Some participants spoke specifically about their comfort level speaking with staff at the disability services office. Frodo indicated that interacting with disability services staff was hard due to her communication challenges (as described earlier). She expressed:

But I don't, um, I don't know how to express what I need. . . . It's really hard. Um, to put in words what I need, is very difficult. . . . And even when I can put it in words, sometimes they don't understand. . . . And so there's a communication barrier. . . . And it's huge.

Frodo appeared distressed every time she spoke about her communication challenges; these difficulties with communication were present even when she was speaking with the disabilities office staff. Frodo was the only participant who indicated perceiving a significant communication barrier with staff from disability services.

William (a sophomore) also described his experience with the disabilities services office at his school: "Their support system's a little different than . . . They haven't been able to help me as much with depression as they have with my, um, with basic anxiety and my Asperger's and ADHD." William did not elaborate on how disability services had assisted more with some challenges and less with depression. William did indicate to the interviewer that depression was a problem that was unresolved; his medication was being adjusted and he felt frustrated that an

adequate dosage had not been determined. The investigator could not ascertain if William's challenges with depression and medication adjustments was the aspect he felt disability services had not been able to assist with, although the interviewer assumed that his medications were being managed by a medical team.

When speaking about disability services, Allyn (a junior) stated, "Recently, I have not used it as much. But it has been really helpful when it comes towards like—more towards like the . . . housing accommodations, I should say." Allyn had been able to move to a lower level in the dorm, as well as having a single room, as an accommodation for her disability.

Mike (a senior) expressed his reluctance to speak with staff at the disabilities services office. He stated:

That was another thing that I was kind of stubborn not to do. And the reason I think came from possibly when I was growing up, being viewed as being different from all of the other kids. And that stuck with me still to a lesser extent today, but definitely was noticeable during my first year of college.

Mike had registered with the disabilities office when he realized he needed some accommodations for courses; however, this had been out of necessity since he was originally reluctant to do so when he started college.

In summary, most participants expressed a positive experience with academic advisors. The experience of the interviewees who spoke about their interactions with staff from the disability services office was mixed. Some participants found it helpful, while other participants felt that their needs were not fully met or understood.

*Talking to classmates.* When asked about their experience speaking with classmates, most participants expressed that they would not speak with classmates that they did not

personally know. However, if they already knew a classmate, they would have less difficulty speaking with them. For example, when asked if she would approach a classmate to clarify an issue covered in class, Megan (a junior), stated:

Well like, what I try to do, in most my classes I like to find someone that I sit by that I talk to, so I usually just talk to that person and if we disagree, we can ask the professor.

Several participants also stated that they were not naturally social individuals. For instance, Frodo (a senior) stated, “I’m not really social.” Carl (a freshman) stated, “I kind of seclude myself.” William (a sophomore) said, “Generally I’m kind of a reserved person.” Marcus (a junior) said, “I never really ever talk to many people. I’m not much of a social person.”

Reluctance and difficulty in approaching a classmate to ask questions or engage in conversation was therefore a common theme.

Marcus expressed a great deal of anxiety about talking to classmates and interacting with fellow students. He stated:

If we ever have to do like group work or something, it’s always like them talking to me. I just can’t bring myself to go and ask someone else because I can’t do it. . . . I always work with the people next to me, that sit next to me. So, I usually just hope some other people help get me into their group instead. Because I just can’t. To me it’s just too hard for me to do that.

Marcus’ anxiety with interacting with classmates was also evident in his fear of sitting in a seat that someone else might have wanted to sit in. He expressed:

The first day is always the most stressful day for me. Because I make sure I get there early just to find a seat. Because to me it’s hard to like—if I get there late, all of the seats are taken. I find it hard to pick a random seat that has a whole bunch of people next to it.

It's like what if they want someone else to sit here, or if somebody else is already sitting there? I just don't know.

Marcus showed anxiety during the interview (sweating, moving constantly on his seat, appearing uncomfortable) when relaying his feelings about working with fellow classmates.

Marcus' challenge with speaking with classmates was also evident during the time he spent at a large university. The expectations from the disabilities service office was that he would facilitate his accommodations, which he felt unable to do. He stated:

They also offered notes. But like the way they did it was so complicated and at the end it just made me uncomfortable to do it because it's not like just emailing someone and then they can like email you notes. What they have you do, is like they say you have to find someone else in the class who is willing to take notes. You have to approach them and basically ask them for their notebook or whatever. You have to get it printed. You have to make sure you get it back to them. I was like, it's just like me trying to find someone in the class to take notes. It's like I just couldn't do it. It was like I already struggle enough, like finding--. It's like I couldn't like try to find someone to take notes. It's uncomfortable for me to—it's not like oh, like you don't know—notes. It's like you know who in your class has autism. Like you're not comfortable about that.

Not only was it difficult for Marcus to communicate with classmates, establish relationships, and work in groups, he also appeared overwhelmed with the challenge of asking a fellow student to assist him by sharing notes. The added challenge of needing to disclose his disability by asking for help from a classmate was distressing to him. He indicated to the interviewer that, at his new university, he did not need to find someone to take notes for him. The disability services office

found fellow students to take notes, without revealing his identity, and all the communication happened confidentially via their office.

Frodo's experience with classmates was mixed. Frodo had a double major, with classes for her computer science major being offered at her college, and classes for her geology major being offered at a neighboring college. At her home college Frodo did not feel connected to fellow students, thinking that her age (42 years) might be a factor. She stated:

And I think because of the age difference and all their standoffish . . . I mean, they're pretty, there's a few that are friendly but for the most part it's kind of, you know, standoffish and not really, you know, I'm not their peer really.

Thus, at her home college, Frodo did not feel comfortable around most fellow students. At the neighboring college, however, she felt more connected with fellow students. She indicated that she might have more similarities with students at the neighboring college. Frodo stated:

They're more friendly and more open. And I'm not sure why. It's really odd. Maybe it's just the department and because we're all like, really into the . . . what we're into. And so I think actually . . . I think there's a lot of people with Asperger's in the class. So, it's a little more comfortable. Because I think a lot of us do have. And plus, we went on a field trip together and you bond, you know.

Therefore, Frodo perceived differences in behaviors among the students in both colleges and her comfort level differed in both environments.

In summary, challenges interacting with classmates was a common theme among many participants. Many interviewees voiced that they were not social or that they were typically quiet in class. Some participants, like Marcus, expressed anxiety about interacting with classmates, worried about finding a seat on the first day of class, and found it stressful when group work was

required. Frodo's experience in two different colleges was salient in that she had a better relationship with classmates at the neighboring college than in her home college. Overall, social interactions with classmates were challenging for the students interviewed.

***Making friends.*** When asked about their experience making friends in college, most participants expressed some difficulty, particularly in their freshman year. Establishing friendships in college was, therefore, a common theme. Most participants, however, had been successful at establishing some relationships over time. Two students, Elizabeth (a senior) and Carl (a freshman), who attended a Catholic college, stated that having Catholicism in common with fellow students facilitated their ability to make friends. Elizabeth stated:

I have liked it that there are so many—well, there are so many good people on campus, and I like it that it is a Catholic campus, since I – I grew up in the Catholic church, and there are so many Catholic groups. It's made it easy to make—just to make friends.

Even though Elizabeth found the common bond of Catholicism to facilitate making friends, she also stated that approaching people was difficult for her:

It was—it was very difficult to just go up to someone and just say hi, my name is—my name is so and so. And it was –yeah, mostly I—I kind of just mostly waited for someone to kind of come up to me, or just randomly start a conversation.

Elizabeth valued having friends in college, yet she still did not feel comfortable initiating activities, but waited for others to do so:

Well, having friends is awesome. . . . And but it is still a little difficult to communicate with them—as far as like asking, “Hey, do you want to go do this?” Or “Do you want to meet up for—for dinner?” I always, again, I always wait to hear like what they are doing.



It's like, "Oh, hey, can—can I join you?" . . . and making new friends is still really difficult.

Therefore, even though Elizabeth had made friends in college and these relationships brought her satisfaction, she was not comfortable initiating activities. Elizabeth indicated to the interviewer that group text messages that the resident assistant had initiated had been of great assistance to her, as she could often join activities with residents from her floor.

Carl also mentioned the commonality of Catholicism as instrumental in meeting a core group of students he regarded as friends. When asked how this had happened, he stated:

Well, it had to do, like my brother recommended, just because of he knew – he knows about the state and like what I suffer from, he recommended the Catholic men's floor, which is a group of guys that are – well, really are – are supposed to be really kind, but also be willing to open or help new people. But also, they are – it is just supposed to be like a really good group of guys. And my brother's friend had done this, two years ago. And he also recommended it to me. So, it was more so I was given the option to try going in a place that I – my family thought would be easier for me to adjust to, and that is how I met a lot of my friends.

Carl's family had therefore been instrumental in encouraging him to reside on the Catholic men's floor in the dorm and to be surrounded by students who would be kind to him, which gave him an opportunity to develop friendships. Despite this, Carl did experience initial difficulty interacting with students at the dorm, he stated:

So, it took quite a bit of effort to work up the courage to go outside and meet people. Just introduce myself and maybe start getting to know some people on my floor, as – which

was basically starting high school all over again, like not knowing anyone, and trying to make new friends.

Despite the challenge, Carl admitted to having a core group of friends, he stated: “Oh, most definitely. I feel like if there is a group of friends that are good to me, that I hang out with, and we just get along together fine.” Therefore, Carl appeared content with having established friendships in college.

Megan (a junior) stated that her family had suggested she join the marching band in college, as a way of making friends. She did this in her first semester and found that being a part of the marching band was instrumental in meeting other students and making friends. She stated that all her friends in college were from band. She was having difficulty, however, making friends in classes. Because she changed majors at the start of her junior year, she found that other students in her current classes already knew each other. Being new in her major was creating difficulty for her in meeting classmates and feeling like she was a part of the group.

Jackie (a sophomore) stated she had a lot of acquaintances but was not sure at what point she would know which of them were friends. Jackie faced two challenges that interfered with her ability to interact socially: auditory processing difficulties and face blindness. Jackie expressed these difficulties as:

I mentioned before that I have issues with auditory processing which limits my ability to socialize or really understand people in certain settings. The other autism problem that I have in regards to relationships is face blindness. I have a really hard time distinguishing between people’s faces. Among, I’ll say good friends that I made in my first year, one of them had dyed her hair purple and the other was morbidly obese, so I could recognize them at a distance without having to know their facial features, but I still literally will

gaze at anyone that I meet for a while in case it's my roommate and I have to say hi to her.

Jackie was the only participant who indicated the challenges of face-blindness and auditory processing difficulty. This question was not asked; thus the researcher does not know if any other participants had the same or similar challenges.

In summary, difficulty making friends in college was a common theme expressed by many participants. Some students made concerted efforts to make friends by selecting a specific dorm floor or being a part of extra-curricular activities. Establishing friendship relationships seemed to take effort on the part of these participants.

***Romantic Relationships.*** Another theme that arose under the area of relatedness was that of romantic relationships. Four students mentioned being in a romantic relationship at the time of the interview. Frodo (a senior) had three children ages 21, 19, and 13. She was also a grandmother since the 19-year-old had an infant. Frodo did not mention the father of her children but stated that she was currently in a relationship and that her boyfriend lived with her and her two children that were still at home. Although the investigator did not ask questions related to her relationship with her boyfriend, in terms of her disability, Frodo alluded to her boyfriend saying, "He just doesn't get it."

Megan (a junior) mentioned having a boyfriend who was the person who listened to her concerns when she was feeling anxious. She stated:

Well if I start like stressing out over it just a little bit, I usually—I almost always talk to my boyfriend first. Like he's just my go-to person. Well with like everything. Well and when he'll just say, "You need to calm down about it and then you'll be fine." Okay, like there's that part and then he's like, "Maybe you should try something," and then that's

when I usually talk to my mom to see like who can . . . like ask her, like do you know who would be able to help me with this kind of thing?

Megan appeared to have a strong support system that included her boyfriend. Megan had also moved home for her junior academic year, which gave her more opportunities to speak with her family about any challenges.

Jordan (a junior) stated that he had been dating for about a year, and that he had not told his girlfriend about his diagnosis of autism. He stated:

One of the biggest things is I don't tend to tell people about it. I told my best friend, and the, obviously the person that I had to talk to about the accommodations. Other than that, I didn't tell anyone, not even my girlfriend knows about it as of yet. One of the biggest reasons is usually there is one of two reactions that people have to it, either they think you're weird or they pity you, and I don't like feeling either of those things. I like to be treated as normal as possible. And usually it's not worth telling people, because that's usually one of the resulting things that happens. Also, when people pity me, I tend to pity myself.

Jordan had disclosed his disability to his best friend; however, he had not shared it with his girlfriend or with any other friends in college. Later in the interview he revealed that his best friend had asked Jordan if he had Asperger's, and he disclosed his diagnosis because of being directly asked about it.

James (a senior) had been in a romantic relationship for about a year as well. James had not told his girlfriend that he had autism. He stated, "I've had a girlfriend for just over a year now, and she and I are both very social, and she's very normal, you know." Like Jordan, James

felt that disclosing his autism was not necessary, and he felt that people would treat him differently if they knew.

In summary, being engaged in a romantic relationship was not uncommon, with four out of the 17 students interviewed in a current relationship. Two of these students (both female) had disclosed their diagnosis to their boyfriends. The two male students had not disclosed their diagnosis to their girlfriends. Both male students had made concerted efforts to improve their communication and social skills, which likely facilitated their ability to keep their diagnosis a secret. Their experiences are described in the next section.

***Conquering social challenges.*** Although most participants had challenges making friends and establishing relationships, two male participants were the exception. James (a senior) and Jordan (a junior) appeared to be very social individuals, not portraying the typical communication challenges of people with autism. During their interviews, both of these participants narrated the efforts they had made, before college, to ameliorate many characteristics of autism. Both participants had achieved a level of social comfort. Neither of them felt that they exhibited autistic characteristics any more.

Jordan stated that he could successfully hide his autism. When asked to elaborate on what he was hiding, he explained:

There are certain like ticks that come with Asperger's, usually lack of facial expression, lack of voice emotion, and I definitely have those emotions. I think there's a disconnect between what my face is saying and what I actually want to be saying. Since I can't see the way that I look when I'm saying something. I can look really angry when I'm actually just sad, or I can be really happy about something, but my face doesn't show it. And so it's just been practicing. Sometimes as simple as just looking at a mirror and

doing stuff like that. I did voice acting for about five or six years, semi-professionally. I read books, and I'd narrate them, and it actually helped me, especially with my tone, how to sound happy or angry or sad ... I made money off of it by posting on YouTube. But it was mostly for fun and then I learned that it helped me learn how to present myself better.

The interviewer perceived that Jordan was proud of his efforts in learning neurotypical communication strategies. Jordan indicated to the interviewer that one reason he had agreed to participate in this study was to share his experience with other students with HFA. He felt that individuals with HFA could make strides to conquer social communication challenges, if they wished to do so.

Jordan stated that he had made a conscious effort to learn how to overcome communication challenges. He stated:

One thing that I have found that works well for me is learning how to become more normal. . . . A lot of people don't want to do that. I've seen people with Asperger's say that they are totally comfortable being the person they are. They're like, "Look at me, I'm awesome. I don't care what you think." I tend to be more of a people pleaser. I like to be accepted. And so, as a result, I do change aspects of myself. There are certain things that I will never change about myself, but learning how to differentiate your tone and facial expressions especially, and just the way that you act, is something that I personally [think] is best.

Therefore, Jordan had made efforts to conquer communication challenges common to autism and preferred to not disclose his diagnosis to others. As stated earlier, Jordan's girlfriend did not know he had autism and they had been dating for over a year.

James (a senior) had also made a concerted effort to overcome many autism challenges, particularly social ones. James stated he started working on social skills in middle-school, and he described the process as follows:

I kind of started to study people a lot more, and kind of, you know-- I feel like Asperger's people are, they're really good with sciences and figuring out the intricacies of how something works, and I kind of became obsessed with . . . in the intricacies of how social life worked. And life became this whole trial and error thing where I was trying to figure out how people reacted to different things, how humor worked, and it was obsession to a point where I focused on that more than school. So, I've never been great at school, but I became really socially good. I was able to, by the time I was in high school, I had girlfriends. I had a good friend group. There was still like a large chunk of people from middle school and elementary school who remembered when I was a weird kid and considering that everybody's kind of weird when they're younger, that kind of wore off, but still affected my social life up through high school and then college came, and people wouldn't guess that I have it.

When James was asked to elaborate more on how he had focused on learning social behaviors in his youth, he explained:

Yeah, because autistic people have very different senses of humor and I think you— humor kind of comes naturally to most people. At least that's my perception, and I think autistic people, it's just not there, that connection. It's, you think of everything too literally and it's like, what? [Laughter] And when I was younger, I'd kind of figure out like okay, what makes this humorous? There's . . . I'd actually kind of break down exactly what made it comedic and then I'd figure out, okay, so this has this baseline joke

to it and that's what's funny. That's the . . . for example, you figure out, oh the baseline humor of this is, oh it's a big jock guy whatever holding a cat, a kitten or something and thinking it's cute or something. And like that same joke has so many different forms and people will laugh at it. Nobody has to explain it. It's just that kind of vibe in any form, people will laugh at it. And so I figured out, like all these individual things that are funny and figured out a couple on my own, and then I'd just figure out how to replicate them or at least understand them. And that just kind of evolves over time. And maybe that's just a natural process for all people. Maybe it happens at an earlier age. I don't know, but it felt much more like something I had to learn and discover than it seems to other people.

When asked if changing his communication style was a conscious effort for him now, James explained:

Through high school, it was definitely a conscious thing. In college it has become second nature to me. It's still not completely covered up. I still will get people who think I'm a little bit weird, but for the most part, people who are willing to be my friend, don't usually notice it all that much. The only person who knew was my best friend, and the reason why is because she has a younger brother who also has it and a father who has it, and she kind of noticed some of the more muted tendencies and habits that people with autism have, and she said, "Hey do you have this? If you do, I'm not going to blame you for it." One of the reasons why I was comfortable telling her was because she's lived in an environment with it and recognized that people like this are people; they're not just weird.



When asked what this friend had noticed about him that prompted her to suspect autism, Jordan stated: “She said that my tone and my facial expressions weren’t quite as natural as most people’s were.”

James also talked about his current ability to make people laugh with his humor, as well as his ability to understand relationships, both due to his intense study of social situations to conquer autism challenges. He stated:

I’m funny, like I have conversations, and I can usually be funnier than a lot of the people in the room just because I became obsessed with it, I feel like there are certain elements of my social life that I’ve excelled above people that, some people that, you know, didn’t have Asperger’s, just because I made it a personal goal to be good at. So, I mean, like I have friends coming to me for relationship advice and I think I understand like people’s interactions really, really well. In fact, I’ve considered being like a psychologist or relationships counselor something, simply because I’ve become good at that. Which I think is unique. I’m very proud of that. It’s . . . there are areas in life where I feel like some people with Asperger’s that they’re lacking in those areas, and that’s what makes them hard to be around for some people. And I’m glad that those have—I’ve actually flipped those around and turned them into strengths.

James’ sense of humor and social skills were evident through the interview; he appeared comfortable answering questions and seemed to enjoy talking to the interviewer.

James was proud of having conquered a lot of his social challenges. He explained that some autism characteristics did become evident in certain situations. He stated:

Awkwardness comes out at certain points, maybe when I’m stressed or when

there's a social situation that I'm just not familiar with. And it's fun to kind of explore myself and see what times the Asperger's comes out of me, because it doesn't quite feel like suppression. It feels more like evolution, but sometimes there are little bits that come out. I do have hyper interest on, interest on—that's a terrible way to phrase that—when I'm interested in something, let's say I'm . . . I love music. I'm obsessed with music . . . and if I'm in a group setting and a subject I'm interested in comes up like music, I become very focused and very . . . I kind of forget all of the things that I've learned about social life and I just analyze. And so, I guess when things I'm really interested in or things I'm really unfamiliar with are around me, that's when my more streamline—which is kind of the way I would explain Asperger's. It's kind of a streamlined way of thinking, and which causes certain functions to work a lot better and certain functions to work a lot worse.

James, therefore, still experienced many of the characteristics of HFA that affect communication and social interactions, which became more salient in times of stress. This question was not asked of Jordan, thus the researcher does not know if his social-communication skills were now part of his typical demeanor.

In summary, the two participants who had conquered many communication and social challenges common to HFA had spent many years working on these skills. Both Jordan and James had studied and practiced how people without autism communicated, how their facial expressions reflected their feelings, how their voice intonations changed according to the emotion, and in James's case, he also studied what people found humorous. Both appeared satisfied with the results of their efforts and felt that they did not outwardly appear to have autism anymore. Jordan had undergone re-testing for autism since he thought that he no longer

had the diagnosis. The re-testing did confirm that he maintained a diagnosis of HFA; Jordan felt that he was still classified as having HFA because the people interpreting the test knew he had this diagnosis.

**Autonomy.** According to the Theory of Self Determination, autonomy is the third area that influences human motivation. The following are the themes related to autonomy that were investigated. Questions aimed at ascertaining how much independence students had in college, as well as how independent they saw themselves in the future, after college completion. The questions asked pertaining to autonomy are in Table 7.

Table 7

*Interview Questions Pertaining Autonomy*

Primary Question	Sub-Questions
Tell me about some of the differences you have felt between being in high school and being in college.	If you are living in the dorm, tell me how easy or difficult that experience has been.
	What new responsibilities do you now have?
	Are there tasks or responsibilities that others help with; for example instructors, support staff, friends, roommates, family? <ul style="list-style-type: none"> <li>• Who are they and what do they help you with?</li> </ul>
Tell me about the future; what do you envision doing after you finish college?	Do you envision living alone or with others?

**Living arrangement.** Questions related to autonomy aimed at inquiring about the level of independence that participants with autism experienced, as well as establishing areas in which they needed assistance from others. Asking about living arrangement, whether the student lived in the dormitory or off campus, led to responses that gave insights into relatedness as well as

autonomy. Of the 17 participants, nine lived in the dormitory at the time of the interview. Two students lived in an apartment, one with relatives and one by himself. Five students lived at home with their family, and one lived in her home with her children and boyfriend. Four of the students who were living at home or in an apartment at the time of the interview had previously lived in the dormitory. Thus, 13 out of the 17 participants lived in the dorm at the time of the interview or had previously lived in the dorm. Out of the 17 participants, 12 had family in the Twin Cities or surrounding areas, and five had family outside of the Twin Cities area or out of state. Table 8 depicts participants' living arrangements and whether or not their families were local (in the Twin Cities).

Table 8

*Students' Living Arrangements*

Pseudonym	Gender	Age	School Year	Living arrangement at time of interview	Local Family
Isaac	M	18	Freshman	Dormitory	No
Susan	F	18	Freshman	Home	Yes
Carl	M	18	Freshman	Dormitory	Yes
William	M	20	Sophomore	Dormitory (apartment first two years)	No
Kirk	M	20	Junior	Dormitory	Yes
Megan	F	20	Junior	Home (dormitory first two years)	Yes
Riley	F	20	Junior	Dormitory	No
Jordan	M	20	Junior	Home (dormitory first two years)	Yes
Allyn	F	21	Junior	Dormitory	Yes
Marcus	M	21	Junior	Home	Yes
Jackie	F	22	Sophomore	Dormitory	Yes
Elizabeth	F	22	Senior	Dormitory	Yes
James	M	22	Senior	Dormitory	No
Mike	M	22	Senior	Apartment (dormitory freshman year)	Yes
Chase	M	23	Senior	Apartment (dormitory first two years)	No
Speed Runner	F	27	Sophomore	Home	Yes
Frodo	F	42	Senior	Home	Yes

Three participants had requested accommodations for their living arrangements in the dormitory. Kirk (a junior) stated, "I had an accommodation for a single room . . . because having a roommate would have been pretty tough for me." Allyn (a junior) did not initially seek accommodations for her living arrangements, however, difficulties arose early in her freshman year. Allyn requested accommodations, and she transferred from a traditional dormitory room with a roommate, to a four-bedroom apartment-style room. Riley (a junior) also had an initial accommodation to have her own room. She stated, "I had a room to myself the first year for accommodation, and so I just really struggled because I was by myself. I didn't have like someone to like be my friend, in a way." Thus, even though Riley had desired her own room as a freshman, she found that being alone was challenging because she had difficulty meeting other students. In subsequent years Riley had roomed with fellow students.

Eight students reported initial difficulty with having a roommate. Jordan (a junior) requested a roommate change during the two semesters he lived on campus. He explained:

I actually switched roommates almost every semester. It was difficult getting along with them for a while. My first one was from another country. He didn't actually speak English all that well, and we didn't really interact all that much, and I wanted to be able to interact with someone. My next roommate, I had my second semester actually had drinking and drug problems, and it made living with him quite difficult. And so, again, I switched. Third semester, I lived with some friends of mine that I had met in previous classes. That was actually, I had three roommates that semester. The other two semesters I just had one roommate, and that semester seemed to work out really well.

Jordan was the only participant who indicated roommate difficulties related to roommates' characteristics that precluded him from befriending them, and not from challenges related to participants' challenges with socialization and communication.

William (a sophomore) had recently moved into a dormitory after living in an apartment during his freshman year; however, his roommate had moved out. He stated: "Umm, I mean the worst part is the fact that I'm living alone right now. They've moved my first roommate out because he had a very, very, very slight allergy to cats." William had an emotional support cat, which prompted moving his roommate to another floor. William stated that he was responsible for finding another roommate, however he was having difficulty with this task because he did not have any friends on campus.

When asked about the people he had met in the dorm, Isaac (a freshman) stated, "Most of them are great, except for my roommate. . . . They're just really passive aggressive." Elizabeth (a senior) expressed somewhat different challenges when describing her experience with her first roommate:

And one thing that—one thing that made it a little difficult, at first, is that my—my first roommate was a junior, and she—she was in the Air Force ROTC. And so, she was—she was gone a lot. And she was living in the dorms because she was going to study abroad, in Spain, in the spring. And yeah, she—she would—she would sometimes be in the room, but other times she would actually mostly—mostly live at home and—and work at a restaurant that is closer to her house. And yeah, so sometimes it would be a little lonely. Elizabeth's account exemplified how she had anticipated that her roommate might be a person to befriend; instead she felt lonely from the lack of being in a more typical roommate situation with a fellow freshman during her first semester in college.

Megan (a junior) had lived on campus during her first two years in college. She described the experience as follows:

Living on campus was interesting. I don't know if I necessarily liked it, but it was a new experience, and I'm glad that I did that. . . . It was kind of stressful. Like it was a new experience, and I was living with people I didn't know, and it was like, "I don't know what to do, but hello". . . I had two other roommates, but like one of them switched out with like someone else. So technically three total my first year, but it was always just three in the room. So, like one person was there for one semester, then she switched out, and we got someone new. . . . It was hard to figure out what like what they were okay with or like how to voice something I wasn't okay with. Like I don't think I actually did that. But like one of my roommates had really smelly feet, and I just never said anything, 'cause I didn't know how to, but my other roommate then said something. So, I was like, 'Yeah, I agree with you,' kind of thing. So, I had tried, kind of, to keep to myself, but like—I don't know, they were really nice, which helped a lot. I didn't have too much in common with them, but we watched movies every once in a while together, so.

Megan did not appear to have problems with her roommates, however she felt uncomfortable living with them. Megan had moved off-campus to save money and lived at home at the time of the interview.

Carl (a freshman) described his experience having a roommate in college as follows:

But it was definitely different becoming—spending—well, staying in a room with another individual. At first, we didn't talk much, but then we started talking quite a bit. We have learned a little bit about each other. But it was definitely a kind of silent start, I would put it, since there wasn't much interaction right away. But as, say, maybe a week or two

progressed, both of us started talking to each other more and more, just getting to know each other little by little.

Carl and his roommate, therefore, progressed in their ability to communicate and interact with each other.

Students who lived on campus and who were living in an apartment-like suite (each person having his or her own room with a common shared area) reported more positive experiences than those who shared a single room with a roommate. One exception was Mike (a senior) who lived in a suite his freshman year. Mike described his experience living in the dorm as follows:

I had a roommate. However, I lived in the dorm that kind of had two rooms, so we were able to separate. . . . It was okay because of the size of the room and that there was a—we were able to separate. I don't think it would have went as well if it was just one room, one small room with two people.

When asked about his overall experience living in a dorm he stated:

Well, it wasn't the best. I ended up kind of not really gaining any friends from the dorms and ended up in some, like I guess, hazing or—in the end. That's one reason why I now live in an apartment is because of that interaction. . . . I vowed never to live in a dorm again. . . . And so, I moved into an apartment, with my older sister and my cousin. . . . It has been less stressful. And it is a lot easier to calm down in an environment where you feel safer, and especially when it's family that you're close with.

When asked to elaborate on the hazing incidents, Mike stated:



Both of the semesters. There wasn't really much that the student life administration did to prevent it. They sent out an email that was very ambiguous, but the RA wasn't really—kind of just brushed it off as college students being college students.

Mike stated that his roommate had friends in other dorms and thus was typically not at the dorm and had not been involved in the hazing. The hazing was done by six or seven men from his floor, who made malicious remarks when Mike walked by, or pasted products on his door, like chewing tobacco. On one occasion Mike told the students who were harassing him about his diagnosis of autism, hopeful they would be more understanding. However, Mike stated that the hazing had not abated and continued through his two semesters in the dorm.

In summary, even though living away from parents can relate to having a greater sense of autonomy for college students, the participants' experiences in the dormitory varied, with some having negative experiences. Establishing a relationship with roommates was difficult for many participants. Some interviewees voiced a desire to interact with roommates; however, communication was sometimes difficult due to language barriers or the roommates being away from the room a significant amount of time. One participant experienced hazing by fellow students in the dorm, which continued even after he reported the incidents to staff, and after disclosing his diagnosis to the individuals harassing him.

*New responsibilities.* Another area related to autonomy pertains to any new responsibilities participants had in college, as compared to the times when they were living at home and were in high school. When asked about new responsibilities they experienced in college, participants had difficulty thinking of many. Most reported that the ability to plan their own schedule and making decisions about their time was new. When the interviewer asked about self-care activities, such as doing their own laundry, most participants expressed that they

had been doing their own laundry since high school, thus washing clothes was not a new task. Marcus (a junior), who lived at home with his parents, reported that his parents continued to do his laundry.

When asked about responsibilities related to shopping and cooking (for those who lived off campus), William and Marcus reported some difficulty. William (a sophomore) indicated that cooking was not challenging, but he did not enjoy grocery shopping. Marcus (a junior) lived with his parents and reported needing to prepare his own meals since his parents dined away from home most of the time. Marcus was on a gluten-free diet, thus he admitted to having a very monotonous diet. Marcus did not know how to cook and therefore prepared the same type of frozen meal most days. Riley (a junior) reported being forgetful about some self-care activities now that she was in college. She stated that she often forgot to wash her sheets regularly and expressed that sometimes she would forget to eat.

In summary, most participants could not think of self-care activities that were new or challenging now that they were in college. Few students mentioned difficulties with self-care, including shopping for food, not knowing how to cook, doing laundry, or remembering to eat.

***Family support.*** The degree of autonomy or dependence on family was also investigated. Participants discussed the frequency of communicating with family and how much they relied on family members for guidance or emotional support. Most participants indicated being in close contact with family members. Most interviewees also reported family members providing advice, guidance, and emotional support. Five students indicated that their mother persuaded them to contact the disabilities office or career services when they were having significant challenges in school. Family members also provided some participants with insights about college life and assisted with academic support. Carl (a freshman) had received advice

from his brother, a former student at his college, about various areas of college life, including living on campus. Speed Runner (a sophomore) stated that her mother helped her with many duties and assisted academically by reading her papers before they were submitted.

Isaac (a freshman) was an exception in terms of relying on family for support. Isaac indicated he was used to taking care of himself, he stated: "I've actually, I kind of had a new experience that—'cause I had a family member who was, had an addiction issue. So, I was, was kind of used to taking care of my own stuff." He stated that he communicated with his family sporadically, "I only called when it's like I know that there's something wrong or like if I needed to." Having a family member with an addiction appeared to have forced him to be more independent when he still lived at home, and this continued through college.

Riley (a junior) stated that her parents accompanied her to register with disability services when she started college. She also stated her father helped her with selecting classes each semester, "My dad actually helps me decide . . . Well we . . . our home is in Iowa, so we normally have a phone conversation to decide." When asked about her mom, she stated, "She's the emotional support." Riley also stated that she did not need emotional support often; "I don't call too often. So, I'd say that I do fairly well managing on my own."

Marcus (a junior) stated that his parents had assisted him with many areas of navigating college life, including registering for classes when he started school at a large university. Marcus stated, "It was basically like the day after. Like I had to get my parents' help because I just didn't understand it at all." He also experienced trouble in some classes at the large university, and his parents assisted as well. "Especially we had to write like three papers for it, so I ended up having to get my parents' help. It was just like typing is just not something that I'm

very good at.” When speaking about changing his major, Marcus also indicated that his father had suggested the new major to him.

When asked about her support system, Allyn (a junior) stated that she relied on her parents for support. She explained:

We sometimes have done like a weekly update, or just talking sometime during the week, or on the weekend. And just talking and sometimes I would call, especially when, you know, something is wrong, and I just tell them, you know, I just had a horrible day. I just want to talk about it.

Allyn mentioned to the interviewer that she went home frequently and maintained employment close to her home, although she only worked on some weekends.

Kirk (a junior) also spoke about the role of his parents as a support system. He explained, “. . . a lot of times they've helped with advocacy type things. . . . If I'm really struggling, they might push me to get in contact with the professor or give suggestions that may help.” Kirk also stated that, every two or three weeks, he spent the weekend at home with his parents.

Elizabeth (a senior) spoke about her mom as a strong support system. When Elizabeth had significant difficulty during her first year in college, her mom encouraged her to get assistance through the disability office and scheduled their first appointment with the office. She stated, “My mom is the best ever. She helps—she helped me communicate with the disability resources and say okay, this is all the problems I am having, can—can you help.” When asked how often she communicated with her mom, Elizabeth said “Mostly almost every day. Either by email, or sometimes we have phone calls. And we usually try to meet up—we try to meet up once—once a week.” Elizabeth explained that her mom worked very close to the college, which

facilitated the frequency of their meetings. Elizabeth indicated that another role her mom served was related to organizing herself, “and she also kind of helps me plot out–plot out my week.”

Carl (a freshman) mentioned assistance from his brother as a support system. For instance, his brother helped him determine which classes to take as a freshman. Carl stated: “And since my brother has already gone here, he has given—he gave me recommendations, what he would think would—I would—would be the best for me to start out with.” Carl also mentioned getting together with his brother, a senior at the college, at least once a week. In terms of parental support, he stated, “But any big decisions, like maybe saying what classes—I talked to them about what classes I was signing up for next semester. And so, yes, I keep in touch with them, and they still help me make big decisions.”

William’s parents lived several states away; he explained how they supported him from a distance:

If something devastating happens in my life, like it did this last weekend, they'll, they'll actually sit on the phone with me, just helping me cope with things. If I have an emergency and I run out of money for any reason, regarding an emergency, my dad will generally just give me just a little bit of money to be able to tide me over till whatever ends up being my next paycheck. . . . So, I mean, they help me out with that, but, then, my mom, she’s an amazing lit teacher. So, whenever I've had a paper, I'd send it to her and she'd give me suggestions on it, and then I'd put in the edits, things like that.

Although William had disclosed suffering from significant depression, he appeared to feel comfortable living away from his parents. William had indicated an uncle lived in closer proximity, however he rarely contacted him, stating that his uncle had his own family to care for.

Speed Runner (a sophomore) also mentioned her mother's support with papers, "So I kind of have my mom read over the papers." On the other hand, Mike (a senior) described his parents as being less involved. Mike stated that his sister had helped him during a time when he was doing poorly in school and his mental health had been affected; his sister had encouraged him to see a psychologist. When asked if he would seek assistance from his parents if he were having difficulty in school, he said:

They usually would tell me to go make an appointment because they're like—they acknowledge that they don't have the skills to talk through that, and they think that it would be better for me to see a professional. So, I will talk to them, but they don't always give the most helpful advice.

Therefore, Mike's parents seemed less prone to giving advice and, instead, they redirected him to support personnel who were qualified to assist Mike.

In summary, many participants relied on parents for a variety of needs. They described parents, particularly mothers, as sources of emotional support. Communication with parents was frequent for some participants. Parents assisted participants with decisions about classes as well as through emotional support during times of high anxiety. Not every student, however, indicated this close contact with parents or family.

***Plans after college.*** Another area related to autonomy explored in this study was participants' plans after college. The intent was to ascertain if participants anticipated moving back home or living independently, and what type of employment they planned to pursue after college. When asked about plans after completing their college degree, three female participants indicated they would stay at home or move home with their parents after graduation. Megan (a junior) stated, "Well like right after college, I'll probably still live at home, because money. And

I don't want to move away from home, because like I'm used to being around family. I don't really want to take that away from myself." Speed Runner (a sophomore) stated, "Um, probably staying locally for right now, until I can get my seizures under control. Um, because, right now, my, what the doctors are trying to figure out, what works, what doesn't." Earlier in the interview Speed Runner had indicated she needed to live with her mom because of her seizure disorder, which was not well controlled.

Riley (a junior) indicated:

At this point, it would probably make more sense and be easier money-wise to go back home, and my parents said that they would like make me pay rent, so that I could act like I was living in an apartment even though it would be at home. And then I'd be able to get a job there.

Riley stated that her desire was to become a potter since her major was studio art. She indicated that living at home after college would be easiest for her, and her parents were supportive of this plan.

The remainder of the participants did not specify if they anticipated living with their parents after college or living independently; they responded in various ways. Carl and Isaac were both freshmen, thus they indicated that they had some time to think about their future. Carl stated he would likely do what most other people do after college. He said, "Just start working for the right—for a good majority of my life. But also, considering like marriage and everything, down the road. . . . I think I would want to do is what a majority of people do." Isaac stated, "Teaching for about a few years . . . going to go get my masters . . . I really don't know yet . . . anything can change in the next four years."

Participants also responded to these questions by indicating the type of employment they hoped to secure after college. Kirk (a junior) stated, “Being an actuary.” Frodo (a senior) stated, “I would like to work in the field that combines the two of them.” She was referring to her double major of geology and computer science. Jackie (a sophomore) stated, “I might want to go into clinical psychology because my special interest is actually studying diseases of what can go wrong in the brain.” Chase (a senior) stated:

Hopefully to teach English as a foreign language, preferably some place like China or South Korea, or maybe Dubai, and I also write graphic novels, so I’m hoping to use the money from that job to jumpstart that and maybe commission somebody to draw up what’s in my head and then split the money 50/50.

Chase indicated that his mind was constantly creating stories; he hoped to write these stories and hire an artist to draw the illustrations. He felt that this might be income generating in the future, although initially he needed another job (like teaching) to fund his writing endeavors.

Three students indicated they would seek a job that was less demanding at first. For instance, Speed Runner (a sophomore) indicated:

Um, so, since my degree is going to be a B.A. in communications and a minor in special education, I would like to be a paraprofessional working in special education. I know you only need a high school credits, but mine, I want to go more into depth with working with special education students. So, I’m waiting on that, because I just don’t want to be able just go into like a mainstream class.

Initially the researcher did not understand why Speed Runner wanted to start as a paraprofessional even though she would have a teaching degree; later in the interview she



indicated that it would be easier to start working as a paraprofessional until she felt more comfortable with the job, then she could pursue being a teacher.

Mike (a senior) also indicated he would start at a job that was less demanding. He stated, “Probably either working as a substitute teacher for the first year or as an EA [education assistant], and then after—and then going into—as a full-time teacher within the second or third year of graduating.” When asked to explain, he stated, “Usually a teacher, once you’re out, you usually become a teacher right away. But I have found that, that might be a little too stressful to transition from college to a very high stress job.” Both Speed Runner and Mike planned to be initially employed in a less demanding role, like that of a paraprofessional, even if they were both qualified for a teaching job once they completed their undergraduate degree.

Allyn (a junior) also indicated pursuing a less demanding job immediately after college graduation. She stated, “Probably working at McDonald’s for a little bit. At the same time, hopefully finding a job that I can do for—that is in the film industry or in the creative writing industry.” She explained the reason for initially expecting to work at McDonald’s after graduation was because jobs in the film industry were hard to find; she also indicated that most entry-level jobs in film were part-time or contract jobs. Allyn had already been working at McDonald’s and was comfortable with that job, therefore continued employment there would provide her with income while she looked for jobs in her field.

In summary, some students spoke about where they might live after college, for instance, at home with parents or near home, while other students spoke about potential employment plans. Most indicated a desire to work in their major’s field. Only one student mentioned getting married in the future, although questions about marriage were not directly asked.

***Current employment.*** Although questions about employment were not asked, some students mentioned being employed during college, which speaks of autonomy. Of the 17 students interviewed, four mentioned having part-time jobs in addition to being enrolled full-time in college. William (a sophomore) stated, “I actually work at the cafeteria on campus . . . if you work for the school, they have a maximum of 20 hours a week . . . and it’s considered work study, so you don’t get paid minimum wage.” Allyn (a junior), stated, “I work at McDonald’s.”

James (a senior) was looking for an internship in the business field since business was his major. James was also employed at the time of the interview, he stated, “Right now I’m selling printers at Best Buy and probably going to work at Green Mill Pizza just to make some money in the meantime.” Frodo (a senior) was also interested in internships given that she was graduating soon. Frodo stated, “And I got an internship. I mean I actually got, it’s a pretty prestigious, a lot of people applied for it.”

In summary, several students interviewed mentioned having a job in addition to being full-time students, which speaks of autonomy. Two students who were seniors were looking for internships that could be stepping stones into potential jobs. The possibility exists that other participants were also employed but did not mention it, since this question was not asked during the interview.

### **What Others Should Know about Autism**

**Ending questions.** At the end of the interview participants were asked about information they wanted others to know about autism. The questions asked at the end of the interview are outlined in Table 9.

Table 9

*Interview Questions at the End of the Session.*

Primary Question	Sub-Questions
What would you like others to know about people with autism?	What would you like instructors or college staff to know?
	What would you like fellow students to know?
	What would you like school administrators to know?

***Suggestions for instructors and faculty.*** Participants had several opinions as to what they wished faculty would know about students with autism. A theme arising from this question was the concept that people with autism learn differently from people without autism. Jordan (a junior) stated:

People with autism learn in a completely different way from everyone else. They don't necessarily need to be treated as dumber. I think a lot of people look at people with special needs, and they think they, you know, don't turn their C's into A's, just allow them to reach their A in a different way.

Jordan was emphasizing that students with autism are different from other students with disabilities, a theme that was brought up by participants at various times during the interviews.

Allyn (a junior) stated:

Or if like, if certain things are not clicking, just if anything, help and say you can adjust the—how you teach to help with that student while also benefitting the other students.

Because I think there was a study of a teacher changes the way they taught students, because there was an autistic child in the class, and then everybody benefitted from that. Allyn was recommending changing the way instruction happened to facilitate learning for students with autism and students without autism. Allyn did not specify what that change would look like. James (a senior) also felt that people with autism did not learn best through traditional ways of teaching. He stated:

I think I would just call for a little open-mindedness and openness to change the structure of classes. I mean, you know, classes have been what they've been for many years, and I think the professors I respect the most are the ones that change the game a little, make it a different environment.

Thus, both Allyn and James suggested changes in the way classes are taught as potentially beneficial for students with and without autism.

Repetition was another theme that arose when students answered the question about suggestions for instructors and faculty. Jackie (a sophomore) mentioned repetition as an advantage for students with autism. She stated "Be willing to explain some parts of the assignment more, because it could be difficult for people with autism to interpret things that may be—may seem common sense for other people." Allyn (a junior) also emphasized the need for repetition. She stated:

I guess it is just really that repetition. Like even though it is just a short amount of a class, if you can just get them to do something again and again and again, just getting them comfortable with that, within that time.

Thus, both Jackie and Allyn suggested that instructors use repetition to help students with autism. Jackie referred to repetition as instructors re-stating directions or concepts to help

students understand and learn. Allyn referred to repetition as allowing students to work on a skill or concept several times in the process of learning.

Several participants also wanted faculty to know that both verbal and nonverbal communication are challenging skills for students with autism. When describing the challenge of nonverbal communication, William (a sophomore) stated:

Nonverbal communication is one thing that a lot of people need be better at, but for some reason, the nonverbal communication of people not on the spectrum versus people on the spectrum—it's like trying to speak Spanish to somebody who only speaks English.

Difficulty with nonverbal communication was also shared as an issue by other participants during interviews.

Participants also alluded to difficulties with verbal communication. They mentioned that people with autism found it challenging to express their thoughts verbally. Participants also indicated having trouble knowing how to ask a question. Jackie (a sophomore) stated, “[Be]cause a lot of times I might know I have a problem, but I don’t really know what question to ask.” Some participants also expressed concern about being misunderstood because people with autism had difficulty verbalizing and expressing their thoughts. Susan (a freshman) stated:

I’d like them to know that if I say something there, if I raise my hand in class or if I ask them a question or whatever, and I project something differently than I intend, or if I say something and it sounds like the words are right but how I say it is wrong. That is not intentional. . . . I don’t mean [to] have an attitude . . . I just don’t know how to do those things quite properly.

Participants therefore wanted instructors to be aware of nonverbal and verbal communication challenges.

Participants also wanted instructors to know they were listening, even when they appeared distracted in class. Elizabeth (a senior) stated: “Sometimes it may look like I’m not paying attention, but really, I’m—I’m basically listening, but with my eyes in a different direction.” Elizabeth expressed having difficulty making eye contact with the professor, she said “Because it feels a little—it kind of wears me out a bit.” She wanted professors to know that she was listening, even though she was not making eye contact and may appear to not be engaged in the class.

Jackie (a sophomore) mentioned that she often scribbled during lectures; she stated:

Or they can understand that if they see me scribbling with my pencil, that’s not me being disrespectful. That’s actually a coping mechanism that helps me to concentrate and think about the material without scrambling for papers or trying to take notes or anything like that.

Jackie explained that she recorded lectures and took notes when she listened to the recordings on her own.

James (a senior) expressed appreciation when a professor understood his difficulty in sitting still for an extended time. He said:

And my professor emailed me once, and I did really well in that class, by the way, that was one of my best classes last semester. But my professor emailed me and she said, “Hey you’re having a really bad time paying attention in class, to a point where even students around you have told me that they’re distracted by you.” Right. “So we need to figure out something. I have some desk toys. I’m going to bring them to class tomorrow, okay?” And so she comes in and she brings this little, this fidgety thing, not like a

spinner or anything, just this like cube thing, and I played with it all class, and it was great.

James expressed being thankful to this professor for understanding he was having difficulty sitting still for extended amounts of time in class and helping him find a solution instead of being frustrated with him.

Most participants stated they were quiet in classes and rarely asked questions, however they wanted instructors to know they were engaged in the class. William (a sophomore) indicated:

I would like for them to know that just because I'm quiet doesn't mean I'm not paying attention. I'd—I don't answer questions posed to me by the professors during class, it doesn't mean that I'm not thinking about them. And if I'm quiet during group work and not talking a lot to my, to my peers who are in groups with me, it doesn't mean—I'm trying my best to help out the group.

Although several students had mentioned being quiet in class, William wanted professors to understand that being quiet did not mean disinterest or lack of engagement.

Four participants mentioned they wanted instructors to be patient with them. When speaking about students with autism, Isaac (a freshman) said, "They're gonna get there, just not, just not the way you want them to get there." Elizabeth (a senior) stated:

I would like to let them know to just be patient . . . if there is something that I don't—that I don't understand right away and continue to not fully understand it. Even in—it is like if I keep asking for like a better explanation.

Speed Runner (a sophomore) stated, “Students with autism may have challenges, but be willing to be very patient, and make sure that you’re very precise about what you’re looking for in goals, instead of trying to go around in circles” James (a senior) also mentioned the need for patience:

I think I would simply like them to know that we kind of just need a break. . . . I need a degree to, you know succeed in the world and so I guess professors should know that like we can learn. We’re smart. You know, it’s not that we’re not smart and it’s not that we don’t get, it’s simply that class structure is difficult, and we might need a little more attention and a little bit more leeway. . . . I think we just need a little sympathy and a little understanding.

Therefore, these participants recognized the challenges related to having autism might mean that instructors needed to spend more time explaining concepts, or they might need to use different approaches to help students understand. These students wanted instructors to be patient with them and assure them that they could learn, though perhaps differently than students without autism.

Anxiety was also mentioned by some participants as an aspect of autism faculty may not understand. Carl (a freshman) stated:

Well, it’s pretty common for someone with any form of autism to suffer from anxiety and depression. . . . But I would have to say that anxiety, for people with autism, is much worse than what I would consider for other people. So, say, maybe if they—it is just a simple homework assignment, but that’s for all the classes. They could easily get overwhelmed. So, maybe if they are informed someone has autism, maybe just maybe give them a little bit of time extension, if they really think they would need it. So, or



maybe just tell them to calm down and just not try to make it so anxiety won't get the better of them.

Allyn (a junior) also explained that many aspects of being part of a class were stressful to her.

She stated:

I guess one of the things, it would be kind of nice to know, is that, especially when you have to speak in front of a class, and you can tell that they are extremely uncomfortable, just know, is like you know that speaking up there is literally like the exact same feeling of like standing on like an edge of a building, or like standing somewhere, like—or just being like you can literally see like the color drain from their face, like okay, if you don't want to talk, that's fine. . . . And it's like I know a lot of people have that fear of public speaking, but to me, it is literally I start like having like my throat tightens up and I just can't do it. And I have to keep my eyes down, even though people are like you have to look straight in—you have to look at the people. It's like it is easier either looking down or looking at the ceiling. There is no in between.

Allyn recognized that public speaking was a common challenge for many people, yet she felt that, in her case, speaking in front of a group was even more challenging and produced a very high level of anxiety.

Other concepts that participants wanted faculty to know about autism included that autism is “an invisible disability,” stated by Frodo (a senior) multiple times. Frodo also stated, emotionally, shaking, and teary-eyed:

Just because we look normal and, in some cases, and especially for women I've found that women are able to mimic better and don't . . . Better than, I think, the men are. And so you might not know that they, you know, but I'm severely disabled. I might not seem

disabled to some people but I am. And they don't get it. And it doesn't . . . there is no understanding . . . just because you can't see my disability doesn't mean I don't have one, and I do struggle. It's just a different type of struggle.

Jackie (a sophomore) stated:

I wish that instructors knew also that every autistic person is different and that it might take some extra time to learn what each individual needs, at least in terms of accommodations, but autistic people have a lot of unique strengths and it is totally worth it to accommodate neuro-diverse students.

Frodo's and Jackie's statements exemplified the desire among the participants to be seen as unique individuals with autism, emphasizing that many of their challenges were not visible.

The need to understand that autism is a spectrum and that every individual is different was also explained by Mike (a senior):

Well that first, it's a spectrum, so that not everyone that is diagnosed with it or labeled with it has the same, for lack of a better word, disadvantages. Like it affects me more socially, but someone else with that label may be better at some social cues and less with some other aspects of autism. A lot of professors don't really know—really only know autism through a more stereotypical.

Thus, Jackie and Mike wanted to emphasize the uniqueness of each person, while Frodo wanted to emphasize that the disabilities and challenges may not always be evident.

Megan (a junior) wanted to emphasize the need for confidentiality, describing a class where the professor pointed out her testing accommodation in front of her classmates. She described:

I don't like, like getting pointed out in the middle of class, like "Oh because you have extra time, you can leave." Like one teacher actually did that, one professor. And I was like I was scared, because then like because everyone in the class knew.

Megan emphasized how uncomfortable she felt when a professor pointed out her disability in front of her classmates. She wanted to remind professors that a person's diagnosis or disability needs to remain confidential.

In summary, participants had various suggestions for instructors. By understanding certain characteristics of people with autism, professors might be able to help students with autism be more successful in classes. Their suggestions ranged from showing more patience to using repetition in the classroom to showing more understanding of their communication challenges, as well as respecting confidentiality, and remembering that people with autism vary from one another as much as people without autism vary from each other.

**Staff.** Participants did not have many suggestions for college staff. Several interviewees expressed satisfaction with their interactions with staff. Mike (a senior) stated, "Doing what they're doing. They've always generally been very proactive and caring for me personally. So it is—so I don't really have much criticism or anything I can add." James said, "I mean they're pretty great."

The need for staff to be patient was mentioned. Elizabeth (a sophomore) stated, "Again—again with the patience." In addition to patience, an understanding of some of the challenges of autism was mentioned. Marcus (a junior) alluded to difficulty making decisions. He stated:

I guess if someone with autism seems like they're indecisive or like not choosing something, it's usually because they struggle with—like I struggle with like making any small decision. To me it feels like—if it's really hard for them to make a decision, it's

kind of because it really is hard. Because to me I never know if what I'm picking is like—is this the right thing? Is like this is what they want me to say or something? Whenever I'm answering something it's like, is this what I'm supposed to say? Or are they looking for some other answer? I just don't know.

As stated earlier in this paper, Marcus' challenges with communication and his level of anxiety while speaking with the investigator were evident during the interview.

Individuality was also mentioned as an area that college staff should be cognizant of when working with students with autism. James (a senior) stated, "Understand that like everybody's individual case of autism is very different, and I don't think it would be uncommon to find somebody who has difficulties that nobody else has ever faced before." Megan (a junior) also spoke about autism being different from other disabilities; she stated:

Yeah and this week in chapel is a disabilities awareness week, but one thing I notice is I don't really like how they go about it. Because they're just like, oh you need help. If you need help. Go seek help, because you're not feeling well, or something. And it's not always that like, oh no, I can't do anything on my own. I just need help all the time, kind of thing. Like it's not like that. Like I can still do things on my own and like sometimes like I will need support from friends or family but that's just like everyone else. So it's not super different. Like there might be things that I like worry about that are different from other people or things that I think that, I think that are different, but it's not like in general as a concept, it's different.

How autism differs from other disabilities, and how each person with autism is different, was also brought up by Isaac (a freshman). He stated:

Don't assume. 'Cause like you can't, which is kind of one thing I'm glad is that they really wanted to get to know us before we really started out. To work together so that we had that relation. But, yeah, just don't assume anything before—you know it for sure. Isaac was referring to the disability services staff trying to get to know him before school started, which he appreciated. He wanted to emphasize that every person with autism is different, therefore staff should not have pre-conceived ideas of how a student with autism might behave.

In summary, many participants expressed satisfaction with support staff and could not think of specific information they wished the staff knew about autism. Some students mentioned that staff needs to have patience when interacting with them; they need to understand that decision-making is difficult, and recognize that each person with autism is uniquely different and their range of disability varies.

*Peers.* Participants were asked what they would like other college students to know about autism. Several interviewees talked about social challenges faced by people with autism as an area they wanted peers to know about. Jackie (a sophomore) stated, "All autistic people, regardless of what they look or act like, want to connect." Carl (a freshman) said:

I would want to say that they should be willing to understand that social interactions may seem weird—those people may seem weird to them, but they—I would want them to understand that their understanding or perception of the way they are acting may seem normal, but if people just kind of to keep away from those people, they won't be able to actually expand and maybe get better or have a better grasp or way to understanding the way that they are acting and maybe be more informed from other people. So, I would say college students have to be willing to give people that may seem—act differently, a chance to maybe learn why that is and be willing to help them. So, I would say keep

open—I would say, for college students, to be open minded to people that aren't what they may consider normal.

Thus, Carl wanted peers to expand their knowledge about what autism entails, including the social and communication challenges, as to understand and accept the behaviors of people with autism.

Riley (a junior) wanted peers to know that her quietness should not be interpreted as indifference about forming relationships. She said, “I’ll be really quiet in class, but it doesn’t mean I won’t be attentive and I don’t want to make relationships with the other people that I’m in class with. It’s just that I don’t really know how sometimes.” Riley desired for peers to understand that she had a desire to connect socially, but she did not know how to do it.

William (a sophomore) expressed loneliness during his interview. He had been living off-campus during his first year in college and was now living on campus. He stated:

Just because I don’t seem socially active, don’t leave me alone. Because the one thing I crave more than learning is social attention. I just can’t phrase it right. I can’t go out and make friends as easily as somebody not on the spectrum. Doesn’t mean I don’t want those friends. So, if I’m sitting there being quiet you know, just doing my work, bug me. Please!

William had difficulty initiating conversations and engaging socially, yet he was verbalizing a deep desire to connect socially with others.

Many participants talked about desiring other college students to know that people with HFA do not differ much from people without autism. When asked what she wanted peers to know about autism, Riley (a junior), stated, “That we’re essentially just like them. We just struggle with a few things and that I wouldn’t really consider it a disability just a challenge to

overcome.” Megan (a junior) said, “Don’t treat me any differently from anybody else. It’s probably like the main thing.” Speed Runner (a sophomore) expressed, “That not to be afraid of someone who has autism, I guess, and not to generalize it, because everybody’s different when it comes to autism, because there’s two different sides to it.” Isaac (a freshman) stated, “I would say just throw the ASD out of the window and just treat them as a person not the disability itself.” Mike (a Senior) stated:

That although we may act differently, we’re pretty much the same as other college students, even though it might take us a while to respond or may have some problems with telling the difference between sarcasm, jokes, and between if it is—they actually mean it, to treat us just like any of their friends.

The common theme among the interview participants was that peers should not assume students with autism did not want to connect socially. In addition, participants wanted peers to understand that students with autism were not significantly different from people without autism.

Interviewees also wanted peers to recognize that every person with autism is unique.

Jackie (a sophomore) shared an analogy about individuality in autism:

My favorite analogy that I ever heard was that autism is a little bit more like an ice cream sundae bar; some people are going to put a lot of chocolate fudge and a little bit of granola and some people are going to put frozen strawberries and a ton of granola on there. Autism is just a real unique heterogeneous collection of symptoms.

In summary, several participants wanted fellow students to recognize that they are similar to typically developing students, and yet each person with autism is also uniquely different.

A few participants wanted peers to know that people with autism do not like to be stereotyped. Chase (a senior) expressed his feelings about being stereotyped as follows:

Probably bear with me here because I know I seem a little odd at first but we're not so different. That every time you—signal about how much you claim to care about people with my predicament it's patronizing. It's kind of like being pandered to. If you pander to me chances are I will not like you. Yes, I get that I don't always catch on to social nuances and social—I get that. You don't have to remind me. You don't have to rub it in my face all the damn time. I get it. There's a reason why I'm painfully blunt; it's because I don't want to have to go through the idiocy of having to go around in a snake path. I'd rather just go directly head-on. Better mutated brains don't make us freaks of nature. If you try and brandish me as a circus animal, you will be sorry.

Chase's demeanor seemed angry as he was relaying this idea, and at several other times during his interview.

Susan (a freshman) also talked about stereotypes:

Just because it's called autism doesn't mean I'm a lunatic. Everybody stereotypes people who have autism. Because look when people hear it they're like, what, you're like so normal. And it's like wow, that's kind of weird for you to say. Because every time I think about autism I think of somebody I knew like a long time ago, and it's like, are you calling him a lunatic or are you calling everybody else like crazy? And just like weird, like these are people who are trying to make it through life too and your, you and your stereotypes aren't helping. So just to stop stereotyping that these people that have autism are crazy or something. That's how God made them. They're different. But that doesn't mean they can't get through college. They can't like have a job or anything like that. Like they don't have to be completely dependent on somebody like they can do some things on their own too like you can.



Susan, therefore, found the perspectives some people have about autism to be offensive.

One participant wanted other students to understand some autistic behaviors that might be difficult for others to comprehend. Allyn (a junior) might have been explaining repetitive behaviors when she shared what she wanted fellow students to know about autism:

I guess one of the things is like if you see someone, especially if they are autistic, and they are doing something that, like physically that looks kind of weird, it's just like covering like a certain part of their face when they hear something they don't like, or and like they are covering—or they do certain movements that seem a little bit odd, it is just be understanding of the situation, because something might be going on that they have just naturally done for many years, and that helps them just get used to their surroundings.

Allyn also explained that people with autism may have a strong affinity to certain topics. She said:

And if they seem to be always going off, in a certain train of thought, and they just want to specifically talk about something, that you know, be patient with them. You know, sometimes they just like to just get everything out, or just really—really like that topic, because they just—it is just something that they really are passionate about too.

Encouraging fellow students to be patient and understanding of behaviors that seemed different was important to Allyn. Earlier in the interview she had talked about her affinity to music, and had explained that she had difficulty not talking too much when she was among fellow students who were discussing music that she was interested in.

Kirk (a junior) wanted peers to know about additional social challenges that people with autism might have. He stated:

You know about how, how situations with lots of people can be really overwhelming? Usually if it's a fairly organized situation, it's not much of a problem. If I'm just eating in the D.C.—dining center—that's usually not much of an issue. [Pause]. But if it's something like a social event . . . or maybe if I'm, or maybe if I'm in a situation where I'm sitting with a group of four, five other friends. Um. I often have difficulty following conversation, or properly being able to interject into a conversation. Say I think just for other students to be aware of that—that social situations can be just kind of overwhelming.

Kirk was referring to people with autism having difficulty in social situations, including being in a group of people or in crowded places.

Chase (a senior) talked about heightened sensitivities, he said:

For my condition I have heightened senses. I can hear things that are going on the second and third floor apartments above us. I can hear things that are going on over in the Somali grill. If there's a soccer game playing on the TV in the very back. I can hear the humming sound from the centralized heating system.

Chase was describing the sounds that he could hear as we sat in a coffee shop during the interview. Chase selected this coffee shop for the interview, which was noisy. However, the sounds he was describing were not sounds the interviewer was aware of or heard. Although Chase was not specifically talking about what he wished peers would know about autism, he provided an example of how crowded places with a lot of noise could impact his ability to socialize.

Earlier in the interview Chase had explained how he was not comfortable meeting someone he did not know (the interviewer) in a private location, thus his selection of a public

meeting location. He explained his distrust as related to not knowing if what the interviewer had said about the meeting was true (a research project), or if the interviewer wanted to meet him in a private location (an office at his school) due to ill intentions.

Marcus (a junior) described his discomfort interacting with others. He stated:

It's just like they might think it's weird that like I don't like—that I eat by myself a lot. But it's just what I like to do because like it's just really hard for me to go and sit or talk to other people. It probably looks really weird that I really don't talk. It's just really hard. For me, talking with someone else is like doing rocket science. To me it's like almost on the same level of difficulty. It might not seem that way, but it is.

Marcus also chose to conduct the interview in a coffee shop. He did not order any beverage or food and appeared very nervous during the interview. He was sweating and was jittery and made only occasional eye contact. His discomfort speaking with the interviewer was evident, which might resemble his discomfort in the social situations he described.

Some participants also wanted peers to know that their facial expression did not always reflect their feelings. Jackie (a sophomore) stated:

I would say if you're not sure if they're feeling a particular emotion like maybe they just look blank faced, ask them, are you happy right now? Are you mad? Are you sad? What emotion are you feeling even though I can't see it on your face?

William also described that people with autism typically did not show outwardly what they were feeling. He stated:

If it seems we're, like, you can't look at us and figure out exactly what's going on

beneath the surface. Our emotions are incredibly complex. Like, we could be at a funeral and I could be sitting there stone faced; you would not be able to tell how I was feeling, when, on the inside, I'm absolutely devastated about what happened.

William had recently lost a friend through suicide, making this idea fresh in his mind. Even though he did not appear sad or distressed, he expressed that, inwardly, he was deeply sorrowful to the point that he could not go to class or sleep well.

In summary, participants shared many aspects of autism they wanted fellow students to know. Many participants alluded to people with autism not being remarkably different from people without autism, yet each was a unique individual. Other participants wanted fellow students to know about specific characteristics of autism, as to help typically-developing students understand certain behaviors and be patient with students with autism. For instance, participants wanted fellow students to know about the difficulty people with autism had socializing, showing emotion, engaging in conversations, and being in crowds.

*Administrators.* When participants were asked what they wished college administrators knew about autism, most stated they did not know who the administrators were or what their roles were. The interviewer explained that these were the people who made the decisions regarding buildings, school policies, and how money should be spent, among other aspects of managing the college or university. Some students stated they wanted administrators to know that every person with autism was different. Elizabeth (a senior) stated:

And every student is different. Even—even students with autism and Asperger's whether it be high functioning or low functioning, it—they are all unique in their own way. They—they process things, their own—in their own unique way.

Thus, just as participants desired that fellow students know that every person with autism was unique, they also wanted administrators to be aware of this fact.

Frodo (a senior) expressed that administrators should include disabilities as part of diversity. She stated:

They're focused on diversity. But their diversity is skin color . . . um, they're, you know, I mean you know it really makes me angry that they focus on . . . I mean they had a bunch of articles out, for example, on white privilege, and that grates me. Because to me it's racism. No, I don't know what it's like to be black . . . But to say that I have white privilege because of the color of my skin is also racism . . . And I have kind of a really big problem with it because I have a disability. And you know they talk about immigration and immigrants and stuff like that and how, you know, all the immigrants should be able to come here. Well, for people with disabilities we are seeing our, like, resources shrink and continue to shrink because there's only so much to go around.

Frodo appeared frustrated as she was explaining her feelings about the college's emphasis on diversity, which in her opinion, did not include students with disabilities as also being diverse. Frodo's words and demeanor showed that conversations about diversity that did not include students with disabilities troubled her.

Megan (a junior) spoke about disability awareness efforts. She said:

Like it's good to have—just to spread the knowledge of it, like they're doing in chapel, it's great, like you spread awareness so that people know. But like don't, don't put such an emphasis on it that it makes those people feel out of place. Which is a hard balance, like I know that they're trying, like I'm not saying like, "They're doing a terrible job." Like they're trying, it's just, I don't know. I just . . . there is a little bit of a disconnect. Like

here's you and there's everyone else kind of thing. And I'm not saying that they do that on purpose, because they don't. . . . It's just that's how it comes off sometimes.

This topic was at the forefront in Megan's mind because her college had recently conducted a disability awareness week, which was highlighted daily in chapel. The way the college had brought awareness to disabilities had made her feel uncomfortable.

Susan (a freshman) wanted administrators to know about her feelings regarding being in close proximity to people; she stated:

I mean I don't like physical touch a lot. That's the thing with me—like somebody who has autism. So, I'm kind of understanding like that if you're going to plan a classroom like be aware of like people who are very touchy feely in that area . . . but like I don't want to be around a million people right. Like I don't want to have physical contact with them. So, kind of being aware of that when they plan like classroom structure, and just kind of being aware that people who are autistic can maybe just not like being in a room full of a million people.

The need for personal space was, therefore, something that Susan wanted administrators to be mindful of when planning classroom space.

Chase (a senior) spoke about routines. He was referring to people with autism who were low functioning and high functioning, and said:

They don't like—this goes for everyone. They don't like having their routines royally screwed with. I get that—I get that so if you're going to royally screw with our routine please let us know so we can properly adjust.

Chase was referring to unexpected changes in schedules, classrooms, or plans. He wanted to emphasize that routines are important to people with autism and sudden changes are hard to adjust to.

Mike (a senior) and Allyn (a junior) spoke about suggestions regarding housing for people with autism. Mike was subject to hazing during his first year at the dorm. His input for administrators was as follows:

To be a little bit more active or investigate, be a little bit more active in claims of potential bullying or hazing. And be a little bit more involved in it, not just send an ambiguous email and make sure that the RAs are actually doing what they're being paid to do.

Mike's experience had been that an email had been sent to all students residing in that dormitory's floor, asking them to treat each other with respect. In his opinion, the email did not highlight that harassment of students was a wrong. He expressed feeling that the situation had been minimized by the housing office. He was also distressed about the resident assistant (RA) witnessing the harassment and not confronting the students involved.

Allyn (a junior) had encountered challenges living in the dormitory and had needed to request accommodations. She stated:

I guess, especially with housing, for me, that I guess it is like—like this is—they are still like, especially with autism, like they have always had like a specific set that they have always been comfortable in. And moving into a new environment is extremely like, in a sense, very foreign to them. That like their usual schedule, so—things they are comfortable with, are now removed and they have to get used to another environment.

And then, if they ask, I like I have always had this kind of setup, or I just want a room by

myself, and where there is like that, you know, small room by myself and like understanding like if just them getting used to it, because they might just have a certain setup that really works for them, or something like that. . . . It's like if they are extremely like uncomfortable, like as for me, like I—they—one year they tried to put me on a 13th floor. And I told them, that is an absolute no. I have to be on a lower floor.

Allyn had suffered from severe anxiety during her first week on campus, needing to go home and commuting for a few days until her anxiety lessened. Her housing arrangement had been one of the issues that had exacerbated her anxiety. She also described other difficulties she had faced with housing, including having been assigned a high floor when her housing application specified she had a fear of heights.

In summary, although many participants stated they didn't know who their administrators were or what their role was, some students verbalized concerns. Some of the thoughts expressed were that every person with autism is a unique individual; individuality was a common theme among what participants wanted other people in college to know (instructors, staff, and peers). A student wanted to highlight to administrators that people with disabilities added to the student body's diversity. A participant spoke about the need for more personal space, also highlighting that many people with autism disliked being touched. Housing issues were also a theme; people with autism may have difficulty living in a dormitory, and may need specific accommodations and time to adapt to living away from home for the first time.

*Others.* Some participants talked about what they wanted others to know about autism, not related specifically to peers, staff, professors or administrators. Kirk (a junior) stated, "I think I just sort of want people to know . . . we're not crazy." During the review of his transcript



Kirk added this statement: “I want people to know not everybody on the autism spectrum is the same; mental health is more complex than that.”

Jackie (a sophomore) wanted people to know about the complexity of a diagnosis of autism. She stated:

I just think autism is super interesting and not the most valid label medically speaking, to be honest, because I think saying someone is autistic is a little bit like saying someone is deaf. That’s a really important piece of data, but it doesn’t necessarily tell you what kind of syndrome or injury caused them to be deaf, what kind of hearing range is still available to you, or even how they communicate best. . . . No one that I have met, expert or otherwise, has given me a real solid definition of autism.

Jackie’s analogy clarified how she viewed autism and explained how she wanted others to visualize autism in the same way.

Isaac and Jackie also spoke about movies and movie character that had predisposed people to think about autism in an erroneous way. Isaac (a freshman) wanted people to know that people with autism are not *Rain Man*. He stated:

So, okay, I hate to use this as a comparison, but that’s how I always heard it. Rain Man or Sling, Billy Bob Thornton from Sling Blade. That’s like how, those are the two main ways they see us. Or Forest Gump. But it’s always those three. They don’t see you as an individual, and it’s like okay.

Jackie (a sophomore) wanted others to know the following:

I think abandon your preconceptions. I’ll pick on *Rain Man*, which was a great movie, but maybe not the best representation of autism because the character of *Rain Man* was actually inspired by a real person named Kim Peek, and Kim Peek was not autistic. He

actually had a different syndrome which affected the physiological development of his brain and among other things, he had agenesis of the corpus callosum, the two halves of his brain were not connected in any way. That's actually also part of why he had these amazing savant skills. Savantism is an amazing thing and it's certainly awesome for me as a psychology student to study, but don't count on it existing. Only about 10% of autistic people develop savant skills or I don't know if develop is the right word. Only about 10% of autistic individuals have any kind of savantism. What everyone does have is strengths. I have a really high verbal IQ, so I'm not sure if that makes me autistic or if that makes me just an average savant. See strengths where you can find them and consider what kind of untapped potential the autistic population has.

Jackie eloquently explained how autism differed from *Rain Man*'s character and explained savant skills. Even though Jackie had a high verbal ability, one-on-one she appeared very reserved and quiet.

Chase (a senior) verbalized his desire that individuals without autism view people with autism as capable individuals. He stated:

Back to what I was saying about the stigma. The stigma of somebody who can't make their own decisions, that's not everybody. Certainly not people on the high functioning end because they will get pissed at you. . . . Rule of thumb is assume that we're adults, we can make our own decisions, and if we open up to you it's either a good way—if you want somebody like me to open up to somebody not on the spectrum then I would then— one rule of thumb that I would have is treat him or her like a normal person. It sounds so cliché and it sounds so obvious and sounds incompatible but it's—because too often people in their misguided efforts of wanting to change the world and—type moron,

they're like hi, it's not a disease, it's a diverse—blah, blah, blah. No, it's a psychiatric disorder caused by a mutation in the brain, at least that's what the DSM classifies it as. Chase expressed frustration with how other people thought of autism and elaborated on how he would not be fond of people who did not treat him as a competent adult.

Although not part of the interview questions, Jordan (a junior) expressed what he would want other people with HFA to know. Jordan had made a concerted effort to overcome many autism-related challenges, particularly social ones. He wanted other people with HFA to know the following:

Again, you don't need to change yourself unless you want to, and if you do want to, a really good book to go read is a book called, *How to Win Friends and Influence People*. It sounds like a super manipulative title, but it's all about how to interact with people in order to be more accommodating. I don't think it was ever really directed at people with special needs, but I've found that it's been a huge help. I recommended it to a few other people and they said it's been helpful.

Chase verbalized that he knew that not everyone with HFA felt like they needed to change or improve certain aspects of themselves. However, he described himself as a people-pleaser and it had been important to him to conquer many of his social challenges, which made it possible for him to have relationships and feel more at ease around people.

In summary, participants provided their views on what they felt other people should know about autism. When speaking about different audiences (professors, fellow students, administrators) some common themes were evident. The fact that students with autism are not significantly different from other students without autism was mentioned by many participants. In addition, participants repeatedly highlighted that each person with autism is unique, this sense

of uniqueness was mentioned throughout the questioning. Some participants spoke about characteristics of autism that make communication challenging, such as facial expressions not matching feelings, having difficulty expressing themselves verbally, and finding crowds and groups of people difficult to manage. The importance of not using stereotypes or thinking about people with autism as portrayed in well-known movies was salient. Participants showcased their desire to be understood and not viewed in a negative way.

### **Mental Health**

Mental health arose as significant theme during interviews. The investigator coded interviews using the labels Mental Health—Depression, Mental Health—Anxiety, and Mental Health—Other. The following is a summary of the participants' comments and descriptions of their mental health while enrolled in college.

***Depression.*** Several participants mentioned suffering from depression and some described how depression affected them as college students. William (a sophomore) several times mentioned having depression. When talking about the classes he had been enrolled in, he stated, "I took that class simply because, I mean, I have depression and I wanted something to, you know, look forward to during the day and it was a great class when I was able to actually make it." William also described how depression had affected him academically. He had failed all his classes during the prior semester because of a debilitating episode of depression; his girlfriend had ended their relationship and had moved out of their apartment. He described his experience: "When you take that, and then you take my depression that is only barely managed by my anti-depressants. . . . Different dosages didn't really work." He explained about not being able to attend classes: "You mix those two together and you get somebody not being able to get out of the apartment to get to class." William described his episode of depression as follows:

My sleep schedule was so screwed up that I was sleeping from 6 o'clock a.m. until generally around, I think it was, 9 o'clock p.m., and then I'd be, at that point it's like, okay, I only have a couple of things that I can really eat now. Because of that, a lot of the time that I would try going grocery shopping, I, either I would have to go all the way to Cub, like one of the Cubs that's open 24 hours, or I'd have to spend a very short amount of time after I wake up to, like, there's all the stuff going on, and it wasn't not. . . it wasn't just that I couldn't get myself up to go to class, I couldn't get myself to go to bed so that I could get up for class.

William also explained that the week before the interview, a close friend had committed suicide, and thus he had been experiencing another spike in his depression. During this episode, however, William had communicated with his professors to alert them of his mental status. He said, “Thankfully, all my professors know that. And they actually reached out to housing, to the housing, yeah, the leaders of the housing board and everything to actually go call and check up on me.”

Mike (a senior) also mentioned having suffered from depression during his first semester in college, which prompted him to switch majors. He stated:

Well it was a very—I was in a depression during the first semester, and I tried a lot of things to get out of it. And so my parents said, “Well maybe it’s the major.” And while I do love engineering and stuff, I guess it was more of a hobby than something that I’d want to do as a career. So, I looked at other—at my other interests and I decided to try education, and I haven’t switched since I switched then.

When asked if anyone had assisted him during this time, he stated: “By the end I finally talked to one of my sisters and I think that I forced myself to go see a psychologist to talk through what I should do and all of that.” Mike stated that he was no longer seeing a psychologist.

Carl (a freshman) also mentioned a diagnosis of depression but did not mention if it had affected him in college so far. Some participants described having been depressed earlier in life, during their middle and/or high school years. They expressed that depression earlier in life had been aggravated by their inability to interact socially with peers, and by peers ridiculing them because of their idiosyncrasies.

In summary, although only three students stated they had a diagnosis of depression, it appeared to be a common diagnosis among the participants interviewed; some participants mentioned having experienced depression early in life but did not state that it still affected them in college. The two students who described in detail their depression in college had experienced significant negative effects during the times when symptoms intensified.

**Anxiety.** Ten participants, 59% of the participants, indicated they suffered from anxiety. Some of these students described their level of anxiety as being more severe and debilitating than what other college students experienced. Elizabeth (a senior) relayed that she used a weighted blanket to help her through anxious times. She stated: “And—yeah, and she—my counselor showed—introduced me to the weighted blanket.” When asked if she liked using it, she stated:

I like it a lot. It is—if I am—if I am feeling stressed, or just—or just feeling like blah, full blown anxiety, I just put it over my shoulders, or just lay under it, and just the weight of the beads, it – it just takes – it kind of takes the pressure off . . . and I used my creativity skills. I actually made my own blanket.

Elizabeth mentioned creativity skills because, earlier in the interview, she had described that people with autism may have some challenges, but they also have gifts. Her gifts included having an artistic nature and the ability to be creative. Elizabeth's anxiety had been severe in her sophomore year, she described:

It was very difficult. It was—it was, well, at first, I was not—I was not being very truthful to my professors and—and my mother, and my disability resource advisor. I was kind of just kind of hiding the fact that I wasn't doing everything. And in my—at the end of my sophomore year, I was supposed to be getting ready for my first voice recital, and I was saying oh, I'm prepared. Don't worry. And I had the date all set, and—for when I was going to do my recital—but I—I wasn't prepared at all. I hadn't rehearsed with my accompanist at all. I was pretty much to the point—with that combined with the two classes that I had that semester that were just very, very difficult, very difficult for me, I was to the point where I was skipping classes, and I was basically spiraling down to the point of—I would get sick, from my anxiety. I would get like really bad headaches, and I would just be worn out. . . . I didn't—kind of the—what was going through my mind was I didn't really want to admit that I was failing. That I wasn't—that I wasn't doing the work and that I wasn't going to pass . . . I couldn't escape from it. And I eventually—there was one point where I was just crying. And I—I finally—or my mom kind of found out that I was—was not doing my work. And she got a little angry with me. And I didn't really blame her for that. And but—yeah, one time we were talking on the phone, and she was getting at me. It's like you weren't doing this and this and this, and —I was at the brink of tears. And I eventually kind of had to force myself to hang up. Hang up on her. And then, I—and then—then my mom emailed me and asked me if—if I could talk with her. And

I—and I told her no, I need some time. And then, I eventually said mom, can I call you? And I told her everything. And we were both—we were both on the brink of—we were both on tears and—and she—she apologized to me, because—after—after I told her how much of a difficult time I was having, and just—I was having—I was just having such a difficult time being humble.

This episode had caused significant anxiety for Elizabeth and prompted her to start getting assistance from disability services; she continued to work with disability services on a weekly basis through her senior year.

Megan (a junior) also talked about anxiety. She had been speaking with the interviewer about her hesitancy to seek help from others, and when the interviewer asked her why, she said:

It's a little hard to answer, partially because of anxiety. Like I have a little bit of social anxiety. But, yeah, it's a lot of things. And like going back and forth kind of thing. Also like—like more like there's a lot of social anxiety that comes into it too, 'cause like I still don't like talking in class a lot. It stresses me out, but I think those were like the two biggest things that have been affecting me in college.

Megan was hesitant to ask for help with classes because of social anxiety, which she first described as “little,” and later as “a lot.”

Jackie (a sophomore) described suffering from significant anxiety in her first year of college. She stated, “I was having real problems with anxiety, which prevented me from being mobile, for lack of a better word, like getting out of my dorm room and getting in the classroom, sitting near the front, talking with professors.” Jackie would not go to class and would not turn in assignments, which caused her to be expelled from this college.



Carl (a freshman) also described feeling anxiety in college and explained that the level of anxiety in autism was more severe than what people without autism might experience. He stated:

Well, it is pretty common for someone with any form of autism to suffer from anxiety and depression. But I would say they are probably well aware of how college students can get anxiety. But I would have to say that anxiety, for people with autism, is much worse than what I would consider for other people . . . well, with tests, like our homework problems, I just don't know, I consider well, what is the professor looking for? How much different is it from high school? How much more time and energy will I need to put in, to get the results I want? So, anxiety has really been afflicting me.

Carl suffered from both depression and anxiety. He attempted to clarify that, even though these are common diagnoses among college students, the level of anxiety suffered by people with autism is much higher than that experienced by other students without autism.

Susan (a freshman) also mentioned having significant anxiety. She described how she managed anxiety during classes:

Yeah, definitely anxiety. If I'm just like if I know I have like a list of 10 things I need to get done. It's just like I'm in lecture and I'm listening like I am listening like I'm just like I'm coloring too. Because like I just like that takes away my stress for me.

Marcus (a junior) also expressed feeling anxious. He stated:

I have been very anxious this semester, but I don't know if that is because I get stressed out all the time. So, like I am going to see a psychiatrist about that because I've just been really stressed out this entire semester.

When asked if he had a support system to help him with his anxiety, he said: “I try talking to my parents, but I feel like they just don’t understand.” Marcus appeared very anxious and uncomfortable during the interview.

Allyn (a junior) described her first few weeks in college as being very stressful. She narrated her experience during the four-day freshman orientation conducted by the college:

I was originally set in the [Name] building, which is like nine stories tall. And I was on the seventh floor. I was away from home, and the day before, I did not sleep at all. So, just so much anxiety and just adjusting to something so new, especially with a new roommate whom I have never met before, prior to that. And just learning that. And then, the next couple days, I didn’t sleep. I barely ate. And then, I was just having so much anxiety, and just—and like for some reason, I was just always like in a weird panic state, in a way. I was just like—something—like I just kept like having like weird—I don’t know. I was just not—like I was just breathing quickly. I was just like not comfortable anywhere. Like I didn’t know who to talk to or who to be near. Like anytime that—usually when—anytime that happens, I am always going towards the closest like adult or older figure for, in a sense, comfort. To the point like it was the third day of like this special like four-day system where we have like [College Name] days where, you know, the freshmen are just getting used to everything and they just keep you busy with certain activities. On Sunday, the third day, I just had to go to the [emergency room] and I was just panicking. And then, I had to go home and—for the first week, I was just going to classes, coming back home, before I was moved to a different building, on a lower floor, with a separate room that I slowly just got back into a rhythm.

When asked how her anxiety lessened once she had her own room, Allyn stated:

It—it dipped down, after a while. Like I just started getting into a rhythm where it was like I am around people for a good chunk of the day. And then I could go back to my own space, in a little quieter environment, and just, you know, just relax and do whatever I wanted to do, and not deal with anything else.

Allyn's initial anxiety during freshman orientation had been significant enough to need to seek emergency services and commute from home for a week. During other portions of the interview Allyn also described other instances that produced great anxiety to her, such as speaking in public.

In summary, anxiety was a common issue among the participants interviewed, with 10 of the 17 participants mentioning anxiety. The level of anxiety they experienced was described as more significant and debilitating than the anxiety that college students typically experience.

***Other mental health disorders.*** Some students described other mental health disorders that had affected them during college. Kirk (a junior) described an inability to concentrate in class during his first semester as a freshman. He stated: "I eventually actually went to see a psychiatrist to be prescribed, to get a prescription to help me concentrate. And that has helped me since then." Kirk was likely describing medication for an attention deficit disorder.

Frodo (a senior) described behaviors and emotional expressions that were difficult for her to control. She stated:

When, like, I want to do one thing. I know what I want to do. I have like a clear vision of what I want to do and then someone tries to, like, deviate from that it's hard. It's just like I have a hard time with it.

When asked how she dealt with those feelings, Frodo said:

I usually, when I get really angry I cry. And I get real upset and so I can't really express that, um, usually my typical reaction to anger. And then sometimes I will go back and send off an email. Uh, and sometimes it's a rash and I probably shouldn't but it's honest and blunt. And sometimes it's not. It's, you know . . . I mean I never call names, you know . . . or rude or anything, but, you know, just like this is how I feel. And sometimes they take it personal. I get that a lot.

Frodo also talked about frustrations at home:

So, ILS [inaudible] did come over today. Because my thing at home is I . . . and my boyfriend doesn't understand this, and he's . . . he has clutter everywhere and I can't live like that because my brain's already cluttered and is seeing the clutter it just, it sometimes will throw me into just, I don't know. I guess they fit or something. I don't really know what it's called but it just it's anxiety, it's stress, and just . . . and it's just, you know, I can't really deal with it and he doesn't really understand that. And so . . . but she's coming and she's helping me just kind of get rid of the clutter and get rid of stuff and doing that because he will not . . . help or . . . it's very frustrating because when I'm spending an hour and a half finding keys that I should be spending, you know, if it was clutter free it doesn't matter where I put my keys. They'll be out and that will be the only thing out. And so, I'll see them and grab them and go. But with everything else out too, I can't. And so, I . . . I mean I've spent, there have been several times I've spent an hour and a half looking for my keys, and that's not right.

Frodo also described other examples of how her boyfriend's actions at home produced anger in her, stating that he did not understand autism and thus he did not change his habits to accommodate her needs.

Frodo also talked about having been diagnosed with autism as an adult, and how she suffered as a child from being different, not knowing why she was different, which has had long-lasting effects in her life. She stated:

I would love to have an average brain, you know. I would, I mean I would . . . that would be great. It's just the trauma that I had growing up and then not knowing when I was going through school why I was different. It was painful. Not having friends. Being picked on, being teased. Being singled out. You know that was painful. That was, that left scars, and I didn't get the help that they have now for people.

Frodo cried several times during the interview. She appeared vulnerable, angry, frustrated, and sad at different times during the interview. She became agitated whenever she could not find words to express herself, and when recalling instances that were painful and frustrating to her.

Chase (a senior) experienced post-traumatic stress disorder (PTSD) because of having lived abroad and stating that he had witnessed violence and death. He explained:

I've had to learn to—it's not like it was as bad as being in a combat scenario or being in—or maybe a scenario where it can mean life or death. It happened to me a couple of times, well these events happened to me a couple of times because I was down there during the attempted coup d'état, it was when the nationalists were trying to overthrow the socialists or the communists and it was—the Venezuelan nationalists were trying to overthrow [inaudible] partner and martial law was imposed and it was—that death part that was part of what was during that time where I really started to see the world through a darker lens because this is what humanity is capable of.

Several times during the interview Chase expressed frustration at fellow college students and other individuals for their inability to see the world as he saw it. He stated:

But some days I feel like it's—by idiots because like they're like “oh, I want to go into the world,” yet they don't know how the world works. They've only seen the glitterati, and the pomp and all the very nice rosy things through little rose-colored glasses but haven't seen all the horror and the blood and the guts, and just the world can be life and it can also be a very dark place.

Chase expressed that he had not done well during one semester in college because of nightmares related to PTSD; he described:

Just the stress of it all I failed a couple of classes I had to retake. I had been having nightmares about things I had seen, and I just didn't tell anyone because I didn't want to come off as crazy. I didn't want to come off as oh, this person needs to be locked up in the psych ward. I didn't really tell my professors I was having nightmares because I didn't trust anyone. I didn't trust . . . I loaded up on coffee, I loaded up on caffeine pills, anything that could keep me awake and then I would sleep. I'd probably take a few two-hour naps a day and then just work like—at, at night.

When asked how he was able to get through this time, he stated: “I had to go to counseling.” He also stated that his counselor had retired, and he didn't trust anyone else to help him. Chase described, “Right now I'm looking for a support group or for sufferers of posttraumatic stress disorder . . . but I just have a very hard time trusting people.” When asked about seeing a counselor at school, he stated:

They have counselors on staff, but I just can't—none of them can relate. Who can I talk to that can relate to having somebody die in your arms, having to react on instinct when you have two dozen screaming jihadis running at you with Kalashnikov rifles.

Chase alluded to not being able to talk to others about his experiences several times during the interview. He mentioned an uncle who had fought in a war as someone that thought he could relate with, but Chase still felt that his experiences were too different. Chase also described a recent episode when he was out with a girl and a car backfired, and Chase took cover thinking it was gunshots. He described how situations like these were embarrassing and frustrating to him. He felt that a support group might be a better fit for him than a counselor would be.

### **Other Characteristics of Autism**

Another theme that arose during the interviews was behavioral patterns or challenges related to having HFA as college students. Elizabeth (a senior) spoke about needing more personal space. She explained:

I guess, sometimes in—I know in—when I am in the choir, and sometimes when we have to do exercises that involves like—like just kind of get-to-know-you exercises, and there are some where it involves like—like a lot—one of the traditions that we do, in liturgical choir, is we do the—the human knot, where you have to like—where you have a group, like a group of like six people and you have to like randomly grab onto one person’s hand and then another person’s hand, and you have to try to like—unwind yourself. And to me, it is a little too close for comfort.

Elizabeth also described feeling uncomfortable in large groups, she said:

Like, if, for example, if I am at a—like a party, and it’s—it is in a house—it is in one of the like off campus houses, and there are so many people in there, it would just be like a little tight. I need some air.

Elizabeth also explained that she had found an area in the cafeteria that was less crowded and loud, and she tended to eat her meals there. Elizabeth was describing some characteristics of autism that affected her in college, like her need for personal space and her avoidance of crowds.

Carl (a freshman) also alluded to personal space when asked what he found challenging about school. He stated:

Maybe just transitioning between classes. Just always different people who are complete strangers to me, just walking in big groups, just maybe being stuck in the middle of them. Being uncomfortable like that. So, the shift between different periods of the day, just with so many different people walking around, I would say would—so far would be my biggest dislike.

Carl further explained that the proximity to other people, whom he didn't know, was the aspect he disliked. This happened during transitions between classes, and the experience was very uncomfortable for him.

Megan (a junior) stated that the two biggest challenges she had in college were needing more time to take tests, and social anxiety. She explained:

Well I do get extra time on tests, because like, sometimes by thinking thing through take me a little bit longer, but if I know something then I'm just like everyone else. It's fine. But like if it . . . like if I have to like sit and think about it, like usually like longer tests, I take more time on, just because there's a lot to think about. And like going back and forth kind of thing. Also like—like more like there's a lot of social anxiety that comes into it too, 'cause like I still don't like talking in class a lot. It stresses me out, but I think those were like the two biggest things that have been affecting me in college.



Megan mentioned, elsewhere in the interview, how she thought through scenarios over and over in her mind. This happened as she anticipated meetings and when she was taking tests. Megan had difficulty choosing from various answers, and she questioned her answers when she had to respond in essay form. Other students also mentioned having extra time to take tests as one of their accommodations.

Jackie mentioned being sensitive to noise; she explained:

Probably any place where there's live music. With few exceptions I have a real distaste for live music because there's always that boom box that people insist on bringing out.

I'm like why do you need to have your concert sound like a rocket taking off? Just play your guitar softly; people will like it better.

Jackie was describing her increased sensitivity to sounds, which was exacerbated by having music played at a loud volume.

In summary, some participants described being affected by characteristics of autism that interfere with their comfort or functioning in college. These included needing more personal space, not liking close contact or touching other people, needing more time to take tests, and loud noises.

## **Chapter Five: Discussion, Implications, Recommendations**

### **Overview of the Study**

The purpose of this phenomenological study was to describe the lived experiences of students with high functioning autism (HFA) enrolled in institutions of higher education. Five staff members from disability services at private schools in the Minneapolis and St. Paul metro area of Minnesota assisted with student recruitment, for a total of 17 participants, each interviewed individually by the researcher. The Theory of Self-Determination was used as the lens through which participants' accounts were studied. According to this theory, three needs are essential to human motivation: competence, relatedness, and autonomy. Meeting these needs influence a person's ability to succeed in life (Deci & Ryan, 2000). This study explored these three areas to the degree in which the participants with HFA described their lived experiences.

### **Research Questions**

The main research question was: What are the lived experiences of students with high functioning autism who are enrolled in institutions of higher education? The research sub-questions were: (1) How do students with high-functioning autism describe their lived experience while attending an institution of higher education? and, (2) How do students with high-functioning autism describe their lived experience as they interact with the higher education system? The following discussion provides insights into participant characteristics and the themes that arose through interviews.

### **Discussion**

**Participant characteristics.** This phenomenological study focused on exploring the lived experiences of seventeen college students who were enrolled in colleges and universities at the time of the interview. The following section highlights demographic characteristics of these

participants, indicating how these were similar or different from what was noted in the autism literature.

*Gender.* Of the 17 participants in this study, nine were male and eight were female. Given that autism is four times more prevalent in males than in females (CDC, 2016b), having a sample with almost equal number of males and females may seem surprising. However, this could be related to the higher number of females than males enrolled in all (public and private) undergraduate colleges and universities in the U.S. (1.3:1 female-to-male ratio), and in Minnesota's private colleges and universities (1.8:1 female-to-male ratio) (U.S. Department of Education, 2017a; U.S. Department of Education, 2018b). This study also had a small sample size and not expected to be representative of the whole body of students with HFA enrolled in higher education in the United States.

*Ages.* Participant ages ranged from 18 to 42 years. The mean age of participants was 21 years and the median age was 22 years, typical of undergraduate student ages. Two participants were classified as nontraditional college students. Speed Runner, age 27 at the time of the interview, was considered a nontraditional student because she delayed her enrollment into higher education as defined by the U.S. Department of Education as not enrolling during the calendar year after completing high school (U.S. Department of Education, 2015a). Frodo, who was age 42 at the time of the interview, was also a nontraditional student per the U.S. Department of Education because she was independent, over 24 years of age, and had dependent children.

*Year in school.* A majority of the participants (65%) were juniors and seniors, and thus had been in college for at least four full semesters (since all interviews were conducted between the months of September and December). Three students were freshman and in their first

semester of college, and three were sophomores with at least two full semesters of college. Interviewing only students in upper classes (juniors and seniors) had been the original intent for this study, however all students who expressed a desire to participate in the study were given an opportunity to do so. One reason for initially desiring to limit the research to upper class students was related to college retention statistics, which reveal that many freshman students do not persist. Approximately 19% of students who start college full-time in a given year do not return to college the following fall semester (U.S. Department of Education, 2017a). Another reason for having desired to limit the study to upper class students was that these individuals would have a longer frame of reference in college, and therefore would be better able to reflect on their experiences. Despite these concerns, and regardless of their academic standing, each participant contributed to the richness of the data gathered.

*Diagnosis.* Most participants (88%) had a diagnosis that reflected a high level of functioning; 12 participants had a diagnosis of Asperger's syndrome, two participants had a diagnosis of high functioning autism (HFA), and one participant was diagnosed with pervasive developmental disorder—not otherwise specified. Almost half of the participants (47%) had been diagnosed in their preschool years, between ages one and four. Being diagnosed early in life is consistent with the median age of autism diagnosis in the United States (Baio, et al., 2018) of 52 months, or approximately age four. Seven participants (41%) were diagnosed in middle or high school, five males and two females. Two female participants (almost 12%) were diagnosed as adults, one at age 19 and one in her late 20s. Being diagnosed in adolescence or adulthood is not surprising, given the high level of functioning of the participants. In a survey of college students with HFA, Gelbar, Shefcyk, and Reichow (2015) found that 54% of the respondents had

been diagnosed after middle school; the present study's findings regarding age of diagnosis are similar to those in the literature.

The finding of later autism diagnosis in females compared to males has been documented in the literature. Rivet and Matson (2011) found that females with autism who did not experience intellectual disability were typically diagnosed later than males. Hiller, Young, and Weber (2016) speculated on several reasons why females with autism without intellectual disability might be diagnosed later than their male counterparts; reasons included females having a higher ability than males to mimic and imitate behaviors, and females exhibiting a higher desire for peer acceptance. These investigators also found that females were more likely to engage in complex social situations, whereas males tended to isolate themselves. Therefore, the finding that two of the female participants in this study were diagnosed as adults is not surprising.

*Majors.* Participants were enrolled in a variety of majors. The only major that was common among the participants (six students, 35%) was education. Three participants (17%) had declared majors in science, technology, engineering, and mathematics (STEM), one in computer science, one in math, and one in computer science and math. The perception has been that students with ASD are more likely to pursue careers in STEM (Wei, Wu, Shattuck, McCracken, & Blackorby, 2013), however only 17% of this study's participants had STEM majors. These results are not unlike reports from recent studies among college students with autism. Gelbar, Shefcyk, and Reichow (2015) found that a liberal arts major was the most common (29%) major reported by participants with HFA who responded to their survey. In an Australian study, Anderson, Carter, and Stephenson (2018) found that the most common set of majors among the college students with autism who responded to their survey was in the

category of psychology, education, linguistics, or other (27.1% of their participants). The finding that students with HFA who enroll in college pursue a variety of majors is significant, since high school and college counselors might have the perception that a STEM career is the most appropriate for people with HFA. However, allowing students to select a major that matches their interests is advisable.

Of interest is that two participants, one female and one male, who started college majoring in STEM disciplines found the coursework too challenging, which resulted in both students changing majors. Megan (a junior) started college majoring in management information systems, and despite meeting with professors multiple times, was unable to comprehend the material; she changed her major to English and creative writing. Marcus (a junior) started college majoring in engineering, and found the coursework too challenging; he eventually changed both schools and majors. Marcus decided to pursue actuarial science, as recommended by his father who was an accountant. These two individual experiences reinforced the need to allow students with HFA to explore their skills and interests as they make career choices. This study did not investigate what factors students had considered when declaring original majors, thus if STEM careers were selected due to proficiency and interest, or if they were chosen based on recommendations relating to their autism diagnosis, was unclear.

Conclusions regarding demographic characteristics of participants in this study can be found in a later section of this paper. The following discussion focuses on questions asked during interviews, and themes that arose based on these questions.

**Most and least liked aspects of college.** Initial interview questions were intended to put participants at ease by asking what they liked most and least about being in college. Although these questions were intended to initiate a conversation, various themes were revealed.

*Future success.* One theme shared by three participants was the promise of future success that higher education offered, particularly for individuals with a disability. One participant expressed how her relatives had not expected her to be able to go to college based on her diagnosis. The literature also reported that adults with HFA who do not have intellectual disability have been found to have a lower quality of life than adults with ASD who have intellectual disability. For example, adults with HFA are up to three times more likely to not be engaged in daytime activities such as being enrolled in school or being employed (Taylor & Selzer, 2011). Therefore, the fact that these participants with HFA were in college was cause for celebration since they perceived it as their opportunity for future employment and success.

*Meeting people.* Another theme that arose in the interviews was meeting people in college. Three female participants indicated that what they liked most about college was meeting other people, particularly people who shared their interests. This theme is consistent with findings from Van Hees, Moyson, and Roeyers (2012), indicating that despite the perception that people with ASD are not interested in having friends, the opposite is true. People with ASD desire to make connections with others, however their social and communication difficulties make it challenging for them to establish friendships.

The three females who indicated their enjoyment in meeting others had very specific interests; the people they interacted with the most in college shared those interests. Elizabeth (a senior) was involved in her school's choir, and due to her major (liturgical music), she also spent a significant amount of her time in the music department. Most of her friends were in choir or music and she appeared to treasure those interactions. Megan (a junior) enrolled in band as a freshman in order to meet people, which proved successful; she stated all her friends in college were from band. Allyn (a junior) was studying film production and indicated that the people in

her major shared her same interests, thus all her friends were from her classes. Allyn stated she enjoyed interacting with people who did not see her as “odd” for having such an intense passion for film and music. These three female participants may have enjoyed not just the ability to have friends, but more so, the shared interests with others. Having intense and specific areas of interest is a characteristic of autism (NIHM, 2016). These three females might have been expressing their satisfaction at feeling similar to other people who also had very intense shared interests.

Another area to consider is the gender of the three respondents who mentioned that what they enjoyed the most about college was meeting like-minded individuals; they were all female. Gender differences in characteristics of autism have been noted (Lai et al, 2011; Ormond, Brownlow, Garnett, Ryenkiewicz, & Attwood, 2018; Ryenkiewicz & Lucka, 2015; Srivastava, 2017). These gender differences include females exhibiting greater social communication ability than males with ASD. The social-communication challenges related to autism are still present, however females appear to learn to mimic behaviors, speech intonation, mannerisms, and other qualities of neurotypical people they admire, and they utilize these learned behaviors to better interact socially with others (Lai et al., 2011). The three females who rated meeting others as salient in their college life could have achieved a certain level of comfort in social interactions. However, based on the investigator’s observations during the interviews and the entirety of the interviews, these three females might feel most comfortable primarily in social interactions with small groups of like-minded individuals. These three participants appeared tense during the interview and admitted, on several occasions, to having great difficulty communicating and interacting socially with others. None of these three females appeared socially comfortable or attempting to mimic neurotypical social behaviors or mannerisms with the researcher.



*Stress of college.* In terms of what participants liked least about college, the most prevalent theme, mentioned by four participants, was the high level of stress related to academic demands. Two participants who mentioned disliking the level of stress associated with coursework were female (one a freshman and one a senior) and two participants were male seniors. The female freshman (Susan) and one male senior (Chase) were enrolled at the same university (HEI-C), and the other two participants who were in their senior year (Elizabeth and Mike) attended the same university (HEI-E). However, the researcher could not infer whether these universities were more demanding than others, or if this finding was a coincidence based on the small number of colleges and universities from which students were recruited. Since anxiety was a theme derived from this study, this finding is likely coincidental. Anxiety will be discussed later in this chapter.

Introductory questions yielded important insights into participants' lived experiences, including pride in pursuing a college degree, satisfaction from meeting likeminded individuals, coupled with feelings of anxiety from a heavy academic load. The questions that followed during the interview were directly related to themes in the Theory of Self Determination: competence, relatedness, and autonomy (Deci & Ryan, 2000).

**Themes related to competence.** The concept of competence as a key feature underlying human motivation was defined by White (1959) as the capacity of an organism to interact effectively with its environment, which is attained through many exposures to learning. An individual's ability to achieve a level of competence in interacting with the environment is therefore integral to functioning independently in adulthood. Competence was the first area of the Theory of Self Determination explored through participant interviews.

*Organization and planning.* When the investigator asked probing questions to inquire about participants' perceived competence in navigating college, several themes emerged. The most prominent theme was related to difficulties with organization and planning. These challenges encompassed difficulty managing competing academic demands, tracking deadlines for multiple courses, and setting up a system to complete assignments in a timely manner. These challenges have been reported in the autism literature; Najdowsky (2000) found that planning and organization are two of the executive function skills that people with autism often find difficult.

Six participants mentioned challenges with organization and planning, yet only two of them had been mentored or received assistance with these skills. Jackie (a sophomore) had received therapy prior to starting college that enabled her to successfully use a planner. Elizabeth (a senior) met weekly with staff at the disabilities office to plan her weekly assignments. The remaining four students who mentioned challenges with planning and organization had not identified a system that worked for them; two of these students were seniors and only a semester away from graduation. Both of the senior participants challenged with organizational skills (James and Frodo) were starting internships in their field of study in the weeks following the research interview. The investigator did not follow up with them at a later time regarding their internship experiences; of interest would be to ascertain if challenges with organizing academic demands resulted in challenges in organizing the requirements of their internship. This question, however, would go beyond the scope of this study.

Eight participants described using a planner to organize themselves in college. No literature was found relating to the use of planners by college students, and thus the researcher cannot determine if these participants were using a common college organizational tool or not.

In addition to utilizing a planner, some participants indicated they needed to use additional tools, including a separate notebook to break down assignments into their multiple tasks, and using phone alarms to remind themselves of activities or deadlines. Writing assignments and appointments in a planner, therefore, did not seem sufficient for some participants; they also needed more detailed checklists to successfully accomplish tasks and meet expectations.

Because only students with HFA were interviewed in this study interviewed, the researcher cannot ascertain if neurotypical college students face the same challenges with planning and organizing their schedules to succeed academically. Limited research exists on adults with HFA or Asperger's syndrome (Barnhill, 2007), thus determining if challenges with planning and organizing persist into adulthood and in the workplace is not possible. Difficulties, however, may be ongoing and may be one of the factors contributing to unemployment or underemployment among high functioning adults with autism (Hofvander et al., 2009; Müeller et al., 2003).

*Communication Challenges.* Another theme that arose in the area of competence was communication challenges. Having difficulty communicating is a prominent characteristic of autism (Griffiths, Vasiliki, Nash, & Hastings, 2012; National Institute of Mental Health [NIMH], 2016). Unlike people with autism and intellectual disability who may lack verbal communication skills, individuals with HFA typically have verbal fluency; however, most have significant communication challenges (National Institute on Deafness and Other Communication Disorders, 2016; Vicker, n.d.). Challenges in communication in individuals HFA include difficulty understanding irony, humor, metaphors, idioms, or sarcasm; responding very literally to what they hear or read; difficulty understanding other people's perspectives and nonverbal

cues; and difficulty envisioning the big picture of situations while concentrating on details (Weiss & Rohland, 2015).

In this study, difficulty communicating was either mentioned by participants during interviews or this challenge was gleaned from interactions between the researcher and the participants. Challenges with verbal communication was mentioned more often than difficulty with written communication. For example, when asked about their degree of comfort asking instructors for assistance in particular areas, many expressed discomfort with approaching an instructor, but feeling more comfortable sending an email. When asked to elaborate, some participants expressed difficulty stating their thoughts verbally; they knew their question or difficulty but did not know how to verbalize it. Some also noted that the responses to their questions did not match what they had asked; thus, participants perceived that they could not clearly state their question. The researcher also noticed that most participants found it difficult to explain their original answers when asked to elaborate on a response; some seemed anxious about not being able to express themselves clearly.

Elizabeth (a senior) had difficulty expressing herself verbally and in writing, however, no other participant highlighted difficulty with written self-expression. Communication challenges are concerning since the ability to effectively communicate with others may affect future employment. Difficulty communicating in written and verbal forms have been identified in the literature as challenges that affect adult employment (DePape & Lindsay, 2016).

Of interest to the researcher was that all but one participant contacted her via e-mail to inquire about the study, and all communications (except the interview) were conducted via email or text messaging. Many of the emails received from participants appeared enthusiastic about the study and some expressed happiness about participating. One participant engaged with the

researcher via text message several times on the day of the interview, utilizing happy emoticons in her messages. What was striking to the researcher was that the written communication did not match that participant's affect once they met.

Whereas written communication with participants oftentimes included expressions of feelings, most participants had a flat affect in person. Most participants did not smile at any point when first meeting, during the interview, or when departing. An additional observation was that many participants' tones of voice failed to reveal changes in affect during the interviews. The participant who had utilized happy emoticons in her text messages had, in the researcher's opinion, the most difficulty expressing emotion than any of the other students interviewed. Her tone of voice never changed, her expressions remained neutral, and the descriptor *robot-like* seemed appropriate several times during the interview. Given that emotions were expressed via emoticons through emails and texts, the researcher was surprised when meeting this participant and witnessing her inability to express those emotions in person and verbally.

Difficulty communicating was one of the most significant themes encountered in this phenomenological study. This challenge precluded participants from asking questions and seeking academic help. It also interfered with participants' ability to seek social interactions, meet fellow students, establish relationships, and have a more positive experience as college students. The observation that many participants expressed emotions in writing but not in person, and that their nonverbal communication failed to reveal emotion, underscored the need to assist people with HFA in conquering their difficulties outwardly expressing their inward feelings.

In summary, several characteristics of autism precluded many students from achieving a sense of competence in college. Difficulty with executive function skills, such as planning, prioritizing, and organizing their academic demands impacted participants' performance. Deficits in communication skills also affected the participants' ability to seek help when facing challenges.

**Themes focusing on relatedness.** After questions related to competence were asked, questions about relatedness followed, which provided insights into participants' lived experiences as they pursued developing relationships in college. Relatedness is the second area explored in relation to the Theory of Self Determination. This quality is considered an important component to human motivation, affecting a person's ability to succeed. Relatedness has been defined as the human desire to be connected to other individuals, which includes a sense of being cared for, and caring for others (Deci & Ryan, 2000). Relatedness was explored through questions about participant's interactions with others in the college environment.

*Socialization challenges.* Most participants indicated difficulty in engaging and interacting with fellow students as well as difficulty in establishing friendships, thus socialization challenges arose as a common theme. The majority of participants indicated discomfort speaking with fellow classmates unless they knew them. Some participants also stated that they did not interact with anyone in their classes. Another challenge often mentioned was difficulty working in groups. Although reluctance to speak to classmates they did not know may be a typical student behavior, the challenge that participants had about interacting with classmates seemed more severe; an underlying perceived inability to be social produced anxiety and discomfort.

Experiencing challenges with socialization is typical in people with HFA. Researchers have investigated how social challenges affect these individuals as adults. Baldwin and Costley (2016) reported survey findings of 82 women (mean age of 32.7 years) with HFA in Australia. Among various findings, 77% of the participants indicated that they had lacked support in the area of making friends and developing social skills through their education (primary, secondary and higher education). Participants indicated that, while they were in school, the most common support systems were academic. Participants' accounts in the current phenomenological study are consistent with literature findings; although academic supports exist in colleges, a lack of support systems for students with HFA in the area of socialization is evident.

Participants in this phenomenological study also expressed difficulty working in groups, which is a common practice in college (Young & Henquinet, 2000). Participants feared they were perceived as not interested in collaborating; however, their barrier was a lack of knowledge about how to interact and collaborate with fellow students. The ability to work in teams is a skill that employers rate as highly desirable in employees; employers also believe that college graduates should have the ability to work in teams (Manley, 2008). Given that most participants were majoring in disciplines that require working closely with others, their challenges with group work, and the lack of support systems to assist them in conquering these difficulties is problematic and can affect their future employment success.

*Friendships.* Some participants indicated having friends in college, although a few stated they did not know the difference between an acquaintance and a friend. Participants who had a roommate indicated that their roommate facilitated meeting fellow students; in some instances, most of the students they knew in college were the result of their roommate's introductions. Common interests were another way in which some students established friendships.

Even when participants admitted to having friends in college, most indicated that interacting socially with these friends was still challenging; they waited for friends to initiate activities, and then followed along. Participants who commuted to college indicated not having friends in college. Students who had a single room during their freshman year, as an accommodation, also indicated that not having a roommate made it more difficult to meet other students in college. The common theme among participants, with few exceptions, was that they appeared to crave having friends and interacting socially. Being part of a group seemed very important to them, however, this desire appeared to be tinted with an awareness that their own social skills were poor.

The literature on adults with HFA and their ability to establish friendships is limited and consists mostly of observations from studies with few participants. For instance, parents of four middle-aged adult men with Asperger's syndrome (AS) in the U.K. have described most of their sons as being socially isolated (Griffith, Totsika, Nash, Jones, & Hastings, 2012). Additionally, adult individuals with AS attending a support group for people with Asperger's syndrome stated that their attendance was based on a desire for socialization. Half of attendees indicated not having friends who were not family members (Jantz, 2011).

In a longitudinal Swedish study, Helles, Gillberg, Gillberg, and Billstedt (2017) reported on the socialization of 50 adult males with Asperger's syndrome. Almost one-fourth (24%) of respondents had no one they considered a friend or acquaintance. Parents of young men with AS in the U.K. have also indicated concern about what will happen to their sons when parents are no longer able to assist them physically and emotionally (Griffith et al., 2012), since their sons lack social supports.



In summary, difficulty establishing social relationships was a common theme in this phenomenological study. None of the participants interviewed were receiving services to assist with their social difficulties. This challenge seems to persist after college, as indicated by the literature. The fact that higher education institutions are not providing support with social skills is concerning, since collegiate life may be the last opportunity for people with HFA to learn social skills before facing the demands of employment; career success may depend on learning these skills. By focusing solely on academic skills, colleges and universities are not preparing youth with HFA for future independence and autonomy in the workplace.

*Romantic relationships.* Although participants were not asked whether they were, or had been, in a romantic relationship, five students (29%)—two females (a junior and a senior) and three males (a sophomore, a junior, and a senior)—indicated being in a relationship at the time of the interview or having been in one during college. No published research exists on the percentage of college students with HFA who are engaged in romantic relationships. Based on various statistics about the percentage of students involved in romantic relationships during college, Shapiro (2015) estimated that approximately 37% of college graduates had not had a romantic relationship in college; 63% had been in at least one romantic relationship in college. Although the percentage of students involved in a romantic relationship in this study was lower than Shapiro's findings, comparing these percentages is not appropriate. The lower number of participants in this study being or having been in a romantic relationship may be due to the limited sample size. Additionally, more participants may engage in a romantic relationship in later years during their college education. Another possibility could be that participants' social communication challenges impeded their ability to form romantic relationships, although this cannot be inferred from this study.

The literature about romantic relationships among adults with HFA is scarce. Of the 50 Swedish adults with AS (mean age of 30 years) interviewed by Helles et al. (2017), 14% were married or living with a partner, 16% had a partner who did not live with them, 22% were single but had been in a romantic relationship in the past, and 48% had never been in a romantic relationship. Therefore, nearly half of the adult participants had never experienced being involved in a romantic relationship. This researcher could not locate published data about the percent of adults in the United States who have never been in a romantic relationship. However, Gallup polls showed that the number of young adults (ages 18 to 29 years) in the United States who were not in committed relationships rose from 52% in 2004 to 64% in 2014 (Saad, 2015). These statistics do not, however, differentiate between those who have ever experienced a romantic relationship and those who had experienced one but were not involved romantically at the time of the Gallup poll. Therefore, comparing Gallup poll findings with the literature on adults with AS is not desirable.

Strunz, Schermuck, Ballerstein, Ahlers, Dziobek, and Roepke (2017) reported on the results of an online questionnaire completed by 229 German adults (mean age 35 years) with HFA, which asked about romantic relationships. Twenty-seven percent of participants admitted to not having experienced a romantic relationship in the past. Of those in a romantic relationship, 20% were with a partner who had ASD. Those participants not in a romantic relationship at the time of the survey stated several challenges: Engaging in a relationship was too strenuous (61%); being afraid of not fulfilling another person's expectations (61%); not knowing how to find and engage a partner (57%); and not knowing how a relationship worked (50%). The researchers stated the percentage of participants with autism who were in a romantic

relationship was low compared to the German adult population at the time. Their findings showed a majority of HFA adults were interested in engaging in romantic relationships.

The underlying theme from the literature seems to indicate that many people with HFA want to be in a romantic relationship, but their social and communication challenges preclude them from achieving this status (Strunz et al. 2017; Weiss & Rohland, 2015). Data from a communication coaching program at a U.S. college indicated that many participants with HFA desired assistance with how to engage in a romantic relationship (Weiss & Rohland, 2015).

In summary, a small number of students in this phenomenological study were in a romantic relationship at the time of the interview. Based on the literature, students with HFA may benefit from support systems and professional mentoring through college that assist them with various social challenges, including an opportunity to learn and practice interacting with people with whom they may be romantically interested.

*Conquering social challenges.* An unexpected theme that arose through this study was that of intentionally studying how neurotypical individuals act and mimicking those behaviors in order to appear normal. Two participants (Jordan, a junior, and James, a senior) described their quest to behave like typically-developing individuals in detail. Through their study of social behaviors and communication modalities exemplified by people without autism, Jordan and James achieved a level of comfort with communication and social interactions, they both stated they no longer showcased the social challenges people with HFA typically exhibit. In the literature, this behavior was more commonly reported in females than in men with autism, and was referred to as camouflaging.

Lai et al. (2011) investigated behavioral differences among adult men and women with HFA through a sample of 83 participants (45 males and 38 females). Their findings showed that

females had fewer socio-communication symptoms than men, and they speculated that females made more progress in compensating for their social challenges than men did. The investigators stated that females had admitted to having “cloned” (p. 6) themselves, imitating someone they admired, mimicking the person’s mannerisms, fashion style, language intonation, and even interests.

Rynkiewicz and Lucka (2015) investigated the gender differences between Polish adolescent males (n=16) and females (n=15) with ASD or Asperger’s syndrome. The authors found that girls more than boys tended to camouflage their social deficits and were more prone to mimic others’ behaviors when interacting socially. An additional conclusion from this study stated that because girls tended to mimic social behaviors more than boys, girls might often be misdiagnosed or not diagnosed with autism until later in life.

In contrast, investigating camouflaging specifically, Hull et al. (2017) reported on a qualitative study of the camouflaging experiences of 92 adults with autism from various European nationalities (55 female, 30 male, seven other gender; age range 18-79 years). Investigators in this study found camouflaging to be equally prevalent in males and females, unlike other studies that had found this behavior more common in females.

Hull et al. (2017) also inquired about reasons for camouflaging. The investigators found that participants camouflaged their behavior because they perceived neurotypical individuals wanting people with autism to change in order to be accepted socially. Another reason for camouflaging was to obtain and maintain jobs. Some participants also expressed that camouflaging was their way of protecting themselves from being bullied. A consistent response from participants included recollections of being ostracized and bullied in childhood when their autistic characteristics were more obvious; by camouflaging, they could integrate better with

others without being ridiculed. Another salient reason for camouflaging was to develop friendships; a goal they desired but struggled to achieve unless they mimicked other people's social behaviors.

Because the current study did not aim to inquire about any one particular behavior, the accounts of Jordan and James and their quest to learn how to act socially in neurotypical ways was not investigated in detail. However, the investigator did ask both participants if they felt as if they were portraying a character when they interacted socially, or if their social behaviors felt natural and effortless. Neither participant expressed feeling like an actor portraying a role or that their social behavior was effortful. Both participants stated they had to make conscious efforts to depict these behaviors when they began their quest to learn how to behave in socially acceptable ways. Both participants had studied and practiced neurotypical behaviors and communication strategies for extended periods of time (several years) before assimilating these new behaviors and feeling natural with them.

Of interest to this researcher was to observe Jordan and James interact with her during the interview; they both portrayed command of social behaviors and one would not suspect they had HFA. Because the researcher knew of their diagnosis, she felt that James appeared to be portraying a character; for instance, making a conscious effort to make eye contact, and approaching the interview through being funny. At the end of the interview James also seemed to seek reassurance that his behavior had been satisfactory. During his interview, James admitted that his autistic traits appeared at times when he was very tired or stressed; at these times he was unable to think about how he behaved or what he said. James also stated that a friend who had a relative with autism had guessed his diagnosis.

Unlike James, Jordan seemed relaxed and comfortable during the interview, made appropriate eye contact, and even though his demeanor was calm and perhaps stoic, the researcher did not perceive any indication that he was portraying a character or masking autistic characteristics. If either participant was camouflaging his behavior or if either of them felt a high level of anxiety about their social behavior is not known. Interestingly, both young men had a girlfriend, and neither had disclosed to their girlfriend that they had HFA.

In summary, when investigating the area of relatedness, participants in this study provided valuable insights into the high degree of difficulty they experience when attempting to establish friendships. Social-communication interactions create great anxiety for participants, and students with HFA enrolled in higher education lack support systems to assist them in conquering these deficits. Participants who verbalized having conquered social-communication challenges had devoted a significant amount of time over several years to achieving a level of comfort and creating the appearance of not having an autism diagnosis.

**Themes related to autonomy.** The next area explored in this study related to aspects of the participants' lived experiences that showcased moving toward being more autonomous individuals. Autonomy is one of the three basic human needs that underpin the Theory of Self-Determination. Autonomy is described as the need to be in control of one's life and destiny, in addition to the ability to regulate one's actions (Ackerman & Tran, 2018; Deci, Vallerand, Pelletier, & Ryan, 1991). Several questions were asked to encourage participants to speak about their sense of autonomy in college and what they envisioned for their future. These questions included inquiring about their living arrangement in college, asking about self-care activities that might be new to them if living away from home (for instance laundry or cooking), learning about

the level of support received from family members, and discovering their expectations and plans post-college (including type of job they hoped to find and where they hoped to live).

*College living arrangement.* The interviewer's intent when asking participants about living arrangements was to gauge the level of autonomy regarding living away from home, and the success or challenge of the endeavor. The researcher also wanted to learn if participants had requested accommodations for housing. Inquiring about roommates aimed to elucidate any challenges that participants might have encountered due to their social and communication difficulties. Although this information is linked more to the topic of relatedness, these questions were asked during this part of the interview to provide a natural flow of questions.

*Dormitory accommodations.* Three participants indicated having received housing accommodations starting in their freshman year, two females and one male, all juniors at the time of the interview (Kirk, Allyn, and Riley). Kirk and Riley requested accommodations before the start of the semester, each of them requesting a single room. Allyn requested a single room in a lower floor after an episode of severe anxiety during freshman orientation. William (a sophomore) also had an accommodation, an emotional support cat. Having the cat had caused his roommate to move out due to allergies, thus he did not have a roommate at the time of the interview and this was his first semester living on campus.

Few findings are available about the types of accommodations students with HFA typically request, or should request, when living in college dormitories. Ackles, Fields, and Skinner (2013) stated that advantages and disadvantages exist related to students with autism requesting a single room as an accommodation. Advantages included decreasing the student's level of stress by allowing the student to relax privately without the need to interact with others, particularly after spending a significant amount of time in class surrounded by people. Allyn

alluded to this advantage and appreciated having a room to herself. Another advantage to a single room, mentioned by Miele, Hamrick and Kelley (2018), was that students with autism are most comfortable when following specific routines; a roommate that does not follow routines might cause distress and create unease for the student with autism. Elizabeth (a junior) described the unease of having a roommate during her freshman year who did not have a routine for when she would be in the room. In addition to the lack of routine, Elizabeth felt lonely because her roommate spent little time in their room, which kept Elizabeth from having anyone to interact with during a time when she did not yet know other students on campus.

Elizabeth's feeling of loneliness exemplified some of the disadvantages of having a single room, as discussed in the literature. Many students with autism report feeling isolated when placed in a single dorm room, particularly since people with autism struggle with establishing friendships (Ackles et al., 2013). Riley and William mentioned feeling isolated and lonely not having a roommate; their expectation had been that the roommate could be their friend, or at a minimum, someone with whom they could converse.

Because of the dichotomy of concerns students with autism may have about having a roommate, Ackles et al. (2013) suggested placing students with autism in suite-like rooms instead of single occupancy rooms. In this type of housing arrangement, students can still have their own room to retreat into but share a common space with a group of other students. This type of living arrangement appeared to work well for Kirk and Allyn.

*Dormitory experiences.* Participants had various experiences living in dormitories. Most participants who had a roommate during their initial year on campus expressed having experienced a level of discomfort living with people they did not know. However, some



participants with roommates appeared to have adapted to living in a dormitory and sharing a room, or to sharing a common space in a suite-like dormitory.

Limited research has been published on the experiences of college students with autism who live on campus and their degree of satisfaction with residential housing or with their roommate experiences. Gelbar, Shefcyk, and Reichow (2015) reported the experiences of 35 adults with autism who were, or had been, in college for at least one semester. Of the survey respondents, 50% indicated they had enjoyed living on campus and 43% reported they had experienced a good relationship with their roommate. For 38% of respondents who indicated they lived in a single dorm room, satisfaction levels varied from being satisfied with being alone to feeling isolated and lonely. Data in the current phenomenological study was not collected in the same manner as the research by Gelbar et al., however, as a comparison, 70% (n=13) of participants in the current study lived or had lived on campus, which is a higher percentage than that reported by Gelbar et al. Of the students with dormitory experience, 77% indicated not having been satisfied with their initial dorm experience (due to roommate problems, feeling isolated, not knowing how to interact socially, or noise level).

Eight participants (47%) in the study by Gelbar, Shefcyk, and Reichow (2015) did not live in a dorm at the time of their interview, and of those eight, five (29%) lived at home. Similarly, in the current phenomenological study, 47% of participants did not live in a dorm at the time of the interview; six participants lived at home (35%). Of these six participants living at home, one was Frodo who was the head of her household (as a mother). The remaining five participants (29% of the sample) lived at home with one or two parents. Susan, Marcus, and Speed Runner (freshman, junior, and sophomore, respectively) had lived at home since the

beginning of their college enrollment; Megan and Jordan (both juniors) had moved home at the start of their junior year.

To determine if the percent of participants living at home in the current study was typical of students in the United States, data was compared to the average number of college students living at home in 2013-2014 (the most recent data available) in the United States. According to Sallie Mae (2014), during the 2013-2014 academic year, 54% of college students lived at home; over half of college students opted to live at home for cost savings. In the current study, Susan indicated she lived at home for financial reasons, Marcus did not state a reason, and Speed Runner explained she lived at home due to a seizure disorder. Megan and Jordan had lived in a college dormitory for the first two years but had moved back home after that. Megan said that moving home was for financial reasons, whereas Jordan was transferring to a new college the following semester, and was living at home in the meantime.

Since only five participants (not counting Frodo) lived at home during the time of the interview, 29% of the total sample, a lower number of participants in this study lived at home as compared to the national average. Although one cannot make inferences due to the low sample size, the finding that most of the participants with HFA in this study did not live at home was of interest; participants might be exercising a higher level of autonomy than what may have been anticipated. Of the nine participants living in the dormitory at the time of the interview, five indicated their parents lived in close proximity to the college; thus distance from home was not deemed a factor influencing the relatively low number of participants living at home.

Three participants showed a high level of autonomy regarding their living situation at the time of the interview: Mike, Chase, and Frodo (all seniors). Mike and Chase lived in an apartment and Frodo lived in her own home. Mike had lived in the dormitory during his

freshman year but, due to bullying, moved to an apartment on subsequent years. Chase had lived in the dormitory his first two years in college but moved to an apartment on subsequent years due to not feeling connected to fellow dorm students. Frodo had children and lived in a home with two of her children and her boyfriend.

*Bullying.* The topic of bullying (or hazing) arose during the interview with Mike when discussing his experience at the dorm during his freshman year. Mike (a senior at the time of the interview) had opted to live in an apartment with family members (sister and cousin) in subsequent years due to a significant amount of hazing during his freshman year in the dormitory.

Most research about autism and bullying involves school-age children, with limited information about college students' experiences. In a review of the literature about prevalence and factors associated with bullying of school-age children with autism, Sreckovic, Brunsting, and Able (2014) found that youth with autism were bullied at elevated rates and were victimized with more frequency than other students with and without disabilities. Focusing on college students, DeNigris et al. (2018) reported on the prevalence of bullying described by a sample of 37 undergraduate college students, 22 who had autism and 15 who did not have autism. The authors found that 22% of students with autism reported having been bullied in college, although the level of bullying was lower than what they had experienced during their primary or secondary school years. For example, students who reported being bullied in college described receiving odd looks or being verbally harassed, but none experienced physical aggression in college, though physical aggression had occurred earlier in their lives.

Interestingly, when compared with neurotypical students, students with autism in the DeNigris et al. (2018) study reported similar levels of bullying before and during college. Based

on that study, bullying may be a common behavior in youth regardless of disability. In the current phenomenological study, Mike was the only participant who reported being bullied in college, however, since experiencing bullying was not a question specifically asked of interviewees, if other students had also been bullied but did not mention it during the interview is not known.

*New responsibilities in college.* Questions were asked about any new responsibilities participants had assumed as college students, compared to their high school duties, to ascertain if participants were more independent since starting higher education. The interviewer could see that participants did not understand what a new responsibility entailed, and thus examples were provided, such as doing laundry or cooking food (for those not living in a dormitory). A recurring theme was that participants could not identify responsibilities new to them in college. With only one exception (Marcus), all students had assumed laundry responsibilities before entering college. William, who had lived in an apartment as a freshman, reported having had difficulty grocery shopping but no difficulty cooking. Marcus lived at home and stated he did not know how to cook, thus he ate microwave meals most of the time. Riley mentioned forgetting to change her sheets as the only responsibility she found difficult, in addition to occasionally forgetting to eat.

Ascertaining if study participants experienced difficulty managing self-care responsibilities in college was difficult because the employed questions and prompts may not have instigated reflection on a broader variety of new tasks. Challenges expressed by William, Marcus, and Riley might be considered typical of college students (difficulty shopping for food, not knowing how to cook, forgetting to change sheets). Additionally, laundry skills may be learned at an early age; thus, this may not be a new responsibility to those entering college.

Participants' responses, however, differed from what parents of adults with HFA have reported about their offspring's self-care challenges (Griffith, Totsika, Nash, Jones, & Hastings, 2012). Several adults with HFA consistently reported challenges managing self-care activities when living independently (Baldwin & Costley, 2016).

Baldwin et al. (2016) reported on survey responses from 82 Australian adult women with HFA. The authors found that some women reported difficulty independently managing daily self-care activities. Responding to open-ended questions, some participants indicated having difficulty with cooking and other self-care duties. However, respondents stated that because ASD is an invisible disability, they felt frustrated that people in their environment assumed they were capable of all self-care activities. One respondent admitted her inability to take care of herself caused such severe anxiety that she often became unable to function or leave her home.

Griffith et al. (2012) interviewed parents of four middle-aged men with Asperger's syndrome. Parents voiced concerns about their sons' self-care abilities. Three of the five parents reported they were the primary support for their sons, in both practical and emotional ways. Practical supports included helping them with doing laundry, shopping, cooking, and cleaning. Parents reported their sons could care for themselves in terms of survival skills, however, three of four sons were described as not being proficient in self-care to the same degree as neurotypical individuals. Concerns about their sons' self-care ability included a propensity for hoarding, not noticing when clothes were dirty, not being aware of personal hygiene or appearance, and needing assistance with minor household repairs (e.g., changing a light-bulb).

Based on the literature describing the difficulty with self-care activities among adults with HFA, ascertaining if participants in the current study differed in their level of competence and autonomy, or if they had not yet experienced the level of independence that might challenge

their ability to function without support systems in the future, was not possible. It also warrants mentioning that the literature included information about people with HFA who grew up during a time when autism awareness was lower than what is currently the case. Individuals described in some studies may not have received an early diagnosis because clinicians might not have been cognizant of signs and symptoms of autism during their youth, since autism was not a common diagnosis then, as the diagnosis is more prevalent today. Being diagnosed later in life may have prevented these individuals from receiving the appropriate levels of intervention during their formative years, as compared to what today's youth receive, which may explain their struggles as independent adults.

Given the difference in responses between the participants in the current study and various accounts of difficulty with self-care activities, further research in this area is warranted. Of particular interest would be to ascertain if people diagnosed with HFA earlier in life and who receive support services in elementary and secondary years might be better equipped to manage self-care activities as adults.

***Family support.*** One of the interview questions asked participants about any tasks or responsibilities with which other people helped. This led to a discussion of support systems, with the recurring theme among most participants being that parents were their primary support system. Most participants indicated their parents provided emotional and practical support.

Whether participants in this phenomenological study relied more heavily on family members than neurotypical college students is difficult to determine since scant literature on this topic exists. Fingerman et al. (2016) studied the degree of parental involvement among college students who resided in two western countries (Germany and the United States) and two eastern nations (Hong Kong and Korea). A cohort of 310 U.S. students participated in this study and

provided information about the degree of parental involvement they experienced in college. Most students, regardless of country, reported speaking with parents about daily college life every week or a few times a month. It would appear the students in this phenomenological study did not differ from students' behaviors in the study conducted by Fingerman et al. in terms of frequency of contact with parents. However, the type of support provided by parents of participants with HFA in the current study might be more than a discussion of daily/common college occurrences.

The current study did not ask specific questions about topics of communication with parents; therefore ascertaining similarities or differences between this study and the literature is not possible. The recurring theme, however, was that parents served as support systems to participants in this study, and that the types of support participants received were emotional (e.g., comfort during stressful situations) and practical (e.g., assistance with decision-making).

***Employment during college.*** Having a college job is another aspect that points toward autonomy. Four participants indicated being employed in addition to their full-time college enrollment. William, Allyn, James and Frodo (sophomore, junior, and seniors, respectively) mentioned having a part-time job during college. Four of the 17 participants (23%) in this phenomenological study were employed while also being full-time college students. This number contrasts with the 43% of full-time college undergraduates who were employed in 2015, the most recent statistic available (U.S. Department of Education, 2017b). Other participants may have also been employed and did not mention it during the interview, however, the researcher suspects that having a job would have been mentioned, due to the questions and prompts used in the interview.

Determining if the difference between the national average of students employed during college and the lower percentage of employed students in the current study is relevant is not known. A college student with HFA might have difficulty with the additional responsibility of working while at the same time managing a full-time college load, however this area has not been studied. The participants who were employed did not mention difficulty managing a job and their coursework, however two participants had new jobs and may not have fully experienced the additional workload. William had just started his job at the college's cafeteria, and Frodo had not yet started her job as an intern at a healthcare facility where she could utilize her information technology skills. Allyn had been employed at McDonald's for several years and worked as a cook; she indicated she would not be able to manage working in customer service due to her difficulty interacting with people. Jordan worked in retail and had held several jobs since starting college; he believed the social skills he had developed were instrumental in being successful at his jobs.

Literature about college students with autism and their employment experiences while in college was not found. However, Bublitz, Fitzgerald, Alarcon, D'Onofrio, and Gillespie-Lynch (2017) published a study about the difference in behaviors exhibited by college students with and without ASD during job interviews. Bublitz et al. found some differences between ways in which college students with ASD responded to mock job interviews when compared to students without ASD. The primary differences were that students with ASD did not mention a desire for social interaction when asked what they expected in a job environment. In addition, students with ASD did not describe themselves as being interested in collaborating with co-workers, as compared to students without ASD who mentioned teamwork-related interests.



Butlitz et al. (2017) also found that college students with ASD were prone to disclose their diagnosis if asked (a question not legal in the United States during job interviews, but asked in the research study). The authors also observed that only one study participant with ASD described the positive attributes of ASD as a potential employee; this individual also mentioned challenges he had overcome in the past. Conversely, other participants with ASD who disclosed their diagnosis did not mention positive aspects of the disorder, which an employer might interpret as a negative diagnosis, based on their own preconceived knowledge of what ASD entails. Bulitz et al. (2017) concluded that college students with ASD would benefit from vocational counseling that included job interviewing skills.

Although the study by Butlitz et al. (2017) was not related to employment during college by students with ASD, it alluded to an important area of neglect in the education of this study's participants. None of the seniors interviewed mentioned any type of job interviewing training—for students with or without disabilities. In addition, when discussing accommodations with disability office personnel, no mention was made of any program being offered that specifically targeted the unique needs of students with ASD. Students with autism were offered the same range of accommodations as other students with disabilities, none of which addressed their social-communication challenges. Therefore, despite these individuals obtaining a college degree, their ability to secure a job may be impaired by their lack of training in one important skill: job interviewing.

***Post college graduation plans.*** Questions about plans after college graduation were asked to ascertain if participants were planning to move back home (less autonomy) after college, and if they planned to seek employment. Three female participants, Speed Runner, Megan, and Riley (sophomore and two juniors, respectively) indicated they would continue to

live at home (Speed Runner) or would move back home after college graduation. Speed Runner needed to live with her mother due to her seizure disorder. Megan and Riley indicated they planned to live at home after college graduation for financial reasons. Other participants had not thought about a plan post-graduation or indicated they would live away from home after college graduation.

Because many participants did not know their post-college plans, the researcher could not determine if the number of participants (17%) with plans to move back home after college graduation was typical of U.S. young adults. T.D. Ameritrade (2017) conducted a survey which found that 48% of the young adults interviewed (n=480) had moved back home after completing their college degree. Although reasons were not ascertained, the same survey indicated a significant number of millennials (defined as being between 20 and 26 years of age in 2017) had college debt they estimated not being able to pay off until age 35; 14% expected to finish paying off college loans at age 50 or older. Based on these estimates, finances are the most likely reason nearly half of millennials move home after college. The study participants attributed their plans to move home after college graduation to finances (Riley and Megan), and the need to be home due to a seizure disorder (Speed Runner). The possibility exists that more than three participants will move back home after college graduation for financial and/or family support reasons, however, this would not be considered an unusual finding given U.S. statistics.

When asked about plans after college in terms of job prospects, many participants indicated they did not know yet (particularly freshmen), however most indicated they planned to get a job within their major. Three participants, Speed Runner, Allyn, and Mike (sophomore, junior, and senior, respectively) indicated they would initially pursue a job below their skill level after college graduation.

Information about the proportion of college graduates that desire to work below their skill level was difficult to find. The statistics regarding underemployment include individuals working below their skill level, as well as those working part-time while desiring a full-time job, and people who are unemployed (Reinhart, 2017). Because this definition, as reported in labor statistics (U.S. Department of Labor, 2018), is broad, these measures do not solely reflect individuals working less rigorous jobs despite their training. Pedula (2016) conducted a study that investigated the effect of unemployment, part-time employment, temporary employment, and underemployment (defined in his study as being employed below one's skill level) on the potential for future full-time job prospects. The researcher found that being underemployed was as detrimental to applicants as being unemployed. Pedula's research indicated that obtaining a job below a person's skill level could ultimately affect their chances of being considered for employment utilizing their full educational level and skillset.

Based on Pedula's (2016) findings, Speed Runner's, Allyn's and Mike's plans to start employment at a level below their skill set may be risky. However, the reasons these participants stated for their plans for underemployment (i.e., the higher level of stress a job in their fields would produce), and the challenges they face due to their HFA diagnosis, likely superseded Pedula's findings against this practice.

In summary, the participant interviews did not offer enough information to draw significant conclusions related to current and projected autonomy. Difficulty with self-care activities was not prevalent. Several participants had difficulty living in a dormitory during their freshman year, and many also relied on parental support for social and practical needs. Few participants were employed at the time of the interview. Although most participants desired to work in their chosen field upon college graduation, three desired to start at a job below their skill

levels. Additionally, some participants also planned to move home after college. Despite these interesting findings, they do not differ significantly from behaviors of current students in the U.S. during college and after graduation.

**Discussion of themes related to mental health.** An unanticipated finding during the interviews pertained to the mention of mental health disorders experienced by many participants. Mental health challenges arose as a theme since several participants mentioned depression and anxiety diagnoses or symptoms. The researcher did not ask questions related to mental health problems or diagnoses; mental health information was offered voluntarily. Other participants may have also suffered from these and other diagnoses or symptoms, however, that information was not disclosed.

Of the 17 participants, three disclosed a diagnosis of depression and 11 disclosed having anxiety (which included the three participants who also reported depression). Therefore, during the interview, nearly 65% of the participants in this study disclosed a mental health disorder. The percentage of participants in the current study who reported suffering from anxiety was higher than the 50% reported in the general population of college students (Reetz, Bershad, LeVines, & Whitlock, 2016). Of the participants interviewed, 17% mentioned depression as a diagnosis; they all also mentioned suffering from anxiety. In the United States, approximately 41% of college students have a diagnosis of depression (Reetz et al., 2016); because this phenomenological study did not specifically ask about mental health diagnoses, the possibility exists that additional participants also suffered from depression.

A significant finding in this phenomenological study was the level to which depression and anxiety affected the individuals who disclosed having these diagnoses. Allyn needed to be taken to the emergency room during freshman orientation due to her anxiety level. William's

depression rendered him unable to leave his apartment and attend class for several weeks during spring semester of his freshman year, and thus he failed all his classes at that time. Jackie also described a time when her level of anxiety precluded her from leaving her dorm and going to class. Carl explained that the level of anxiety experienced by people with autism was more severe and debilitating than what neurotypical people experienced. Based on participants' stories, this researcher believes Carl's assessment is factual: the anxiety symptoms in people with autism are more severe than those exhibited by neurotypical individuals.

**Discussion of autism awareness by instructors.** The last set of questions asked of participants related to what they wanted other people at college to know about autism. Prompts for these questions included asking participants what they wanted instructors/faculty members to know, what they wanted fellow college students to know, what they wanted people that worked at the college (staff) to know, and what they wanted college administrators to know about autism. Several themes arose pertaining educating others about characteristics of people with autism.

***Different learning style.*** Jordan, Allyn, and James (junior, junior, and senior, respectively) wanted instructors to know that students with autism learned differently from other students. Allyn and James stated that instructional methods seemed to not have changed over time (lecturing), however they felt that innovative teaching strategies might benefit students, both those with and those without autism.

Baldwin and Costley (2016) discovered learning difficulties among people with HFA in a survey by of 82 adult women with HFA in Australia. Several women reported learning challenges through their school years (including primary, secondary, and higher education). Of the respondents, 51% stated they had learning difficulties, and 53% stated they had attention and

concentration problems. The researchers found, through open-ended responses, that many of the participants had difficulty with executive functions that affected their ability to learn. These challenges included difficulty concentrating for an extended time, understanding language that was ambiguous, listening and writing at the same time, finishing assignments on time, studying for exams, and taking exams. When asked what support systems were lacking during their school years, over half of the survey respondents (51%) reported lack of support for studying and learning.

The learning difficulties described above were also mentioned by several participants in this phenomenological study. Jackie and Allyn stated the need for instructors to use repetition, based on their difficulty interpreting concepts or instructions. Jackie and James mentioned difficulty concentrating. They both utilized tools to help them concentrate, which, to an instructor, might appear as distractions: Jackie doodled on a piece of paper during class in order to concentrate; James needed a fidgeting tool to help him remain focused. Elizabeth, Speed Runner, and James (senior, sophomore, and senior, respectively) stated they wanted instructors to be patient with them because grasping concepts or completing assignments often took them more time; however, they emphasized they were capable of learning and performing well if given the additional time.

As stated earlier in this section, some participants in this phenomenological study recommended that instructors utilize different teaching strategies to facilitate learning for all students, including those with HFA. Students appeared to desire that instructors incorporate a variety of teaching techniques, in addition to repetition of key concepts. The higher education literature regarding instructional strategies for students in general (not limited to those with autism) indicates that utilizing clear and organized instructional strategies benefit higher

education institutions, including modestly increasing student retention (Pascarella, Salisbury, & Blaich, 2011).

Limited research exists regarding instructional techniques that might aid students with HFA in higher education. Gobbo, Shmulsky, and Bowen (2018) reported on input from 12 STEM college instructors who provided insights into teaching strategies that might benefit college students with ASD. Five themes and recommendations arose from their qualitative study, indicating that college instructors should: (1) carefully select partners and group members when assigning group work; (2) provide clear and detailed instructions to students with ASD; (3) individualize instruction and capitalize on intense areas of interest of students with ASD; (4) utilize various teaching and assessment modalities to meet the various learning styles of students; and (5) use structured lessons because students with ASD perform best with an established routine.

In summary, some students in this phenomenological study indicated a desire for various educational strategies to be utilized by instructors, which could facilitate their learning. The literature regarding learning difficulties among individuals with autism indicates that several challenges exist (Baldwin & Costley, 2016). In addition, the high level of anxiety expressed by many participants in the study is concerning, since stress coupled with learning challenges can produce a poor academic outcome (Saunders-Scott, Braley, & Stenners-Spidahl, 2018). More research is needed regarding instructional strategies that may benefit students with HFA in higher education. However, faculty may benefit from implementing recommendations made by instructors with experience in teaching students with HFA until empirical evidence is available.

***Increased knowledge about autism.*** Several participants in this study wanted instructors to know more about autism to better understand students with the disorder. Elizabeth (a senior),

used difficulty in making eye contact as an example; an instructor might perceive that lack of eye contact indicates not being attentive, yet the opposite is the case. William (a sophomore) emphasized that even though a student with HFA may be quiet in class or in group projects, it did not mean that the student was disinterested or not engaged. William highlighted that the communication challenges students with HFA experience may keep them from being more vocal in class and in group projects.

Susan and William (freshman and sophomore, respectively) wanted instructors to know their nonverbal communication may not match their feelings. In addition, Allyn and Carl (junior and freshman, respectively) wanted instructors to know that students with HFA could experience anxiety to a much higher level than neurotypical students. Thus, duties that may be stressful for someone without HFA produced a significantly higher level of anxiety in someone with autism (e.g., speaking in front of a class). Frodo (a senior) expressed that college faculty needed to understand autism is an invisible disability, and students with the disorder may not appear to have special needs, but they do.

Minimal data exists regarding how much college instructors know about autism. Zeedyk, Bolourian, and Blacher (2018) reported on insights gathered through individual interviews and survey responses of college instructors about their knowledge of ASD. Their interviews found that some faculty did not know students with non-evident (invisible) disabilities could need classroom accommodations to succeed. Some instructors also verbalized a desire for training on effective instructional strategies to work with students with ASD. Several instructors also expressed interest in learning more about autism and requested continuing education to help them understand the disorder and how to better support these students. Interestingly, of the 132 survey respondents, 88% of faculty indicated a willingness to participate in training about



working with students with ASD, yet the remaining 12% stated that they would not be willing to attend such training. Reasons for not desiring additional training could not be determined through survey responses.

**Autism awareness by peers.** Participants were asked what they desired college peers to know about autism. Several themes arose regarding this topic.

***Social challenges.*** Many participants wanted peers to know that students with autism experienced great difficulty interacting socially; social challenges was a recurring theme. Carl, Jackie, William, and Riley (freshman, sophomore, sophomore, and junior, respectively) expressed that people with autism may appear to not want to interact socially, or may interact in ways that appear eccentric to neurotypical peers. However, these participants explained that people with autism want social connections but lack skills for doing so. Carl emphasized that neurotypical students could help people with autism learn how to interact in socially-acceptable ways.

Social challenges in childhood and adulthood among people with HFA have been reported. Findings from a survey of Australian adult women with HFA highlighted the social challenges these women had faced in school (elementary, high school, and college), many of whom continued to have difficulty understanding social interactions and communication as adults. When the authors interpreted social challenges as adults with the participants' age of diagnosis, they found that those women diagnosed with HFA after age 18 reported less social support systems during their school years, as compared to those diagnosed before age 18 years (91% versus 61% respectively). This discrepancy is an important finding since it could indicate that earlier diagnosis may provide more opportunities for social support systems for those diagnosed with HFA. With more social support systems in place during formative years, the

hope would be that individuals with autism could gain social skills that could assist them in establishing friendships and navigating social environments.

Regarding how social challenges affected adults with HFA in work settings, several participants in the study by Baldwin and Costley (2016) provided examples. Challenges that affected employment included difficulty interviewing for jobs, being social with co-workers, speaking on the phone, interacting with clients, and working in groups. Of female respondents, 60% indicated that socializing challenges were among their top three most negative experiences on the job. In contrast, 40% of male respondents indicated that socializing challenges were among their top three most negative job experiences. These findings indicate that lack of socialization support systems during school years for students with HFA could translate into life-long future challenges. These difficulties can affect their ability to obtain and retain a job, thus interfering with their independence and autonomy.

As Carl indicated, neurotypical college students could be instrumental in assisting students with HFA to understand social-communication dynamics, thus providing life-long skills that can help them become autonomous individuals. At an Australian university, Hamilton, Stevens, and Girdler (2016) designed a peer mentoring program, which included five peer-mentors who met with students with HFA on a weekly basis to assist them with social-communication difficulties. Peer mentors expressed a high level of satisfaction with the program's structure and support, however feedback from the student participants (with HFA) was not reported. Additional research on the effect of peer mentors working with college students with ASD is needed to elucidate if this might be a possible avenue to assist these individuals enhance social skills and gain social confidence.

***More similar than different.*** Another theme that arose when participants were asked what they wanted fellow college students to know about autism was the concept that people with HFA are not significantly different from other college students. Several participants alluded to desiring other students to *not* see them as different, strange, or disabled. They also wanted other students to know that stereotypes were not helpful; every person with HFA is uniquely different, just as every neurotypical student is individually different. Although not verbalized by participants, the researcher perceived a recurring theme: students with HFA want to be given a chance to show others who they are, to open their lives to them, and to prove that they are human beings just like them, with their own sets of gifts and challenges.

MacLeod, Lewis, and Robertson (2013) investigated how six college students with HFA perceived their diagnosis of autism. A common theme among the participants was that they did not self-identify with the descriptors of their diagnosis of autism or Asperger's syndrome. Each participant indicated a perception that they were atypical from what the literature reports regarding characteristics of autism. Because of this, study participants reacted negatively to stereotypical perceptions of autism (like the movie *Rain Man*).

Findings by MacLeod et al. (2013) confirmed what participants in this phenomenological study showed: People with HFA are uniquely different from one another. Participants clearly indicated their desire for fellow students to know that they are not significantly different from neurotypical individuals. This desire to be understood points to a need to approach each person with HFA with a sense of exploration, desiring to know the person's lived experience, strengths, and areas needing support. Participants indicated being like neurotypical students who may also need assistance and support navigating higher education.

**Autism awareness by staff and administrators.** Most participants did not have feedback for college staff; Mike and James (both seniors) expressed satisfaction with their interactions with staff from disability services. Elizabeth and Marcus (sophomore and junior, respectively) wanted to remind college staff to be patient with them because people with HFA have difficulty making decisions or understanding concepts. Thus, participants in this phenomenological study verbalized overall satisfaction with the work performed by college staff, although through their conversation the investigator could tell that they were speaking specifically about disability services staff. Some of the suggestions made by students regarding what they wished administrators knew about autism would also be beneficial for college staff to be aware of, as explained below.

**Individuality.** When asked what they wanted college administrators to know about autism responses were varied, with most participants appearing confused with this question because they did not know who the administrators were. However, when asked to think about the people that made major decisions about the college's functioning, the theme of individuality arose. Elizabeth (a senior) emphasized that everyone with HFA is different, thus services for this population need to be created with individual needs in mind. Megan (a junior) alluded to the same concept by explaining that disability awareness efforts described people with disabilities as unable to care for themselves, which does not apply to her and others with HFA. Frodo wanted administrators to remember that people with disabilities are also individuals that add diversity to college campuses.

**Autism characteristics.** Another theme that arose when speaking about what participants wanted administrators to know was more knowledge about autism in general. Some participants

expressed that if administrators learned more about the characteristics of autism, they could plan college structures and activities with their needs in mind.

For example, Susan (a freshman) spoke about a need for more personal space as compared to what neurotypical individuals might need. Although Susan was referring to classroom spaces and the placement of seats and tables, the need for personal space was also mentioned by Allyn (a junior) when referring to student housing. Allyn referred to the need for single rooms in the dorms to help individuals with autism feel more comfortable. Referring specifically to housing, both Allyn and Mike (a senior) indicated the need to listen to the concerns and requests of students with HFA; both students felt their needs and complaints had not been prioritized, which caused them great anxiety in their freshman year. Chase (a senior) spoke about people with autism needing routines, and how a sudden change (e.g., in a class schedule or location) could produce a high level of anxiety in someone with HFA.

In summary, participants in this phenomenological study had difficulty describing aspects of autism they wished college staff and administrators understood. When thinking about college staff, most thought about their interactions with disability services personnel, which was positive. Participants could not identify who college administrators were, however, when thinking about those who controlled major decisions, a few common themes arose. Participants wanted administrators to know more about characteristic of autism, in addition to considering that each individual with autism is uniquely different.

## **Conclusions**

The following are conclusions gathered from this study, outlined by the different areas highlighted through the discussion.

**Demographic Characteristics.** Because of the small sample size and the nature of this phenomenological study, participant demographic characteristics are not expected to resemble those of the general population of students with HFA in the United States. Almost half of this study's participants were women, even though autism is almost four times more commonly diagnosed in males than in females. The larger ratio of females to males enrolled in higher education in this country may have affected the number of females participating in this study (U.S. Department of Education, 2017a; U.S. Department of Education, 2018b).

The age of most participants was typical of students enrolled in higher education in the United States. (U.S. Department of Education, 2015a), with only two participants being considered nontraditional college students. The age of diagnosis of autism among study participants exemplified the heterogeneity of signs and symptoms of autism among people with HFA. More than half of the participants had been diagnosed in early childhood, although not surprisingly, many had been diagnosed in middle or high school, and a few as adults. The difficulty in diagnosing youth with autism who do not have intellectual disability resonated among the participants who were not diagnosed in early childhood. Having been diagnosed earlier in their lives may have provided support systems and therapies that could have alleviated some of their symptoms.

**Majors.** An important finding was that participants in this study had selected a wide variety of college majors, with only three students with a major or minor in a STEM field (mathematics and computer science), and two students having changed from a STEM to a non-STEM major in their freshman year. This illustrates that the perception that people with autism are particularly proficient in STEM careers may not be empirically supported (Wei, Wu, Shattuck, McCracken, & Blackorby, 2013). It seems pertinent to allow students with HFA to

discover how their gifts and aptitudes, as well as their interests and hopes, are aligned with their career goals.

**Introductory questions.** Although meant to put participants at ease and not expected to yield insights into lived experiences, the introductory questions yielded valuable information. Pride in being able to pursue higher education despite the challenges related to autism was evident in some participants' accounts. Another salient finding was how some participants viewed the opportunity to meet like-minded individuals as their favorite part of attending college. Whereas some people might assume the communication and social difficulties frequently seen in autism might translate into not being interested in establishing friendships, the opposite is often the case.

**Competence.** Given their intellectual ability, many people assume that youth with HFA are well suited for college, however multiple ASD characteristics can negatively affect their success (Anderson & Butt, 2017). The prominent themes related to participant's competence in college were challenges with planning, organizational skills, and communication skills. Because of the multiple competing priorities college students face (e.g., studying, completing assignments, writing papers, working on projects), deficits in planning and organizational skills can negatively affect their success in higher education.

A shortfall in planning and organizational skills, coupled with difficulties communicating, can be a further detriment to college success among students with HFA. Difficulty communicating with instructors and teaching staff can negatively impact students' ability to ask questions and seek clarification when needed. These challenges are examples of how students with HFA, who may not outwardly appear to have a disability, may struggle through college due to skill deficits. To compound their difficulties, the skills students with

HFA need to acquire to succeed in college are skills not formally taught in courses and not part of accommodations for students with disabilities.

**Relatedness.** The area of relatedness is one that greatly affects students with HFA in higher education, yet the area of assisting students with HFA establish relationships appears to receive the least degree of support by college staff (Gelbar, Shefcyk, & Reichow, 2015).

Whereas disability services personnel, other support staff, instructors, and faculty tend to focus on a student's academic success, little to no effort appears to be expended on aiding students with HFA to learn skills to communicate successfully and thrive in social environments. Given that adults do not live or work in isolation, youth with HFA who do not progress in their social and communication skills may be ill equipped to successfully manage future employment and independence. Thus, the ability to effectively communicate and establish relationships is an area worthy of exploration as to ascertain strategies to assist the growing number of students with HFA pursuing higher education.

**Autonomy.** Living arrangement was reviewed as one way to explore the level of autonomy participants exhibited in college. Most participants in this phenomenological study lived in a dormitory or in an apartment/home, even when many had family members near the college. This finding highlights most participants' desire for autonomy. A common theme was that participants who lived, or had lived, in a dormitory needed to adjust to many changes in their routines. However, participants who had been in college longer than one year made the necessary adjustments to their living situation in subsequent years and continued to adapt to living away from home. These adjustments required participants to exercise resiliency, in addition to learning coping skills through difficult situations; the learned skills may be



instrumental in their future lives as they continue to adapt to changing environments as more independent adults.

Other areas explored relative to autonomy included the ability to perform self-care activities, the degree of continued family support, employment during college, type of job they wished to pursue after college, and whether they planned to move home after college. The need for assistance with self-care activities did not arise as a theme; however, continued dependence on parents for emotional and practical supports was found to be a common practice among participants.

The literature indicates that frequent communication with parents is also common among college students in the United States (Fingerman et al., 2016). Few students reported being employed in addition to being enrolled as full-time college students. In addition, few participants reported planning to move home after college graduation, although several participants had not thought about future plans. Among participants who had considered employment options after graduation, three were planning to pursue employment below their skill level to first adapt to a work environment with fewer demands and stress. Among adults with HFA, no research exists to indicate if starting a career in a job below their skill level impacts their long-term career goals.

**Mental Health.** Many participants disclosed suffering from anxiety, and some also experienced depression. Compared to the U.S. population of college students (Reetz, Bershad, LeVines, & Whitlock, 2016), a higher percentage of participants experienced anxiety (50% in the U.S. population versus 65% of study participants). Depression was reported by 17% of participants. Particularly significant is the level to which these mental health disorders affected the participants who disclosed them. Participants reported needing to go to the emergency room

due to anxiety, as well as being unable to leave their room to attend classes. The level of anxiety many students with HFA experience may be more severe than that experienced by neurotypical students. The heightened and debilitating anxiety experienced by many students with autism, as well as resulting consequences, may be poorly understood by college personnel.

**What others should know about autism.** Through individual interviews, participants in this study were given a voice about what they desired people in the college community (instructors, peers, staff, and administrators) to know about autism. The underlying theme could be described as acceptance and understanding. Participants want to be fully known as the unique individuals they are, through instructors, peers, staff, and administrators taking an interest in learning more about autism. At the same time, participants desire to be recognized as being individually unique.

The challenges many students with HFA experience navigating college academically are significant; a desire for instructors to understand these challenges was evident. In addition, the tremendous need most of the participants expressed about having friends and interacting socially was also apparent. They described a high desire for social interaction coupled with an equally high level of discomfort in their ability to navigate social situations. Their desire to know others and be known by them, whether it be with instructors, peers, staff, or administrators, was both evident and touching. These students with HFA who are seemingly quiet and reserved are, on the inside, clamoring to be understood, accepted, and cared for.

### **Implications**

Several participants expressed difficulty with planning and organizational skills, in addition to reluctance to ask questions or seek clarification due to their communication challenges. Typical accommodations provided to students with disabilities (e.g., extra time for

exams, note-taking assistance, ability to audio-tape classes) do not meet additional support systems that students with HFA may need (Barnhill, 2016; Smith, 2007). An individualized approach to accommodations is needed in institutions of higher education. Although students with HFA benefit from many of the accommodations provided to students with various learning disabilities, expanding the repertoire available for students with autism is important (Barnhill, 2016). Suggestions of accommodations that may benefit students with HFA are found in a later section of this paper.

Learning difficulties were commonly mentioned by study participants, a finding that is supported by literature (Baldwin & Costley, 2016). Because many individuals with HFA who enter college have challenges in completing their degree (Shattuck et al., 2012), noting that students with autism may need additional academic supports is warranted. People with HFA may have the intellectual capacity to enter college, however they can experience challenges that may preclude them from completing their academic goals (MacLeod & Green, 2009). In addition to learning difficulties, students with autism may also experience heightened levels of anxiety, which can affect student retention (Saunders-Scott, Braley, & Stenners-Spidahl, 2018). Heightened stress levels could, therefore, affect the ability of students with HFA to persevere in college and complete their degree. Additional research is needed in this area, focusing specifically on students with HFA in higher education.

Although participants in this phenomenological study wanted peers to understand the challenges they experienced with socialization, the implications of these challenges go beyond establishing friendships in college. As the literature showed, social-communication difficulties can negatively affect the ability of someone with HFA from securing and retaining a job (Baldwin et al., 2016).

## **Recommendations for Practitioners**

**Transition planning.** Several participants indicated not registering with disability services in college until they encountered challenges that warranted accommodations. Participants also indicated that advocating for themselves in college was challenging and a new skill that they had needed to develop. Services for students with disabilities vary greatly between secondary and higher education institutions (U.S. Department of Education Office of Civil Rights, 2018b). Although higher education institutions are required to provide accommodations to students with disabilities to assure equal access to education, many of the support systems students with HFA may need are not covered by this mandate (U.S. Department of Education, Office of Civil Rights, 2010; U.S. Department of Justice, n.d.). Families may need to invest additional funds for services that the college may not offer, for instance, assistance with social skills development. Students and families should be informed of these changes during transition planning meetings while students are enrolled in high-school and include self-advocacy skills in Individualized Education Plans (Adreon & Durocher, 2007). A recommendation is made for transition planning personnel to inform families of students with HFA about the difference between services offered in public schools (Kindergarten through 12<sup>th</sup> grade) and disability services offered in higher education. Transition planning personnel should also encourage students with HFA to register with disability services offices at their college (disclose their disability) as to receive accommodations for challenges related to autism upon enrollment.

**College major.** Participants had declared a variety of majors, with only 23% enrolled in a STEM major or minor. This finding contradicts the perception that students with ASD may perform best in STEM majors (Wei, Wu, Shattuck, McCracken, & Blackorby, 2013). In fact, two participants had started college in STEM majors and changed to another discipline due to

difficulty with the subjects in that course of study. Emerging literature also supports the finding that many students with HFA do not enroll in STEM majors; instead they pursue college degrees according to their interests and long-term goals (Anderson, Carter, & Stephenson, 2018; Gelbar, Shefcyk, & Reichow, 2015). A recommendation is made for high school and college career counselors to guide students with HFA in selecting college majors based on their individual strengths and interests, not on perceptions of heightened ability for STEM careers and their related professional paths.

**Executive function skills.** Several challenges not typically addressed by standard accommodations provided to college students with disabilities (Barnhill, 2016) were mentioned by participants in this study. Difficulty with executive function skills, such as planning and organizing schedules, were commonly mentioned. Based on participant's accounts, a recommendation is made for higher education staff to consider that many students with HFA need guidance to plan and organize their college schedules.

In addition, students may need assistance breaking projects down into specific steps and prioritizing competing priorities. Some participants mentioned using planners to organize their schedules, emphasizing that they had needed assistance to learn how to *effectively* use planners. In addition to using planners, some participants mentioned utilizing a notebook in which they outlined the steps needed to complete projects and assignments, and using checklists to track their accomplishments. Some participants also mentioned utilizing alarms on their phone to remember deadlines and appointments. Support personnel could utilize the strategies that participants in the current study mentioned as instrumental, in addition to other strategies cited in the literature (Barnhill, 2016).

**Instructor recommendations.** Several participants in this phenomenological study indicated a desire for instructors to know about their unique learning difficulties and needs. Given that the needs of students with autism may not be fully met through standard accommodations (Barnhill, 2016), a recommendation is made for higher education institutions to provide training to educators about the characteristics of autism and the unique needs that students with ASD may have. Through greater understanding of the disorder, college educators may be able to recognize the academic challenges these students face. With increased knowledge of autism, educators can implement didactic strategies that enhance student comfort and learning. For example, through understanding students' difficulty with communication and social interactions, educators might choose to assign students to groups, rather than asking students to self-select group members.

Based on participants' accounts of their classroom and academic experiences, many benefits to providing training about autism to higher education instructors exist. College educators who understand the unique challenges of students with autism can contribute to their success by assuring that all instructions are clear, by using repetition in their teaching, by assisting students when they are having difficulty asking questions, and by clarifying procedures. For example, students with autism may appreciate specific directions as to how to utilize office hours, including whether students should join fellow students during office hours, or if the instructor prefers to speak with each student individually.

Utilizing a variety of learning strategies was also recommended by some participants. Lecturing was mentioned as a strategy that was often utilized by instructors, however incorporating other teaching strategies in addition to lecturing was recommended. One participant commented on her need for visual reinforcement of the content covered, thus having

difficulty when instructors did not utilize visual tools during class. The need for repetition was also mentioned by several participants, indicating that their learning was enhanced when concepts were reiterated several times.

Based on participants' input, a recommendation is made for instructors to incorporate a variety of educational strategies in their teaching, as to accommodate the different learning styles of students. For example, instructors could utilize videos, assigned reading, discussions, in-class projects, essays, and lectures as part of the curriculum. Instructional strategies that consider the challenges of individuals with autism can assist those with HFA adapt to the classroom environment, fulfill class expectations, and work collaboratively with others; these skills may prove beneficial to their future employment.

**Staff recommendations.** Several participants indicated a desire for college staff to know more about autism in order to understand their unique challenges and needs. Although most participants expressed satisfaction with disability services staff, some participants indicated the need for other support staff to know more about their disorder as to honor their needs. For example, a need for housing staff to understand autism might help these employees understand why certain requests made by students with HFA are important (e.g., not being placed in a high floor or close to a high-traffic/noisy area). A recommendation is made for college staff who work with students in various capacities to receive training about the characteristics of autism and challenges students with this disorder may face in college. Staff should also receive instruction about ways in which they can assist students with ASD in their respective areas (for example housing, academic advising, etc.).

**Administrator recommendations.** Some participants indicated a desire for college administrators to also know more about autism. This knowledge would assist them as they

planned buildings and classrooms, for instance, by considering the need for more personal space. Additionally, one participant indicated that administrators should include disabilities as a component of campus diversity, not focusing solely on race and ethnic diversity. Lastly, one participant also expressed a need for administrators to be sensitive to students with disabilities during disability-focused events. This participant wanted to emphasize that students with autism have similar capabilities as neurotypical students, however they also face some unique challenges. A recommendation is made for college administrators to receive training about the needs of college students with autism, given that the number of individuals with HFA entering higher education is rising (Gardiner & Iarocci, 2014). Additionally, a recommendation is made for higher education institutions to take a strong stance against bullying and hazing behaviors that may be directed at students with disabilities, including those with autism.

**Student body recommendations.** Many participants indicated a desire to meet more students in college. Social and communication challenges, however, interfered with participants' comfort level in developing friendships and initiating social interactions. A recommendation is made for higher education institutions to investigate avenues to assist students with HFA with social and communication challenges. One study participant stated that fellow students could be instrumental in assisting students with HFA learn social cues. Assigning peer mentors is one approach that has been utilized in some colleges to assist students with HFA with social communication difficulties (Hamilton et al., 2016). Additional research is needed to ascertain the value of peer mentors for individuals with HFA in college. When carefully planned, implemented, and evaluated, peer mentoring may be a valuable resource for students with HFA as they navigate the complexity of college life, particularly its social aspects (Hamilton et al., 2016).



Most participants indicated a desire for fellow college students to know more about autism. Through increased knowledge of ASD by college students, participants desired a higher level of understanding of their behavior. For example, fellow students could appreciate the social communication challenges faced by people with autism and be cognizant that a lack of outward emotional expression is consistent with the disorder, yet not an indicator of a lack of feelings. A recommendation is made for college students to receive training about autism and the challenges that students with this disorder face in higher education. This training could be incorporated to instruction about diversity and inclusion that colleges may already be conducting.

**Family support.** Most participants were in frequent contact with family members; parents and some siblings served as a strong support system. A recommendation is made for higher education faculty, staff, and administrators to consider that students with autism may need family support to a greater degree than many neurotypical students. Although student confidentiality laws (Family Educational Rights and Privacy Act) preclude college personnel from contacting family without a student's consent, staff should inquire about the students' support system and their relationship with their family during interactions with the student. This knowledge would be instrumental, for example, if a student with HFA experiences a crisis, at which time the suggestion can be made for the student to contact family, or permission to contact family can be acquired.

**Mental health.** Many participants reported experiencing mental health disorders, with depression and anxiety being mentioned most often. College personnel should account for the higher prevalence of mental health disorders of students with autism. With increasing numbers of youth with autism entering higher education (Gardiner & Iarocci, 2014), colleges may need

additional mental health providers to meet the needs of these students. In addition, a recommendation is made for mental health providers working in higher education to receive guidance about working with students with autism, if not part of their professional training.

Appendix D contains a summary list of recommendations for practitioners based on findings from this study. Below are research recommendations for academic professionals striving to elucidate strategies to assist students with HFA succeed in higher education.

### **Recommendations for Academics**

Additional research is needed in various higher education areas to enhance the experiences and improve the outcomes for students with HFA in higher education. These areas include investigating ways to increase the level of understanding about autism within the higher education community (college staff, professors, students, and administrators), exploring the benefit of specific support systems for students with HFA in college, and researching the outcomes of college graduates with HFA to ascertain gaps in current higher education programming for students with this disorder.

This phenomenological study showed that participants desire people in the college community to better understand their disorder. Some research has been conducted to explore the level of understanding about autism among higher education staff, faculty, and students. The few studies that have investigated knowledge and understanding of autism in higher education have found concerning results. Gillespie-Lynch et al. (2015) found that many college students who participated in their study had negative ideas about autism, males more than females, and that the level of stigma lessened with training about the disorder. Nevill and White (2011) found that college students having a first-degree relative with autism were more open to befriending a

person with autism, compared to students with no prior experience with a person with the disorder; they were reluctant to do so.

Tipton and Blacher (2014) surveyed students, faculty, and staff at a college about their level of knowledge about autism and found limited knowledge and understanding about autism among the majority of respondents. Zeedyk, Blourian, and Blacher (2018) investigated the level of knowledge about autism among a group of college faculty in California. They found that, even though several faculty members were supportive of students with autism in their classes, several faculty expressed not knowing enough about the disorder or how to help these students succeed in class. Given research findings about lack of knowledge and understanding about autism among many individuals in the college community, it seems important to improve efforts to increase awareness of the disorder. How these efforts should be conducted, however, is an area that needs further investigation. In addition, finding ways to incentivize college communities to participate in programming to increase their understanding of autism is another area of need.

Another area warranting further investigation is the types of support services students with HFA may benefit from when enrolled in higher education. For example, difficulty with communication and socialization are prevalent in autism; students with HFA who struggle with these challenges typically receive little support to ameliorate their struggles during college (Gelbar, Shefcyk, & Reichow, 2015). Although some colleges offer programming specific for students with autism HFA (Gelbar, Smith, & Reichow, 2014), evaluation of their efficacy is lacking. Therefore, it would be worthwhile to explore effective ways of supporting students with autism to enhance their communication and socialization skills to a level that benefits them as future employees.

An additional area in need of investigation is the impact of difficulties with executive function skills (Gobbo & Shmulsky, 2014), learning difficulties (Baldwin & Costley, 2016), and the high level of anxiety often seen in autism (Lever & Geurts, 2016) on college success for students with HFA. Research is warranted on strategies that can be implemented to minimize these challenges among college students with HFA. Without sufficient support systems in place, many students with HFA enrolled in higher education may not succeed in attaining their desired degree. Those students who are able to graduate may encounter many challenges once they seek employment, since their performance may be affected by their ability to learn job-specific procedures, organize their work, and manage stressful situations.

Research pertaining the outcomes of college graduates with HFA is also limited. Among those people with HFA who earn their college degree, it would be helpful to ascertain the extent to which they continue to have difficulties that affect their ability to acquire and maintain a job, as well as their ability to successfully live independently. Such information would be instrumental to informing higher education of areas that need to be strengthened.

An additional area in need of investigation is the effect that initial underemployment might have on future career goals. Three participants in this phenomenological study were planning to obtain a job below their skill level upon graduation, as to adapt to work demands before pursuing employment that matched their college career goals. Research about the effects of underemployment on future job prospects among the general population has indicated negative consequences (Pedula, 2016). However, given the challenges faced by people with HFA, initiating their employment through a job that is less demanding could produce different results; this area warrants further investigation.

In summary, through reviewing the literature and reflecting on the lived experiences of the participants in this phenomenological study, the investigator was able to identify many areas in need of further research. Some participants verbalized their pride and satisfaction from being enrolled in college, in addition to the hope that a college education would enable them to succeed as adults. However, their many challenges in college were evident. Additional understanding about autism by the college community is needed, though it remains unknown how to increase knowledge to the many constituents in higher education. Identifying empirically supported strategies to assist students with autism in managing their unique challenges is also needed. Academicians with an interest in autism can find many areas in need of investigation.

### **Concluding Comments**

As the investigator having the privilege to meet these individuals and spend time learning about their college experiences, I feel both honored and humbled. When I reflect on the themes that arose through these interviews, my heart feels heavy. This is not because I feel pity for these courageous young students with HFA, but because a significant amount of work is yet to be done to support college students with this disorder. As college and university professionals we must work together to equip students with HFA to grow both academically and socially. We must invest time and effort to help these individuals face future employment and life opportunities with suitable skills.

Deci and Ryan (2000) stated that psychological health requires meeting the three basic human needs of competence, relatedness, and autonomy; “one or two are not enough” (p. 229). Higher education professionals have a unique opportunity to assist students with HFA. We can help them grow in their competence through academic instruction, and find greater comfort in relating to others by helping them develop social and communication skills. In so doing, we can

move students with high functioning autism toward a brighter future in which they can achieve their goals with autonomy and confidence.

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## Appendix A

### Interview Questions:

- Tell me about your experience in college so far. (Introduction, easy question)
  - What do you like most?
  - What do you like least?
- Tell me about your classes, what classes are you taking? (Questions about competence)
  - How are your classes going so far?
  - How did you decide to register for these classes?
  - Did you get the advice and support you needed to register for your classes?
- Tell me about how you keep yourself organized for your classes and schoolwork.
  - How well is this system working for you?
- If you needed help, how comfortable are you with getting help with your courses?
  - Who are you comfortable asking for help, if you needed it?
    - For instance, are you comfortable asking an instructor for help?
    - Are you comfortable asking a teaching assistant for help?
    - Are you comfortable asking fellow students for help?
- Tell me about the people you have met in school. (Questions about relatedness)
  - What has been your experience in talking to faculty or instructors?
  - What has been your experience in talking to support staff (these could be people that work for the university, other than instructors)?
  - What has been your experience with meeting other students in your classes?
  - What has been your experience with making new friends in school?
- Tell me about some of the differences you have felt between being in high school and being

in college. (Questions about autonomy)

- If you are living in the dorm, tell me how easy or difficult that experience has been.
- What new responsibilities do you now have?
- Are there tasks or responsibilities that others help with, for example instructors, support staff, friends, roommates, family?
  - Who are they and what do they help you with?
- Tell me about the future, what do you envision doing after you finish college?
  - Do you envision living alone or with others?
- What would you like others to know about people with autism? (Ending questions)
  - Instructors/ college staff
  - Fellow students
  - School administrators

## Appendix B

The following table shows the alignment between the research questions, the study objectives (based on the Theory of Self-Determination) and the interview questions.

### Alignment of Interview Questions

Research Questions	Objectives based on Theory of Self Determination Themes	Interview Questions
Introduction	Easy Question	<ul style="list-style-type: none"> <li>• Tell me about your experience in college so far.               <ul style="list-style-type: none"> <li>○ What do you like most?</li> <li>○ What do you like least?</li> </ul> </li> </ul>
<p>Q.1. How do students with high-functioning autism describe their higher education experience?</p> <p>Q.2. How do students with high-functioning autism interact with the higher education system?</p>	<p>O.1. To describe areas of the students' lived experience in higher education that support or hinder their sense of competence.</p>	<ul style="list-style-type: none"> <li>• Tell me about your classes, what classes are you taking?               <ul style="list-style-type: none"> <li>○ How are your classes going so far?</li> <li>○ How did you decide to register for these classes?</li> <li>○ Did you get the advice and support you needed to register for your classes?</li> </ul> </li> <li>• Tell me about how you keep yourself organized for your classes and schoolwork.               <ul style="list-style-type: none"> <li>○ How well is this system working for you?</li> </ul> </li> <li>• If you needed help, how comfortable are you with getting help with your courses?               <ul style="list-style-type: none"> <li>○ Who are you comfortable asking for help, if you needed it?                   <ul style="list-style-type: none"> <li>▪ For instance, are you comfortable asking an instructor for help?</li> <li>▪ Are you comfortable asking a teaching assistant for help?</li> <li>▪ Are you comfortable asking fellow students for help?</li> </ul> </li> </ul> </li> </ul>

	<p>O.2. To describe aspects of the students' lived experience in higher education that facilitate or hinder their ability to develop socially.</p>	<ul style="list-style-type: none"> <li>• Tell me about the people you have met in school. <ul style="list-style-type: none"> <li>○ What has been your experience in talking to faculty or instructors?</li> <li>○ What has been your experience in talking to support staff (these could be people that work for the university, other than instructors)?</li> <li>○ What has been your experience with meeting other students in your classes?</li> <li>○ What has been your experience with making new friends in school?</li> </ul> </li> </ul>
	<p>O.3. To describe the students' perception of their level of autonomy while enrolled in an institution of higher education.</p>	<ul style="list-style-type: none"> <li>• Tell me about some of the differences you have felt between being in high school and being in college. <ul style="list-style-type: none"> <li>○ If you are living in the dorm, tell me how easy or difficult that experience has been.</li> <li>○ What new responsibilities do you now have?</li> <li>○ Are there tasks or responsibilities that others help with, for example instructors, support staff, friends, roommates, family? <ul style="list-style-type: none"> <li>▪ Who are they and what do they help you with?</li> </ul> </li> </ul> </li> <li>• Tell me about the future, what do you envision doing after you finish college? <ul style="list-style-type: none"> <li>○ Do you envision living alone or with others?</li> </ul> </li> </ul>
<p>Closing</p>		<ul style="list-style-type: none"> <li>• What would you like others to know about people with autism? (Ending Question) <ul style="list-style-type: none"> <li>○ Instructors/ college staff</li> <li>○ Fellow students</li> <li>○ School Administrators</li> </ul> </li> </ul>

## Appendix C

### Consent Form

#### Informed Consent for Research

You are invited to participate in a study of the lived experiences of people with high functioning autism who are enrolled in a four-year college or university. I hope to learn what your experience has been in college as a person with high functioning autism. You were selected as a possible participant in this study because you are enrolled in a four-year college or university and have high functioning autism (Autism with an average IQ and/or Asperger's syndrome).

If you decide to participate, I, Aida Miles, will ask you questions about your experiences in college. There are no right or wrong answers to any of the questions. The interview will last approximately one hour and will be audio-recorded. Prior to starting the audio-recording, you will be asked to come up with a pseudonym (alternate name) that will be used through the interview. This is to assure that your name is not mentioned on the recording and maintain confidentiality.

After the interview, the audio recording will be transcribed and you will be given a copy of the transcription. You may add, delete, or edit any portion of the transcription. Your name, contact information and transcription will be kept in a password-protected, secure, and encrypted drive in the investigator's computer. The audio-recording will be sent to a transcriptionist in encrypted form via a secure server. Audio recordings will not contain any identifiable information and only the participant's pseudonym will be used. At the conclusion of the study, all audio-recordings will be permanently deleted.



Any information obtained in connection with this study, which can be identified with you, will remain confidential and will be disclosed only with your permission. In any written reports or publications, pseudonyms will be used instead of names.

There are no physical risks for participating in the study. There may be psychological/emotional risks related to experiencing anxiety about meeting with the investigator, and/or about answering questions related to your lived experience. You can choose to not answer any questions and you can also end the interview at any time without any negative consequences. Your decision whether to participate will not affect your future relationship with your college or university in any way. Participants who choose to end the interview and no longer be a part of the study will be sent (electronically) a \$15 Amazon gift card for their interest.

There are no tangible personal benefits for participating. However, the intent of this study is to expand knowledge on the lived experiences of students with high functioning autism when enrolled in institutions of higher education. Your experiences can assist adolescents and young adults with high functioning autism who are contemplating enrolling in college. As a token of appreciation, you will be sent (electronically) a \$40 Amazon gift card after the conclusion of the in-person interview and transcription review.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the research and/or research participant's rights or wish to report a research-related injury, please call Aida Miles at 651-829-0660 or Jessica Daniels, Ph.D., at 651-635-8972. You will be offered a copy of this form to keep.

You are deciding whether to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without prejudice after signing this form should you choose to discontinue participation in this study.

_____	_____
Participant Signature	Date
_____	_____
Investigator Signature	Date

## Appendix D

### Recommendations for Practitioners

- Transition planning personnel should inform families of the difference in services provided for students with disabilities between secondary and postsecondary institutions. Families should be informed that many services offered in public schools are not available in college; if needed, families may need to incur additional costs to provide additional services for their son/daughter. Students should be encouraged to register with disability services offices at their college (disclose their disability) to begin receiving needed accommodations upon college enrollment.
- Secondary and postsecondary career counselors should guide students with high functioning autism (HFA) in selecting college majors based on their individual strengths and interests.
- Higher education staff should consider that many students with HFA need guidance to plan and organize their college schedules. Difficulties may include breaking down projects into steps, prioritizing competing priorities, utilizing planners effectively, and finding tools to remember deadlines and appointments (for example, using phone alarms).
- Higher education institutions should provide training to educators about the characteristics of autism and the unique needs of people with autism. Some relevant topics include difficulty people with autism may have becoming a part of a group, understanding information that is not clear or repeated, and difficulty asking questions.
- Higher education instructors should utilize a variety of teaching strategies to meet the various learning needs of students with HFA. A variety of teaching strategies may

include utilizing lectures, visual aids, videos, assigned readings, discussions, in-class projects, and essays.

- Higher education residential staff should receive training about characteristics of autism that can impact their comfort in residential housing. Some topics include the need for personal space, difficulty interacting socially, and the need for routines.
- Higher education administrators should receive training about autism and the characteristics of this disorder that affect the college success of students with HFA.
- Higher education administrators should consider students with disabilities as adding to the diversity of the school's environment.
- Higher education staff and administrators should take a strong stance against bullying and hazing of students in general, including students with disabilities.
- Higher education institutions should investigate avenues to assist students with HFA with social and communication challenges. Assistance may include peer mentors.
- Students attending higher education institutions should receive training about the challenges students with autism face; this instruction could be part of diversity and inclusion training already taking place at schools.
- Higher education faculty, staff, and administrators should be aware that students with HFA may need family support to a greater degree than many neurotypical students would. College personnel should inquire about the student's support system and relationship with family during initial interactions with the student with autism.
- Mental health professionals working with students in higher education should receive training about working with students with autism, including prevalent mental health disorders among people with autism.