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# Exploring the Social Experiences of College Students Who Have Autism Spectrum Disorders: Examining Neurodiversity on Campus

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**EXPLORING THE SOCIAL EXPERIENCES OF COLLEGE STUDENTS**

**WHO HAVE AUTISM SPECTRUM DISORDERS:**

**EXAMINING NEURODIVERSITY ON CAMPUS**

by

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Old Dominion University in Partial Fulfillment of the  
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## **ABSTRACT**

### **EXPLORING THE SOCIAL EXPERIENCES OF COLLEGE STUDENTS WHO HAVE AUTISM SPECTRUM DISORDERS**

Monique N. Colclough  
Old Dominion University, 2016  
Director: Dr. Chris R. Glass

Research and discussion on the prevalence of autism spectrum disorders in education is longstanding, albeit almost exclusive to secondary students. Within less than ten years the number of secondary students who were receiving special education services for autism doubled, two percent of which later self-identified at 2yr and 4yr institutions upon enrollment. This phenomenological study explores the experiences of college students who have autism spectrum disorders, focusing on the social experiences that impact college persistence and retention. The following research questions were guide to this study: what are the social experiences of college students who have autism? What role(s) do various social experiences play in the persistence and retention of college students who have autism? Future research recommendations and implications for the results of this study include use among student affairs practitioners and disability services advocates to examine and challenge existing campus culture related to student engagement and involvement.

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This dissertation is dedicated to “Charles” for evoking such a passionate response 5 years ago that I found THE purpose for my doctoral work and contributions to the academy. I am equally indebted to each of the participants who were candid in our conversations about their experiences. Thank you for making this research possible.

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But God. This journey would not be possible without the tremendous journey of faith and prayer that I have experienced. Faith has carried me through late nights, early mornings, long days, sickness, doubt, adversity, discouragement, encouragement, affirmation, and victory....it winds through like a stream in barren places and ravages through lush spots all at the same time with expert calculation. I am often speechless and overwhelmed by the gift of God's grace, mercy, and protection throughout this journey.

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## TABLE OF CONTENTS

	Page
LIST OF Tables.....	8
Chapter	
<b>1. Introduction of the Problem.....</b>	<b>11</b>
1.1 Problem Statement.....	12
1.2 Purpose of the Study.....	13
1.3 Research Questions.....	13
1.4 Definition of Key Terms .....	14
1.5 Significance of the Study.....	15
1.6 Shifts in Practice .....	16
1.7 Overview of Methodology .....	18
1.8 Delimitations.....	20
1.9 Assumptions.....	20
1.10 Summary .....	20
<b>2. Literature Review .....</b>	<b>22</b>
2.1 Introduction .....	22
2.2 Student Development Theory.....	22
2.3 Existing Disabilities Research.....	24
2.4 Existing Higher Education Autism Research.....	26
2.5 Existing Autism Research.....	28
2.6 Summary.....	31
<b>3. Methods.....</b>	<b>33</b>
3.1 Previous Research .....	33
3.2 Research Design .....	33
3.3 Site Population .....	34
3.4 Participant Population.....	35
3.5 Sampling Procedures.....	36
3.6 Researcher .....	38
3.7 Instrumentation.....	38
3.8 Data Collection Procedures .....	39
3.9 Data Analysis.....	40
3.10 Credibility & Trustworthiness.....	42
3.11 Limitations .....	43
3.12 Summary.....	44
<b>4. Findings.....</b>	<b>45</b>
4.1 Methodology .....	46
4.2 Sample.....	46

4.3 Participant Population.....	47
4.4 Criterion for Selection.....	48
4.5 Participants.....	49
4.6 Theme #1.....	52
4.7 Theme #2.....	54
4.8 Theme #3.....	55
4.9 Theme #4.....	57
4.10 Theme #5.....	59
4.11 Theme #6.....	61
4.12 Theme #7.....	62
4.13 Mary.....	64
4.14 John.....	67
4.15 Susan.....	69
4.16 Gary.....	72
4.17 Norris.....	74
4.18 Don.....	77
4.19 Summary.....	80
<b>5. Interpretation and Recommendations.....</b>	<b>82</b>
5.1 Summary of Results.....	82
5.2 Discussion of Findings.....	85
5.3 Summary Statement.....	90
5.4 Implications for Further Research.....	90
5.5 Implications for Practice & Recommendations.....	93
5.6 Limitations.....	95
5.7 Self Reflection.....	96
5.8 My Role As Researcher.....	98
5.9 Summary & Conclusion.....	100
<b>REFERENCES.....</b>	<b>104</b>
<b>APPENDICES</b>	
A. Educational Accessibility Participants Call.....	110
B. University Announcements.....	111
C. Email to Pilot Participants.....	112
D. STEM Participants Call.....	113
E. Qualtrics Snapshot.....	114
F. Contact Summary Sheet.....	115
G. Participant Demographic Questionnaire.....	116
H. Interview Protocol & Questions.....	117
I. Informed Consent.....	129
J. A Priori Codes.....	122
K. VITA.....	124



**LIST OF TABLES**

Table	Page
1. Research Participants	63

## **Chapter One: Introduction of the Problem**

Research and discussion on the prevalence of autism spectrum disorders in education is longstanding, albeit almost exclusive to secondary students (Connor, 2011; Moores-Abdool, 2010; Newschaffer, Falb, & Gurney, 2005). Importantly, two-year and four-year institutions each report 2% of the surveyed student body self-identify with autism (NCES, 2011). Although this statistic presents a broad picture of college students who have autism at two-year and four-year institutions, as identified in Zager et al. (2012), statistics about the number of college students who have autism and the experiences of these college students is yet elusive. Furthermore, there is a gap in the research literature that does not capture the first person experiences of college students who have autism, limiting the basis by which colleges and universities have to create retention practices for this unique community. For the purpose of this study college students who self-identity with autism and college students who have been diagnosed with autism will be identified as a college students who have autism (CSA); likewise students will refer exclusively to college students.

Almost 200,000 secondary students aged 6-21 in 2007 were identified as receiving special education services for autism under the Individuals with Disabilities Education Act (IDEA) (Newman, 2007). Less than ten years later (2013) the National Center for Education Statistics (NCES) identified that almost 450,000 secondary students or 7% of the 6.4 million secondary students who were receiving special education services were students who have autism. This two-fold increase is critical to note as it provides background for the 11% of college undergraduates in 2011-2012 who self reported a disability (NCES, 2015).

The Centers for Disease Control (n.d.) define autism spectrum disorders (ASD) as a body of developmental disabilities that can impact a person's speech, behavior, and ability to make social connections with others. Autism spectrum disorders includes Asperger's Syndrome, autistic disorder, and pervasive development disorder, not otherwise specified (PDD-NOS). Identified as impairments in both intellectual processing and adaptation, intellectual disabilities (Schalock & Luckasson, 2004) are often identified as a comorbid diagnosis with autism (Matson, Wilkins, & Ancona, 2008; Sappok et al., 2013). The relationship between autism and intellectual disabilities (ID) is often misunderstood as intellectual disabilities, like autism, impacts functioning and reasoning in as early as the childhood years, like autism, and is influenced by the specific scenario(s) and environment a person experiences (AAIDD, n.d.). Unlike the terms slow learner or learning impaired, intellectual disabilities are identified after clinical evaluation by a medical professional (AHEAD, n.d.).

The relationship between autism and ID is important to note, also as Matson and Shoemaker (2009) report that up to 70% of autism diagnosis coexist with intellectual disability. The importance of recognizing the existence of comorbid diagnoses, specifically autism spectrum disorders and intellectual disability is rooted in guiding persons with ASD and ID to adaptive behaviors. Understanding the foundation of adaptive behaviors is important to understanding the experiences of college students who identify with autism, because in many instances the adaptive behavior model closely parallels the disability accommodations approach that college students likely faced during their K-12 education tenure (Taylor, 1997).

In addition to research and discussions that focus on the elementary and secondary school experience, awareness campaigns by Autism Speaks, one of the most visible advocacy organizations in the United States, focuses on the diagnosis and experiences of persons under 18 years of age (Connor, 2013). The Autistic Self Advocacy Network (ASAN) and the Autism Society appear to provide a counter spotlight, drawing attention to issues across the lifespan of persons who have autism, including college students.

Specific to higher education, Henderson (2001) reported that approximately 6% of 66,000 first time enrolled, full time first-year students self-reported a disability at four-year institutions in the fall of 2001. The self-reported disabilities in Henderson's work include learning disabilities, visual and hearing impairments, speech and other health related impairments. Eight years later, during the 2008-2009 academic year there were over 700,000 students who self reported a disability (NCES, 2011). Over 70% of two-year and four-year colleges and universities report enrolling students who have autism, with over half of the same college and universities also enrolling students with cognitive difficulties or intellectual disabilities (NCES, 2011).

Actionable information on how to support college students who have autism that is driven by personal narratives from college students who have autism is missing from post-secondary education literature. As scholars we know that this gap in literature includes how college students who have autism navigate the social idiosyncrasies of college life, the persistence and retention of college students with autism, and student readiness for career and workforce opportunities, which influences earning power and

reliance on state or federal support (Promoting College Access and Success for Students with Disabilities, 2014).

Existing research explores the learning experience and persistence factors for college students who have autism (Gobbo & Schmulsky, 2012; Gobbo & Schmulsky, 2013). Intentional techniques can be used in class to be inclusive of the different cognitive abilities and learning styles present, as well as designing varied tests or assignments that give diverse learners opportunity to present their comprehension of the course's material (McKeon, Alpern, & Zager, 2013). Conducting a survey of college/university faculty, McKeon et al. (2013) found that 50% of the 69 faculty participants reported using pedagogy that valued the diversity of their students' learning styles, inclusive of lecture, group assignments, PowerPoint presentations, and paired discussions. Over 80% of the responding faculty provided additional student conferences to meet with students individually outside of the scheduled class. Although valuable research that speaks to the multi-dimensional efforts for academic success for students who have autism, there are limitations. McKeon et al.'s data may not be transferable to other higher education settings because the study was conducted at a private teaching intensive university where mentorship was encouraged; the factors at the study site are not universal to other private colleges/universities, or public colleges/universities. Most importantly the social experiences of college students who have autism was not explored.

### **Problem Statement**

The academic performance and experiences of college students with disabilities, particularly specific learning disabilities (Henderson, 2001; e.g., Hughes & Smith, 1990), is thoroughly documented, yet there is a gap in the existing literature related to the social

experiences of college students who have been diagnosed with autism. Gobbo and Shmulsky (2013) cautioned against assuming that students who have autism are homogenous, instead recognizing that the abilities and needs are diverse. I intend to contribute to the scholarship gap by providing first person narratives from college students who have autism related to their social experiences, and what, if any, impact their experiences have on college persistence and retention.

Understanding these social experiences could spotlight transition planning and positively impact retention, providing persistence strategies for higher education's response to the emerging body of college students who have autism (Kelley & Joseph, 2012).

### **Purpose of the Study**

The purpose of this phenomenological study (Miller & Salkind, 2002) is to explore the social experiences of collegiate life in the context of college students who have autism, focusing on the social experiences that encourage persistence in college.

The transition and experience of college students who have autism is often influenced by support services or structures at universities (Hammond, 2015; Hughes, 2009; Pillay & Bhat, 2012). Gobbo and Shmulsky (2013) cautioned against assuming college students who have autism are a homogenous group, therefore a qualitative study is best positioned to account for this diversity by allowing the students to illustrate their experiences in their own voice.

### **Research Question(s)**

The following research questions will guide this study: what are the social experiences of college students who have autism? What role(s) do various social experiences play in the persistence and retention of college students who have autism?

### **Definition of Key Terms**

**Accommodations:** Adaptive supplements to the learning environment for secondary and post secondary students as mandated by the 2004 Individuals with Disabilities Education Act.

**ADA:** Federal civil rights law that prevents discrimination based on disability. The Americans with Disabilities Act provided the foundation for IDEA and 504.

**Adaptive Behavior:** Body of skills, practical and social, that are performed daily to promote inclusion. In the Construct for Adaptive Behavior (2009, p. 291) adaptive behavior is defined as “the collection of conceptual, social, and practical skills that have been learned and are performed by people in their everyday lives.”

**Asperger’s Syndrome:** Attributed to the work of Hans Asperger, Asperger’s Syndrome is often characterized as a higher functioning form of autism, noticeably without significant speech or cognitive delays in childhood.

**Autism Spectrum Disorders (ASD):** A body of developmental disabilities impacting speech, behavior, and ability to make social connections with others. ASD is inclusive of Asperger’s Syndrome, autistic disorder, and pervasive development disorder, not otherwise specified (PDD-NOS).

**CSA:** College student who has autism.

**Comorbid Diagnosis:** Dual or multiple diagnosis in addition to autism. As an example Intellectual Disability and autism would be a comorbid diagnosis.

**IDEA:** Individuals with Disabilities Education Act provides adaptive supplements to the learning environment for school-aged students through the age of 21, as mandated by the United States federal government.

**Intellectual Disability:** Identified after clinical evaluation by a medical professional, intellectual disabilities, or ID, are influenced by the specific scenario(s) and environment a person experiences, impacting functioning and reasoning abilities.

**Social Experiences:** Singular or repeated engagement with peers, classmates, and/or friends not related to academics, occurring on or off campus. Common collegiate social experiences include attending a college sporting event, participating in a service project, attending an event sponsored by student support services like student activities, participating in intramural athletics, etc. Social experiences are not limited to the student's home institution, and can occur at neighboring colleges/universities.

### **Significance of the Study**

Uncovering rich data from distinctly diverse college students who have autism will inform factors related to their college experience, course completion, and graduation (Wehman et al., 2014).

Understanding the social experiences and perceptions of interactions with peers, faculty, and administrators for college students who have autism is the first of many steps in strengthening transition plans developed in secondary education. Secondary transition plans likely do not include the insight of successful college students who have autism (Cullen, 2015). How then, can we, as educators, illustrate possibilities and support student dreams if we do not have a rich picture? As a scholar and practitioner with experience supporting college students who have autism I witnessed first-hand the



negative impact that some social interactions can have on the student, faculty, and peers. A body of educators better informed can equip college students with the support needed to meet their individual goals (Cullen, 2015) and offer student success programs that are more inclusive of diverse communication and social abilities. These efforts can directly impact college efforts for student persistence and retention.

Although the participant narratives in this study are unique to the college setting, learning the degree to which young adults navigate scenarios where social capital is at stake can also provide context for the work environment by influencing the type of outreach and programs created to prepare students for job interviews and employment (Wehman et al, 2014). Likewise narratives reflecting self-determination and communication are critical in understanding how college and university staff can better communicate with and meet the social needs of college students who have autism. Specifically, rich data from college students who benefit from better informed student success initiatives could be reflected in college/university policy recommendations, as well as peer reviewed publications. This study will also contribute to the existing literature as it may establish new research threads for college students who have autism, including: the role of self-advocacy and self-determination, factors contributing to student retention, the influence of peer mentors, and persistence to graduate school. Lastly, coded transcripts from the interviews will help create a report of student success recommendations to be presented to student affairs practitioners in key areas like new student orientation, housing and residence life, as well as academic advisors, disability support staff, and faculty.

### **Shifts in Practice**

Students with cognitive disabilities are completing high school at an increasing rate, many with the goal of attending college. Support in the secondary system should include preparing students for life after high school (Gardiner & Iarocci, 2014). IDEA affords students aged 3-21 equitable access and accommodation to public and private education. Upon disclosure of a disability, secondary students are automatically provided classroom and extra circular support, including but not limited to: universal design of the curriculum, physical access to the education site itself, and supportive technology. The secondary model of supporting students with disabilities is extensive and at no-cost to the student and family, instead school districts and states bear the costs associated with providing reasonable disability accommodations and support (Eckes & Ochoa, 2005). The team of educators responsible for coordinating and providing student accommodations is designed to be fluid, timely in communication, and capable in identifying resources within the school, as well as in the community. Secondary education accommodations are a student based, and school driven process (Eckes & Ochoa, 2005).

Accommodation services provided in higher education differ greatly from the secondary model. Specifically, the student-centered model in higher education, determined solely by self-identification, often presents a contextual shift for first-time college students and their parents, who are used to a school guided process. As a college student, receiving disability accommodations requires a level of awareness and self-identification (Eckes & Ochoa, 2005). The college student must initiate all action with their college or university's disability support staff, requiring the student to present current records of diagnosis and support recommendations. Additionally, unlike the

secondary experience, securing disability accommodations in college requires a student to be organized, timely, and an advocate for their own needs.

Logistical differences aside, college students with disabilities have to meet the definition of disabled based on a substantial limitation of a major life function, due to a learning disability, mental disorder, or physical impairment (Gordon & Keiser, 1998). Whereas a disability is defined in broader terms for students aged 3 to 21 years old, not requiring substantial limitation of a major life function but requiring support as a result of speech, visual and hearing impairments, learning disabilities, traumatic brain injury, cognitive disabilities, etc., (Schalock & Luckasson, 2004). Uncovering rich data from distinctly diverse college students who have autism will reveal the lived experiences of life as a college student with neurodiversity. This is important because data about this population could positively impact higher education persistence and retentions strategies, transition services coordinated in secondary education, college graduate rates and subsequently career planning and employment (Wehman et al., 2014; Wenzel & Rowley, 2010).

### **Overview of Methodology**

This phenomenological study will use semi-structured interviews to identify the social experiences of college students who have autism and the role(s) that they perceive these social experiences play in their persistence and retention. Informal social experiences like roommate relationships and campus involvement, as well as formal social experiences like working with classmates on group projects, and preparing for job interviews may impact the persistence and retention of college students who have autism (Pillay & Bhat, 2012; Wehman et al., 2014; Wenzel & Rowley, 2010).

Undergraduate students who self-identified with autism, as well as recent college graduates who completed degrees within the prior six months will also be included in the sample population. As to not exclude any student the inclusion criteria will simply be self-identification with autism. The sample site is a urban, research, intensive doctoral granting institution with extensive course(s) and degrees offered through distance learning. The sample site will be selected as a result of this diversity in course delivery for non-degree and degree seeking students, which is believed to be appealing to diverse learning needs (Remy & Seaman, 2014).

Simultaneous data collection and analysis will be used to take advantage of qualitative research's features, while intentionally identifying patterns and textural themes among the data (Miller & Salkind, 2002; Rubin & Rubin 2012). Specifically, the data collected will be analyzed using the 8-step process as identified by Hays and Singh (2012). I will reduce the data by identifying the topic, respective of my prior experiences as an education coach for a college student who has autism. I will identify keywords that can become a-priori codes, the research questions, and literature relevant to college students, disabilities, and autism. I will also assess access to potential participants, identifying ways to recruit participants, and create trustworthiness strategies. The audio recording from the semi-structured interviews will be transcribed, complimented by contact summary sheets, which will be used to record observations and experiences immediately after each interview. A bulleted summary of the transcribed interview will be presented to each participant within two weeks of the interview as a commitment to member checking, providing each participant an opportunity for clarification or amendment. A-priori codes will be used to analyze and code the transcribed audio data

line by line, identifying common themes, pertinent participant quotes, and unique language, creating patterns of loosely identified thick descriptions that will be used for comparative pattern analysis. A-priori coding will assist in identifying etic codes (Hays & Singh, 2012), the expansion and revision of the initial codebook, and creating narrative themes and textural data for the final codebook. The final codebook and a cross-case analysis will reflect the comprehensive data identified throughout the data analysis, becoming the foundation for the comprehensive narrative that reflects the diversity of student perspectives, experiences, and recommendations for supporting college students who have autism.

### **Delimitations**

There is one delimitation for the study: not seeking out college students who identify exclusively with high functioning or Asperger's Syndrome instead using autism spectrum disorders as an umbrella for ability labels. This is done to be inclusive of the autism community, without focus on a specific autism identity.

### **Assumptions**

One primary assumption will guide this work: college students who have autism will be reflective of their experiences and matriculation from secondary to post-secondary education. This assumption is important because it presumes that college students who have autism will consider participating in the study.

### **Summary**

This qualitative study will explore the social experiences of college students who have autism, contributing to the existing gap in literature that focuses on the accommodations and transition services available to college students who have autism.

Understanding more about the social experiences, persistence, and retention of college students who have autism will likely impact academic advising, student support services and transition programs that are designed to supplement the collegiate experience. In the next chapter I will outline the existing literature, making a case for the critical need for first person narratives, while establishing the methods for the phenomenological study in the third chapter.

## **Chapter Two: Literature Review**

### **Introduction**

Research about the prevalence of autism spectrum disorders in education focuses almost exclusively on secondary students (Moores-Abdool, 2010; Newschaffer, Falb, & Gurney, 2005). There is a gap in the research literature that does not capture the first person experiences of college students who have autism, limiting the basis for which colleges and universities have to create retention practices for this diverse community. This chapter will explore four elements of the literature: the role of student development theory in persistence and retention; disability studies research that is not inclusive of autism spectrum disorders; existing autism research relative to higher education, and existing autism research related to adolescence.

### **Student Development Theory**

Astin's work (1999) on involvement and student development theory created the framework for understanding the relationship among student identity, persistence, and student involvement; moving the needle in student development theory beyond anecdotal references towards intentional longitudinal study. Astin (1999) identified several key environmental components that can shape a student's college experience, and subsequently impact retention. The environmental factors include: on campus residency, engagement in university Greek life, faculty interaction, undergraduate research opportunities and faculty mentorship, participation in campus athletics, honors programs, and being involved in student leadership or government. A "unifying construct" (Astin, 1999, p. 527), student development theory provides the foundation for student success initiatives, challenging higher education administrators, student affairs professionals, and

faculty alike, to identify commonalities in a student's collegiate experience that foster persistence and retention.

Engstrom and Tinto (2008) expand on Astin's work (1999) by explicitly linking institutional accountability to student access, equity, and success:

To promote greater student success, institutions have to take seriously the notion that the failure of students to thrive in college lies not just in the students but also in the ways they construct the environments in which they ask students to learn (p. 50).

Ultimately, institutions are accountable for their environment (Engstrom & Tinto, 2008; Longtin, 2014). Although Astin generally wrote about all students, and Engstrom and Tinto (2008) wrote about low-income student persistence and retention, these researchers paved the way for similar arguments for the emerging and diverse body of college students who have autism. The environment that we ask college students who have autism to adapt into needs improvement. Institutions must acknowledge, welcome, and strategically support college students with diverse cognitive and social abilities, encouraging their involvement and subsequently supporting persistence and retention (Couzens et al., 2015; Engstrom & Tinto, 2008; Milem & Berger, 1997). In Engstrom and Tinto's work (2008) we learn that the inclusion of learning communities for low-income students helped foster social engagement with peers, safe spaces to engage, learn, and challenge each other without ridicule, and created a common platform for persistence and retention. In this fashion, learning communities could be a model for responding to the diverse student development needs of college students who have autism. As Engstrom and Tinto (2008) described, intentionally crafted learning communities create



an environment of contextual learning, an area that is often underdeveloped for persons who have autism (Robertson, 2010). Contextual learning environments allow college students who have autism to engage with peers, faculty, and university staff for integrated learning opportunities, guidance, affirmation, and mentorship (Robertson, 2010).

Engstrom and Tinto's (2008) call for extending institutional support beyond traditional disability accommodations preceded Longtin's (2014) and Couzens et al's (2015) call for student centered support that focuses on the logistical elements of time management and planning, in addition to the social needs of college students who have autism (Burkhardt, 2008). Longtin's work on designing institutional infrastructure within existing resources to meet the diverse and unique needs of college students who have autism, champions the ability to create the inclusion and access that Engstrom and Tinto promoted (2008). This recent shift to the inclusivity of college students who have autism is important to note in the history of student development theory, as literature about college students who have autism in this context is scarce (Tinto, 2006-2007). The student development literature that does exist focuses on autism as a deficit in ability, instead of considering autism as an element of diversity, uniquely existent in each student, and an asset to the institution itself (Ne'eman, 2009; Robertson, 2010).

### **Existing Disabilities Research**

The academic performance and experiences of college students with disabilities, particularly learning disabilities (Henderson, 2001; Hughes & Smith, 1990), is thoroughly documented, dating as far back to World War II (Elliott, 1995; Gordon & Keiser, 1998; Pelka, 2012). In Rawson's 1968 work, *Developmental Language Disability: Adult Accomplishments of Dyslexic Boys*, as cited by Hughes & Smith

(1990), and in *College Freshmen with Disabilities: A Biennial Statistical Profile* by Henderson (2001) college students with disabilities have been jockeying for access and equity in post secondary education since the establishment of the Galesburg campus at the University of Illinois Urbana-Champaign for student veterans returning from World War II (Tamura, 2008). The first university with wheelchair access points at curbs (Tamura, 2008), under the leadership of Dr. Tim Nugent, who founded the Division of Disability Resources and Educational Services (DRES) in 1948, Urbana-Champaign led the response to access and equity in higher education for students with physical disabilities.

In the 2000 national statistical profile, Henderson (2001) reported on the background, perceptions, and expectations of first-year students. In the student profile approximately six percent of the total number of first time enrolled, full time first-year students at four-year institutions in the fall of 2000, self-reported a disability. Henderson's work captures the student data in six unique categories: preparation for college, personal and family background, high school performance, self-perceptions, opinions, and educational and career expectations. The profile revealed growth in the types of disabilities that college students were self-identifying with, and unlike the previous years, first-year students in 2000 were overwhelmingly self-reporting learning disabilities. Compared with data from 1988 twice the number of first-year students specifically reported learning disabilities (Henderson, 2001). This marked change paved the way for another projected increase in how students self identify, that is, students with autism spectrum disorders who are enrolling in post-secondary studies (Kelley & Joseph, 2012).

In contrast to reports about the number of students self-reporting a disability, a longitudinal study exploring retention and academic success by Wessel, Jones, Markle, & Westfall (2009) offered that with or without disabilities, the mean number of years to complete an undergraduate degree is relatively the same for all students. Of greater significance was the student's prior academic achievement in high school, which reiterates Reis, Neu, & McGuire's (1997) work that explored the combination of giftedness and learning disabilities through a case study of twelve successful undergraduate and graduate students. Questioning prior notions that students with disabilities cannot be gifted or excel academically, Reis, Neu, & McGuire's (1997) work can be considered a foundation of support for college students with autism spectrum disorders who consider themselves higher functioning, i.e., self-identifying with Asperger's Syndrome.

### **Existing Higher Education Autism Research**

There are some elements of the existing literature about college students with disabilities that speaks to the academic experiences, needs, and success of college students with autism spectrum disorders. However, there is plenty of room for new literature to specifically provide qualitative perspective from students, faculty, and university administrators.

Through research that explores the learning experience and persistence factors for college students who have autism we learn that intentional techniques could be used in class to be inclusive of different cognitive abilities and learning styles. Designing varied tests or assignments that give diverse learners access to present their comprehension of the course's material (McKeon, Alpern, & Zager, 2013) can also be implemented.

Conducting a survey of college/university faculty, McKeon et al. (2013) found that 50% of the 69 faculty participants reported using pedagogy that valued the diversity of their student's learning styles. Additionally, over 80% of the responding faculty provided additional student conferences to meet with students individually outside of the scheduled class. Although this is valuable research that speaks to the multi-dimensional efforts for academic success for college students who have autism, McKeon et al.'s data may not be generalizable to other higher education settings because the study was conducted at a private teaching intensive university where student mentorship was encouraged. The factors at the study site are not universal to other private colleges/universities, or public colleges/universities.

Chiang, Cheung, Hickson, Xiang, & Tsai's (2012) exploratory study sought to identify the factors and predictors of high school students with autism spectrum disorders who persist to post-secondary education. One of the factors associated with success in post secondary education was the connection between IQ and academic achievement, specifically those with a higher IQ; much like the gifted students in Reis, Neu, & McGuire's work (1997). Chiang, Cheung, Hickson, Xiang, & Tsai (2012) captured the connection between IQ, academic achievement, and post-secondary success through the following independent variables: verbal skills, mental retardation, and high school academic performance. The study's findings (2012) show that for a student who has autism, above average high school academic performance is a predictor of enrolling in post secondary education, echoing Reis, Neu, & McGuire's (1997) findings. The Chiang et al., study is limited in that the predictors for the retention of college students who have autism were not examined.

Hart, Grigal & Weir (2010) further add to the body of existing literature by exploring postsecondary education options for individuals with a co-morbid diagnosis of ASD and intellectual disabilities (ID). The relationship between autism and intellectual disabilities is important to note, as they are often co-occurring diagnosis (Matson & Shoemaker, 2009). Particularly, Hart, Grigal & Weir (2010) assert that for college students with autism and ID, success in postsecondary education should not be measured primarily by grades or graduation rates, but should also include growth in self-advocacy and self-determination, independence, and social experiences that enrich personal growth. Instead of assuming that students with ASD will seek academic accommodations that reduce course content and expectation, Hart, Grigal, & Weir (2010) assert that students seek access to courses with appropriate disabilities accommodations that include an in-class education coach or a peer note taker.

### **Existing Autism Research**

Led by the Centers for Disease Control and Prevention (2014), research and literature about autism primarily includes detection and diagnosis, cognitive and social deficits, treatment, adaptive behaviors, and tracking for persons who have autism (Ditterline, Banner, Oakland, & Becton, 2008; Matson, Rivet, Fodstad, Dempsey, Boisjoli, 2009). The Autism and Developmental Disabilities Monitoring Network (ADDM) investigates and tracks the prevalence of autism in children throughout the United States. The most recent Community Report on Autism (2014) records the existence of adults who have autism by briefly mentioning vocational rehabilitation, and the lack of employment data for adults who have autism on the forty-fourth page of the forty-nine-page report. The apparent lack of attention to adults who have autism is even

more apparent in the Executive Summary of the Interventions for Adolescents and Young Adults with Autism Spectrum Disorders (Lounds, et al., 2012) report. Focusing almost exclusively on the review of studies on medical and behavioral interventions for 13-30 year olds with autism, the 2012 report did not take into consideration the diversity within autism diagnosis, leaving out adults who persist to higher education.

Due in part to a student's decision to self-identify in college, and the likelihood that diagnosis can occur later in life (Colclough, 2015; White, Ollendick, & Bray, 2011), the number of college students who have autism is difficult to track (White, Ollendick, & Bray, 2011). However, college students who have autism is a community that requires our attention (Ne'eman, 2009; Robertson, 2010; White, Ollendick, & Bray, 2011).

In recent literature about adolescents who have autism, focus has shifted from emphasis on school based and community disability accommodations and the Individualized Education Plan (IEP), to the role and impact of autism on the adolescent's family. Specifically, attention has shifted to the quality of life and resilience of parents or primary caregivers of adolescents who have autism (Gardiner & Iarocci, 2012; Hock & Ahmedani, 2012). This is important to note because it recognizes the multi faceted identity of autism, specifically the roles that parenting, resilience, and familial identity play in the persistence of adolescents who have autism to adulthood. Despite this recent increase in extant literature exploring the multiplicity of autism, this is yet another example of the targeted focus on autism almost exclusively to adolescence, as if adolescents do not become adults and college students.

Targeted attention on adolescents who have autism is uniquely flawed in that it does not provide empirical data about the employment experiences of college students

and adults who have autism, as Shattuck et al.'s (2012) work does. Nor does the targeted attention on adolescents who have autism address the role that self-determination plays in self sufficiency and reduced dependence on familial or institutionalized care in adulthood (White, Ollendick, & Bray, 2011). Adults with disabilities face a lower employment rates than adults without disabilities, however access to equitable college support can positively impact employment rates (McMahon, Cihak, & Wright, 2015). Previous research (Colclough, 2015; Robertson, 2010) confirmed that college students who have autism are concerned about the job search, interviews, and gaining meaningful employment, but are not engaged with existing college services. Following Tinto's (Milem & Berger, 1997) warning about student persistence and retention, colleges and universities will soon be unable to choose inaction as a response to this emerging body of students (White, Ollendick, & Bray, 2011). College students who have autism contribute to the diversity on college campuses: cognitively, in idea, thought, and creativity, as well as in communication style and abilities. This diversity is valuable and critical (Robert, 2010).

Self-determination, as presented by Robertson (2010) and Schwitzer (2005), works to the benefit of young adults by encouraging autonomy and self-guided decision making. This maturation process is inclusive of college students who have autism. Yet, there is very little first person narrative data that captures their evolution and maturation in the college experience. This research study's phenomenological focus on the social experiences of college students who have autism, will attempt to address the void.

As evidenced by Kelley & Joseph (2012) and Prince-Hughes (2002) there is a gap in the literature that does not capture the first person experiences of college students who

have autism. McMahon, Cihak, and Wright (2015) attempt to fill this void with empirical research on college students with ID and autism who use navigational tools to independently travel to a job prospect, i.e., interview or local position advertisement in a urban city. Blending emerging navigation technology, cognitive, and social ability, McMahon, Cihak, and Wright's (2015) work relied heavily on quantitative analysis of the three navigation tools, a printed map, Google map, and an augmented reality navigation application. Direct input from the participants was captured in just two questions. The first question addressed which of the three navigation tools the student preferred, and the second question asked how the preferred tool could be enhanced. The inclusion of detailed participant narratives is missing, leaving McMahon, Cihak, and Wright (2015) with the missed opportunity to address the literature gap of first person experiences as a college student with autism in greater detail.

### **Summary**

Hughes and Smith (1990, p. 66) argued "a better understanding of the needs and characteristics of LD college students is necessary to make decisions about adoption of service delivery models (e.g., remediation of basic skills, accommodations, instruction in study skills/learning strategies)". The same can be said for college students who have autism. Literature presently explores predictors for post-secondary enrollment and the pedagogy practices of faculty; however, this presents a gap in the research about the college experiences from the perspective of college students who have autism. Gobbo & Shmulsky (2013) caution against assuming that college students with autism spectrum disorders are homogenous, instead, the abilities and needs of college students are as diverse as the type of diagnosis they may have. Abilities may include passion about a



course topic that manifests into expert knowledge, but may be negatively impacted by difficulty navigating the social experience of group projects, in class peer review assignments, or responding to Blackboard discussions in an asynchronous class. College students with autism spectrum disorders face a unique array of circumstances that both directly and indirectly impact their readiness and success in higher education. It is this study's intent to explore the social experiences of college students who have autism through semi-structured interviews to inform the academy.

### **Chapter Three: Methods**

This chapter provides an overview of the framework, research design and methodology that will be used in this study. Using a social constructivist framework this phenomenological study will record the diverse experiences, backgrounds, and identities of college students who self-identify with autism spectrum disorders, focusing on the social structures that support their persistence in college. An alternative to the deficit approach of research centered on the challenges or accommodations of disabled college students (Gobbo & Schmulsky, 2013; McKeon, Alpern & Zager, 2013), this person-first descriptive research study will explore the impact on persistence and retention that social experiences can have on college students who have autism (Chown & Beaven, 2012; Gobbo & Schmulsky, 2012).

#### **Previous Research**

In a prior research study where the researcher interviewed college students who have autism, all of the students discussed the need for support in non-academic parameters like job searching and interviewing, navigating on-campus housing accommodations, as well as integrating into the cultural experiences of campus life (Colclough, 2015). Data from the prior study was used to affirm selection of the qualitative design, as well as the semi-structured interview questions.

#### **Research Design**

The purpose of this phenomenological study is to explore the social experiences of college students who have autism, focusing on the social experiences that support their persistence and retention in college. Undergraduate and graduate students who have self-identified with autism spectrum disorders will be invited to participate in semi-structured

interviews lasting at least 45 minutes. Recent college graduates who completed degrees within the prior six months will also be included in the sample population. At the conclusion of the semi-structured interview the researcher will ask the participants to assist in identifying additional potential participants meeting the inclusion criteria. This process of snowball sampling will allow the researcher to intentionally identify other participants whom identify with autism (Hays & Wood, 2011). The following research questions will guide this study: what are the social experiences of college students who have autism? What role(s) do various social experiences play in the persistence and retention of college students who have autism?

To date there is little existing research that includes the first person experiences of CSA's (Prince-Hughes, 2002; White, Ollendick & Bray, 2011). Understanding first person experiences will draw attention to the importance of transition planning, and provide persistence strategies for higher education's response to the emerging population of CSA's (Hughes & Smith, 1990; Robertson & Ne'eman, 2008). This awareness and analysis of the increasingly diverse student population can positively impact student retention rates.

### **Site Population**

An urban research intensive, public doctoral granting institution and a leader in distance learning, the sample site, which is located in the Southeastern U.S. offers multiple ways to complete coursework via the main campus, several regional higher education centers and through distance learning options. The sample site will be selected as a result of this diversity in course delivery for non-degree and degree seeking students, that which is believed to be appealing to diverse learning needs (Remy & Seaman, 2014).

Additionally the sample site is where the prior research study occurred, which will allow for purposeful snowball recruitment for new participants (Colclough, 2015). During the 2014-2015 academic year the sample site's Office of Educational Accessibility served almost 1,000 registered undergraduate and graduate students. To date, during fall semester 2015 almost 800 undergraduate and graduate students are registered, of which 3.5% percent self-identified with autism and/or Asperger's Syndrome (E. Dickie, personal communication, October 2, 2015).

### **Participant Population**

The enrollment trends of college students who have autism is not clear (Kelley & Joseph, 2012), and as to not exclude students who were not continuously enrolled in courses each semester, inclusion criteria for this study's participants will include undergraduate students who were enrolled at least part-time within the prior two academic semesters. Undergraduate students who self-identified with autism, as well as recent college graduates that completed degrees within the prior six months will also be included in the sample population. Participants will not have to disclose a specific autism diagnosis, for example, Asperger's Syndrome. Several factors including current age, age of diagnosis, and prior history of misdiagnosis, can impact a student's autism identity. As to not exclude any student, the inclusion criteria will simply be self-identification with autism. Students who identify with other cognitive impairments, not autism spectrum disorders, will not be included in the sample population. The inclusion criteria for this study will allow for semi-structured interviews with a diverse body of participants, potentially reflective of the overall student population diversity in gender, race, and age as it is at the host site (ODU Factbook, 2015).

### **Sampling Procedures**

For college students, registration with an institution's disability services is voluntary. In addition to a call for participants circulated through the Office of Educational Accessibility (Appendix A), the participants will be purposefully selected through snowball sampling, which will allow students who self-identify with autism but are not registered with the Office of Educational Accessibility to be included in the sample population. Additionally, as to not exclude reaching students who are not registered with the disability services staff, a call for participants will be widely circulated through multiple postings in the daily University Announcements that all undergraduate and graduate student receive (Appendix B). Participants in the prior research study will be asked to help identify other CSA's, to whom an email invitation to participate will be sent (Appendix C). Participants will also be recruited through a email/memo sent to science, technology, engineering and mathematics (STEM) academic departments where CSA's tend to major, as discussed by Baron-Cohen, Wheelwright, Burtenshaw, & Hobson (2007). The email/memo to the academic departments will include the purpose of the study, a brief explanation of the literature related to STEM majors and autism, and a call for participants (Appendix D) that can be posted and circulated amongst faculty, academic advisors, and graduate teaching assistants. This purposeful sampling strategy will be used to help gather diverse accounts of student experiences, while being inclusive of students who were not registered with the Office of Educational Accessibility.

Each call for participants will instruct the interested student to complete a brief survey, "Conversations with Monique" (Appendix E), to confirm interest in the study.

The email address and name provided in the Qualtrics survey will be used to contact each participant to identify a date and time to meet for the in-person interview, as well as share the interview questions prior to the scheduled date and time. Participants in the previous research study requested and appreciated having the interview questions ahead of the interview date to prepare for the context of the conversation without the pressure of processing the question and answering it in the same moment. Interviews will be arranged based on the participants class and/or work schedule, and will be held on campus in various locations based on accessibility, privacy, and room reservation availability. Some interviews will be held in the university library study rooms, while others may occur in empty classrooms in the Education Building. Participants will receive a \$15 gift card for a local vendor at the completion of the interview. Participants with additional follow-up interviews will not receive additional gift cards.

The participant interviews will be conducted over the course of one semester, and will be complete when saturation is met. Influenced by the phenomenological research tradition and Creswell and Miller's (2000) recommendations for developing a sample size where rich, thick descriptive data can be obtained, saturation is described as "when no new information is forthcoming" (p. 63 Rubin & Rubin, 2012). The abilities and needs of CSA's are quite diverse (Gobbo & Schmulsky, 2013) therefore conducting semi-structured interviews until saturation is met will draw on the diversity of academic classifications, learning styles, cognitive and communication abilities, and reasons for attending college.

### **Researcher**

A doctoral student in the Higher Education program at Old Dominion University, the researcher served as a one-on-one education coach for a CSA through the ACE-IT in College program while completing doctoral coursework. The researcher also worked for ten years in student affairs at several public universities. These professional experiences led the researcher to believe that the experiences of CSA's are influenced by several readiness factors including: social connections with faculty and peers, disability accommodations in college, and familial support. Reflexive journaling will be used throughout the research study to capture thoughts and expectations about the student interviews, bracketing researcher subjectivity. To increase trustworthiness contact summary sheets (Appendix F) will also be used after each interview as a bracketing tool to record observations, salient points, and reflections (Hays & Wood, 2011).

### **Instrumentation**

The following research questions will guide this study: what are the social experiences of college students who have autism? What role(s) do various social experiences play in the persistence and retention of college students who have autism? Semi-structured interviews will be used for data collection. The participant demographic questionnaire (Appendix G) will capture gender, race, age, and college classification, for example first year student, sophomore, graduate students, etc. Data on post-secondary experiences, importantly, prior colleges or universities attended, and registration with the Office of Educational Accessibility will also be collected. Created to capture the research questions without directing the participants to focus on a singular element of their collegiate experience (Rubin & Rubin, 2012), there are twelve semi-structured interview

questions (Appendix H). The semi-structured interview questions are intended to be a conversation guide and frame for the experiences that the participants will be asked to recall. The interview questions include main questions and probes (Rubin & Rubin, 2012).

### **Data Collection Procedures**

This study will collect data through semi-structured interviews with CSA's until saturation is met (Hays & Singh, 2012; Rubin & Rubin, 2012). At least one in-depth semi-structured interview will be conducted with each participant. Subsequent interviews will be based on the need for additional and/or clarifying data, as a result of transcribing the audio data and creating the member-checking memo. After review and signature of the Informed Consent form (Appendix I), the interviews will be recorded digitally for subsequent transcription. In addition to the Informed Consent, each participant will complete the participant demographic questionnaire (Appendix G). For confidentiality purposes the participant's demographic questionnaire, informed consent form, and interview audio file will be all be labeled with a pseudonym, reflective of where the participant falls in the sample. For example, the first participant will be labeled P001, the second P002, the third P003, and so on.

The audio data will be collected through in-person interviews. Interviews will last approximately forty-five to sixty minutes. As needed, subsequent interviews will be scheduled to gather additional data and seek clarification, an element of member checking. Contact summary sheets will be used to record observations and experiences immediately after each interview, fulfilling the third step of the process (Hays & Singh, 2012). The fourth step, organizing and coding the data, will occur within one week of



each interview as the audio data will be transcribed and coupled with each participant's contact summary sheet, and demographic questionnaire. A summary of the transcribed interview will be presented to each participant within two weeks of the interview as a commitment to member checking. Audio files will be transcribed professionally for consistency and to ensure that member checking occurs within the two-week timeframe. The use of professional transcription services will also allow each participant an opportunity to clarify or amend their comments within a reasonable period of time, maximizing participation.

After each interview the participant will be presented with a summary of their interview transcript for member checking. Each summary will be less than 500 words and include key words or acronyms that the participant used, a review of the participant's talking points in bulleted format, and in some instances direct quotes that the researcher found salient. Each member-checking summary will be emailed to the participant within two weeks of the interview. Participants will be asked to return the memo with their comments or addendums one week after receiving it. Responses to the memo will be used as new additional data.

### **Data Analysis**

Simultaneous data collection and analysis will be used to identify patterns and textural themes within the transcribed interview file. The interview data that is collected will be analyzed using a multi-step process as identified by Hays and Singh (2012).

First, the data will be reduced by identifying the topic, respective of the researcher's prior experiences as an education coach for a college student with autism. The research question will be identified and relevant literature for the following terms will be

collected: college students, disabilities, and autism. From the relevant literature and conceptual framework keywords will be identified that evolve into a-priori codes (Hays & Singh, 2012). Established prior to data collection a-priori codes will guide the emergent codes that develop during data analysis. Collectively the codes will create the initial codebook that will be used during data analysis of the first interview. A-priori codes for this research study will include self-disclosure, job searching, career readiness, face-to-face communication, and communicating through social media. An example of the a-priori coding is included in the appendix (Appendix J).

QSR NVivo software will be used with the previously identified a-priori codes to analyze and code the transcribed audio data line by line, as the first step in data analysis. During this step emergent themes, pertinent participant quotes, and unique language will further be recognized. The data will be organized, tying together the previous five steps by creating patterns of narratives and rich, thick data. Codes and themes will be collapsed, building upon the initial codebook developed with the a-priori codes, step two of the data analysis process. Each interview transcription will be used to code subsequent interview transcriptions, thereby building iterations of the codebook. As an example, the a-priori codes will be used to code the audio transcription for P001, resulting in a revised codebook. The codebook for P001 will then be used to code the interview transcript for P002, and so forth.

As the participant interviews progress the researcher will consistently code and identify data patterns (Hays & Singh, 2012). This process will display the complexity of the transcribed interviews by identifying themes, creating multiple collapsed codebooks during data analysis. The initial a-priori codes will assist in the identification of etic

codes (Hays & Singh, 2012), which will allow for expansion and revision of the initial codebook, step three. Step four; the creation of the final codebook and cross-case analysis will reflect the comprehensive data that will be identified throughout the data analysis in steps one through three. An adaptation of comprehensive narratives that reflect the diversity of student perspectives, experiences, and recommendations for supporting college students who have autism, the final codebook will be used to identify recommendations for retention and student support services on campus.

### **Credibility & Trustworthiness**

Trustworthiness for this study will be achieved by implementing several strategies, including the triangulation of data sources achieved by reaching data saturation. To capture salient thoughts and experiences each participant interview will be paired with a contact summary sheet. Reflexive journaling will also bracket any researcher subjectivity. Both reflexive journaling and contact summary sheets will present the opportunity to reflect on the qualitative journey by capturing the progression of the research process, thereby building the audit trail and subjectivity. Prior to transcription, trustworthiness will be increased and researcher bias will be reduced (Hays & Wood, 2011), through bracketing, which will record reflections, assumptions and preconceived notions about the experiences of college students who have autism.

Confirmability will be demonstrated through a third strategy, member checking (Creswell & Miller, 2000). Two weeks after each interview an executive summary of keywords and themes less than 500 words, in bulleted format will be presented as a memo to each participant for their review and feedback. Each member-checking summary will be emailed to the participant and participants will be asked to return the

memo with their comments or addendums one week after receiving it. Responses to the memo will be used as new additional data. Although the qualitative interviews will occur over the course of a semester, the researcher will continue prolonged engagement with the CSA's until data saturation is met.

Reflexive journaling throughout the participant selection and interview process will increase trustworthiness by recording salient observations, thoughts, and reflections (Denzin & Giardina, 2015). Subjectivity, the researcher's internal understandings of the experiences of CSA's, and negative case analysis will be reflected in reflexive journaling. Commitment to the qualitative design will also present in the use of an external reviewer who has access to the audit trail to further evaluate trustworthiness and subjectivity.

### **Limitations**

The nature of self-reported experiences is based on the participants' recollection and alliance with the study's subject. In a convenience sampling with snowball recruitment it will be quite possible that college students who identify with autism in distinct negative or positive ways may be quick to participate. Students who self-select may be more comfortable talking about their college experience, eager to talk about a great experience or a particularly negative one (Hays & Singh, 2012), and may feel a personal duty to participate to inform the researcher and subsequently the university of the experiences and needs of CSA's. Likewise snowball recruitment may yield a population with very similar sentiments, although Gobbo and Shmulsky (2013) cautioned against assuming college students who have autism are a homogenous group as there will be a positive uniqueness in the descriptive experiences of CSA's. However, this uniqueness will also be a limitation, as it impacts the transferability of recommendations

derived from the data analysis. Despite this there will be value in exploring and recording the first person narratives of CSA's to fill the void in the existing literature about college students who have autism.

A second limitation recognizes that the diversity of participant' diagnosis or misdiagnosis may impact the collegiate education experience. Eighty percent of the participants in the previous research study (Colclough, 2015) reported misdiagnosis and subsequent medication treatment before being diagnosed as having autism. It is unclear the impact that misdiagnosis may have on matriculation and retention in post-secondary education.

### **Summary**

A phenomenological study with a social constructivist framework, this research study will explore the social experiences of collegiate life in the context of college students who have autism, focusing on the social experiences that support their persistence and retention in college. Data that is collected through the participant demographic questionnaire and semi-structured interviews will capture the social experiences of college students who have autism, and the role(s), if any, that these social experiences play in persistence and retention. The researcher will be instrumental in identifying meaning from the rich narratives provided by the participants.

## **Chapter Four: Findings**

This chapter provides an overview of the methodology, selection and recruitment process, participants, and summary of findings for this study. Using a social constructivist framework this phenomenological study records the diverse first person narratives of college students who self-identified with autism spectrum disorders. Social constructivism allowed multiple identities, as it relates to co-morbid diagnosis, gender, sexual orientation and age for each participant.

To explore the impact that social experiences can have on the persistence and retention of college students who have autism (Chown & Beaven, 2012; Gobbo & Schmulsky, 2012) participants were asked about their high school experiences, including what, if any, influence those experiences played in the transition to college. Likewise participants were asked about their college experiences with peers, classmates and faculty, including their engagement with or attendance at events on campus.

### **Methodology**

Qualitative design, specifically, semi-structured interview questions present an opportunity for participants to honor their respective multiple identities while reflecting on their social experiences as a college student. Informal social experiences like roommate relationships and campus involvement, as well as formal social experiences like working with classmates on group projects, and preparing for job interviews can impact the persistence and retention of college students who have autism (Pillay & Bhat, 2012; Wehman et al., 2014; Wenzel & Rowley, 2010). “John” captured the multiple identities of participants when stating “...I tend to keep my school and social lives

separate.” As did “Mary,” who also presented with multiple identities that influenced her social experiences as a college student with autism:

...so I was diagnosed with a PTSD. The psychiatrist that I was just seeing, he was to figure out how else to classify...to classify me...he said I'm not bipolar...but I've got, uh, other elements. He said so he thought I was borderline...Okay, HFA...

This study's participants do not navigate life with autism as their lone identity. Instead identity is a richly layered and complex lens that the participants expertly experience life through, inclusive of autism.

### **Sample**

The purpose of this phenomenological study was to explore the social experiences of college students who have autism, with attention to persistence in college.

Undergraduate students who self-identified with autism spectrum disorders were invited to participate in semi-structured interviews. Recent college graduates who completed degrees within the prior six months were also included in the sample population. At the end of the semi-structured interview the researcher asked the participants to assist in identifying additional potential participants, a process known as snowball sampling.

Snowball sampling is a purposeful sampling method that had the potential to increase sampling complexity, variation, and diversity (Hays & Wood, 2011). Mary's commitment to increasing the narrative capital for fellow autistics was especially noteworthy in snowball sampling as she volunteered to share her research experience with fellow autistics that she regularly interacted with in an online support group. She encouraged them to participate, thereby attempting to add complexity and richness to the

narratives that were collected. The researcher also asked participants to consider inviting a family member or friend to an additional interview, whereas the researcher could learn more about the participant's college experience from the perspective of the student's support system. family members were offered and were contacted, only one participated, Mary's spouse.

The sample site was selected because it was a urban research intensive doctoral granting institution and a leader in distance learning that offered multiple ways to complete coursework for non-degree and degree seeking students, which is believed to be appealing to diverse learning needs (Remy & Seaman, 2014). Additionally the sample site is where a prior related research study occurred, which the researcher believed would allow for purposeful snowball recruitment for new participants. At the sample site, during the fall of 2015 almost 800 undergraduate and graduate students are registered with the Office of Educational Accessibility, of which 3.5% percent self-identified with autism and/or Asperger's Syndrome.

### **Participant Population**

Numerous calls for participants were distributed throughout the sample site through the Office of Educational Accessibility to reach students who had an established relationship with university support services (Appendix A); invitations to participate in the study were also sent through the University Announcements (Appendix B), a daily digest of academic, event, and promotional announcements for students, faculty and staff; and to prior research participants. College students who have autism spectrum disorders often pursue majors in Science, Technology, Engineering, and Mathematics (Baron-Cohen, Wheelwright, Burtenshaw, & Hobson, 2007) and may also not register with



disability services on campus. In an attempt to reach more university students the researcher attempted to share the research announcement and call for participants with faculty advisors in the Batten College of Engineering & Technology and with academic advisors in the Student Success Center's Advising & Transfer Programs. Although neither participant recruitment effort was successful since the gatekeepers did not agree to share the research announcement it was important to attempt, as it could have additionally supported purposeful snowball sampling strategies.

To increase the number of participants and enhance the complexity of data collected, in the third month of participant recruitment the researcher extended the call for participants beyond the initial site to include regional programs supporting young adults with autism spectrum disorders, and national organizations focused on autism advocacy. The following programs and organizations disseminated a recruitment announcement for participants on behalf of the researcher: the Autism Society of Tidewater Virginia, the Social Communication Group of the Speech & Hearing Clinic at the sample institution, Think College, the US Autism & Asperger Association, and Autism New Jersey. These programs and organizations were identified and selected because they offer transition support programs for college students, social communication support groups, and community-based resources for high school and college students, and their families. Each of the organizations disseminated the researcher's recruitment for participants (Appendix E) to their membership through established email list serves and newsletters.

### **Criterion for Selection**

Undergraduate students enrolled at least part-time within the prior two academic semesters, and recent college graduates that completed degrees within the prior six months, who self-identified with an autism spectrum disorder were included in the sample population. Students who identify with other cognitive impairments, not autism spectrum disorders, were not included in the sample population.

### **Participants**

The purposeful sampling method and snowball sampling strategy yielded six participants ( $n = 6$ ). Five of the participants self-identified with an autism spectrum disorder and confirmed receipt of diagnosis by a medical professional during their educational career, as highlighted in Table I on page 63. The sixth participant was the spouse of participant Mary who participated to provide her perspective of Mary's social experiences as a college student. The confirmation of diagnosis is important to note, as Mary shared that there is internal community discord amongst persons who have autism around the notions of "having your papers." Persons without formal diagnosis of autism are viewed skeptically and with caution, although still included in online support groups for adults with autism, similar to the one that Mary and Don participate in. The five participants' ages ranged from 19-36 years old, two participants attended either a community college or another 4yr university during their post-secondary educational career, while 3 participants only attended 4yr universities. Four of the five participants were registered with the institution's disability services and many received support in secondary education through an Individualized Education Plan (IEP). However, two of the participants were not accurately diagnosed with an autism spectrum disorder until adulthood, in their 30s specifically. In Mary's instance accurate support was not received

until college enrollment, whereas “Don” did not receive any support at all in because his diagnosis occurred after he completed college. All but one of the participants lived off campus with family members, “Norris”; four participants were male, one female, and two participants identified as a person of color, i.e., Hispanic/Latino, Biracial/Multiracial, and Asian American.

### **Snowball Recruitment Participants**

Mary, “John” and Norris responded to the researcher’s call to invite a family member or friend to an additional interview, whereas the researcher could learn more about the participant’s college experience from the perspective of the student’s support system. However, only one family member responded to the invitation, “Susan,” the spouse of Mary. Additionally Mary contributed to snowball sampling by inviting “Don” and “Xavier” to contact the researcher to determine eligibility. Although several attempts were made to contact Xavier the researcher was unsuccessful in determining eligibility, therefore Xavier did not participate in this study. The researcher determined that Don met the self-identification criteria, however, did not meet college enrollment criteria. Nonetheless because of Don’s unique adult diagnosis post degree completion the researcher found the rich perspective valuable to include.

### **Incomplete Participants**

It is important to note that five additional people showed interest in participating in this research. Two unique Qualtrics submissions (Appendix E) were recorded without name or email address, rendering it impossible for the researcher to follow-up. Two female students completed the Qualtrics submission (Appendix E) and exchanged multiple emails with the researcher over several weeks but would not commit to a

meeting date for an interview. One female student completed the Qualtrics submission (Appendix E), however, later rescinded participation in the research on the basis that she identified with ADHD, and not autism.

### **Summary of Findings**

The data for this research will be presented in two parts: seven themes both common and unique to all participants, followed by individual case summary review of each participant. Analysis of the participant interviews identified seven shared themes amongst the social experiences of college students who have autism: diverse experiences in campus engagement, the impact of noise on participation and campus engagement, living accommodations, faculty engagement and socialization, intentionality with peer and classmate interactions, romantic experiences and peers as mentors.

Half of the participants shared that they are either intentionally not engaged or cautiously engaged with social events on campus. Engagement was influenced by the size of the crowd, potential noise levels, general disinterest, and anxiety associated with being spread too thin and not being able to focus appropriately on academics. Likewise noise was linked closely to the decision to engage socially with campus. The decibel range at campus events, and the lack of control over the noise presented a concern for some participants.

All of the participants, with the exception of the lone first year student, lived off campus with family and commuted daily. The additional financial burden of on campus housing was overwhelmingly the primary reason the participants decided to reside off campus. A third of the students reported that not living on campus did influence their social engagement on campus; one participant particularly noted that living on campus

could increase his attentiveness to events, yet the financial return of living at home was of greater benefit. Although not engaged with campus events each of the participants reported engaging with faculty without any reluctance, finding it effortless to talk with faculty about courses, their academic major, and other relevant topics that arose. Specifically, unlike being intentionally reluctant and selective to engage socially with the campus community participants recalled their relationships with faculty with fondness and admiration for supporting academic success in individual courses, as well as overall undergraduate enrollment. Faculty engagement is a complement to intentionality about peer and classmate interactions. Building connections with faculty, around selecting a major, academic achievement, and related topics furthers a student's connection to campus. Half of the participants talked about creating friendships with purpose, i.e., to support academic achievement, or to create a social identity and also referenced romantic relationships during their college career in their discussion. Familial support, connections with faculty and friendships with other peers outside of campus events were influential in the participants' persistence and retention. Although none of the participants attended college with the hope or intention of meeting their significant other, sexual identity and orientation also played some role in their social experience.

Unique to the sole first year and only student living in university housing, developing a relationship with peer Resident Assistants was a salient theme for Norris. Purposefully focused on academic success, with concern for being able to incorporate co-curricular activities without failure, Norris looked to his Resident Assistant for guidance and invitation to participate in specific extra curricular opportunities on campus.

### **Theme #1 – Campus Engagement**

When asked about attendance at events or activities on campus, and more specifically, if they felt engaged with the social events/offerings on and off campus, half of the participants shared that they are either intentionally not engaged or cautiously engaged with social events on campus. Specifically, Mary shared that her intentional decision to not engage is based on sensory needs, preferences, and disconnectedness with what seems to be the standard identity of a undergraduate student, that is, incredibly social, eager to attend campus events amongst throngs of other people, and willing to participate in athletic events:

Um, there's all of these expectations to participate in all of the stuff and these things and attend a football game, attend...uh, uh, attend here, attend...I'm like noise, noise is bad. No way. I'm not going to do it and everybody is always talking about "Did you see this? Did you do that? Did you just..." "No." "Well how come did you...Don't you found..."...Um, it's being...it's almost as if social interaction is demanded at times...and if not, uh, then people think...they'll think you're just one of those people...and I'm like, "No." "I'm not absent. I'm, I'm happy at home...where it's quiet. I have my cat and my books. I'm perfectly fine there. If I want a whole bunch of noise, I'll cut the grass...When I was 18, I attended an Aerosmith concert that was, uh, ungodly assault on my senses. Never again <laughter> but we won't forget. <laughter>

This reminds us that what seems to be a simple decision to attend a campus event, small or large, as in a lecture, pep rally or athletic event, can actually be a more complex decision for college students with autism. The noise level, crowd control, as Susan later shares, all play a significant part in the decision to engage in social events on campus.

And perhaps by default shape a student's identity, or at the very least their perceived identity by peers. Mary asserts peers may consider her to be "one of those people." John expressed his sentiment about campus engagement with the following, "As it is...I go, I come here to learn. I don't care about the sports. Never have, never will. Even if I lived on campus I wouldn't care about the sports." The diversity in campus engagement is further illustrated by Norris's honest and cautious hesitancy to disrupt his rhythm of academic focus that he committed to, thereby positively influencing his persistence and retention, by engaging more with campus events and organizations. When asked if there were anything that he wished were different, he responded that like other college students he wished that he could, "And also, like getting involved. Like, I wish I could do, I could like, uh, do well in my academics and simultaneously participate in lots of organizations."

### **Theme #2 - Noise**

An intentional decision about not engaging with campus socially is also connected to the excessive noise that crowds present. Mary illustrated this best when she shared two questions that she asks of herself before considering attending an event. "Is there going to be a lot of noise? Okay. Am I able to manage it? If not, don't go....if I could change anything it would be all the heavy emphasis on participating in all of these things." She can trace this conscious avoidance of noise back to her adolescence, age 12 specifically, when she began to separate herself from people and scenarios that were excessively noisy. As an adult she typically enters stores with headphones on to buffer the surrounding noises. Her spouse, Susan, provides additional support by thinking

ahead about environments that they are entering together and offering a physical barrier in crowded spaces:

I mean, I guess I always think about stuff like that especially if, um, if we go in like a crowd...I'll have her walk behind me, so I can be as a buffer so people don't touch her because, um, I'm sure she told you that, you know that they don't like being touch...Um, and if we have to, I would say I just try and act as a general buffer because things that don't make me uncomfortable you know I know stress her out and make her uncomfortable.

From Themes 1 & 2 we learn that campus engagement is often avoided due to sensory needs related to crowds and noise levels. Half of the participants intentionally do not engage with campus events for these two reasons. For many students managing their environment is critical and determines what, if any, social experiences they take advantage of on campus.

### **Theme #3 – Living Accommodations**

The third theme examines common and unique themes in reference to living accommodations across the sample population. Norris currently lives on campus and is the only participant that chose university housing. Unlike the other participants who are non-traditional aged, Norris is a traditional aged first year student and at 19 years old, decided that living on campus would be less of a headache than commuting from off campus, dealing with local traffic and finding a place to park on campus daily. Keenly aware of potential stressors associated with commuting daily, he is pleased with his decision to live on campus, and is actively participating in residence hall activities at the invitation of his Resident Assistant, whom he describes as a friend, confidant and father



figure. Norris intentionally chose to live on campus, as all of the other participants chose to live off campus, either with parents, as John and “Gary” does, or spouse as Mary does. The cost effectiveness of living at home with parents is the primary reason that the participants decided not to live in university housing. In particular unique pre-existing medical needs and reluctance to share a room with a younger, perhaps less mature college student swayed Mary away from living in university housing as an unmarried student. It is important to note that two of the participants, Mary and Gary, did view living off campus as a factor for their social engagement on campus. In particular when asked about what role commuting to campus plays in campus involvement, Gary replied:

No, I mean to me it's just like getting to work on time, you know, I don't really feel like it plays a part in me being here for certain social events....I'm not like a social type of person, I can be, like if there's let's say there's a young lady that I find attractive I will actually be social, I will try to be social. And that's it, or if there's like a friend, like a person in class that actually knows what's going on I will be social and say, “Hey, um, you seem like you got a handle on this can you see if you can fill me in on what's going on?”

Gary's response provides insight into his social experiences as a college student.

However, John presented a different perspective on how living in university housing could impact his engagement with campus events, “ If I lived on campus, and was exposed to it more and had interacted with it on a daily basis. I probably would be more attentive to it.”

Decisions to reside on campus were not made without considerable forethought by each of the participants. Living on campus presents an opportunity to eliminate any

anxiety associated with commuting, while creating opportunities for campus engagement and peer relationship building. Although it can also influence campus engagement, residing at home with family presents an opportunity to reduce the cost of education and also builds the familial web of support and affirmation which influences persistence and retention. Gary described this when reflecting on how inspiring his mother's own education pursuits have been for his goals:

...um, I usually look up to my mom. Yeah, and she tells me, you know, you have it, you can do it, you know, you just need to want to do it that's it. And, um, the affirmation that's where the affirmation comes from, I get like, "Oh so if my mother can do it so can I", you know.

#### **Theme #4 – Faculty Engagement**

All of the participants reported engaging with faculty without any reluctance, finding it effortless to talk with faculty about courses, their academic major, and other relevant topics that arose. At the beginning of one course Norris was not using his disability accommodations, and as a result was not passing several of the class assignments. The faculty member took notice and Norris emailed the instructor and explained that although he was working hard his grade was not an accurate reflection of his ability. Soon he began using his extended time accommodations and "established a closer, a strong relationship well with my math professor for the semester."

In a similar fashion, John has found it easy to talk with his faculty by staying after class and asking questions, "and sometimes that will lead to conversations that are related to the question and we kinda just get to know each other that way." There is a natural ease that each of the students described, an ebb and flow when talking with their

instructors that is not pretentious nor rooted in student, faculty hierarchy. Mary described her interactions with faculty as one of the successes that she took away from her college experience. In particular her experience with a history professor who supported her personal development:

...and that guy if he sees that you're working hard and that you're trying and you're open and honest, he'll do whatever it is he has to do to help you...anything. I-to him, it doesn't matter, how can I help...he, he helped me understand that it's okay to talk to professors and say, "Okay. Like here is the issues I'm having..."

Unlike the prior accounts of being intentionally reluctant and selective to engage socially with the campus community as a whole, the participants recalled their relationships with faculty with fondness and admiration for supporting academic success in individual courses, as well as overall undergraduate enrollment. Don recalled faculty within his major fondly. Involved heavily with student learning there was a "substantial amount of access to professors," that he attributed to the small number of STEM majors admitted with each incoming class.

Talking with faculty often began with course content and extended to become a mentee/mentor relationship as the participants progressed towards graduation.

Instrumental to persistence and retention each participant recalled engaging with faculty as a natural occurrence, seemingly easier than the more broad campus engagement.

Mary's recollection of a conversation with her faculty advisor underscores the influence that faculty had on persistence and retention:

Mary: He was a-absurd in helping me.

Researcher: <laughter>

Mary: Like ridiculousness. Okay, well how...which is how he said, "Okay. If I'm not able to help, I'll pray instead."

### **Theme #5 – Intentional About Peer/Classmate Interactions**

Some of the conversations about interacting with peers and classmates were rooted in the participant's contributions to group dynamics through assignments, study groups, or classwork that was collaborative. A small group of three young men who met in an advanced high school program decided to apply to and attend the sample institution together, building an intentional academic and social network for the group, including Gary.

Yeah we're helping each other out....yeah a relatively small social network but social network nonetheless....we just, we help each other out, you know, like we'll help each other study, like my friend he's going to graphic design and he's like, "--- how do you draw this, how do you do that? Where does, where does...how do you stick a light source?", you know, stuff, you know.

This small yet integral social and academic support group was intentionally created to continue the relationships that were established in high school. Despite different living accommodations and class schedules Gary intentionally connects with a group of pre-selected peers that helps define his undergraduate experience.

By far the most intentionally and creatively crafted peer interaction was developed by Don who created a disc jockey radio show and subsequent well-known campus persona during his first year of college. With a weekend show dedicated to disco

music, “Saturday Fever” became a campus hit. Don recalled that he “...had to be extreme, I couldn’t just fit in.”

Unfortunately, not all of the peer and classmate experiences shared were positive. Mary recalled experiences where her high intensity work energy and attention to detail were taken advantage of by classmates, perhaps because she did not understand some of the social cues in conversations and was unfairly burdened by elements of the project. As a result she shared that communicating through email became her preferred method.

Uh, uh, I always had to hold it in the forefront how I operate isn’t how everybody else operates...so it’s just easy for me it’s not necessarily easy on everybody else so in terms of that social aspect I’ve kept a huge chunk of it in email so, uh, so I also had evidence...because <laughter> that’s a paper trail it goes a long way.

The environment for peer interactions also exists outside of the classroom and purposefully crafted friendships, as Mary expressed. As an example of the complexity of the lived social experiences of college students who have autism spectrum disorders, Mary also described how she intentionally sought out attendance at a campus based student ministry with fellow students:

...I did it to help quiet down my mind. It’s always all over the place. It’s always active and thinking and everything so the, the routine of, of the sacraments and the prayers and the meditation stuff. It pushes a whole lot of the noise. So I was still out if everybody is over here and I’ll...and all singing and praising, I was over here in the corner somewhere...

The diversity of peer interactions is influenced by context of when they occur: in class or as the result of a group project, in a social setting like a dining hall, or within a

constructed opportunity like a radio program. It is important to note, that each participant's interactions with peers, positive or negative, occurred within an environment that the participant sought out. No one was forced to engage outside of their comfort zone.

### **Theme #6 – Romantic Experiences**

Although the interview protocol and questions did not reference romantic relationships, three of the participants introduced dating and spouses in their conversations. Both Don and Gary shared about the innocence of talking to a woman with whom they had interest and the relative ease in which a conversation or an invitation to lunch would be extended. During new student orientation the Dean of Students is remembered to have said "...look to your left, look to your right, maybe you'll find your mate," Don recalled.

While an undergraduate student Mary began to date her current spouse whom she describes as patient, even-tempered and the perfect compliment, i.e., someone who understands how to communicate with her, as opposed to her first spouse who she described as deficient in these areas. Unlike her first marriage where yelling was commonplace, and prior to her autism diagnosis, her current marriage exists within her autism diagnosis without negative connotations:

...I have episodes of where it's like, "Oh that's an autism...that's just autism and my wife, I love her, she kills me. I'll, I'll say or do something bizarre and her answer is autism awareness, yep I'm aware. Next. <laughter>

Talking with Mary's spouse revealed that communication was different initially but has become manageable and rewarding. Prior to the marriage, Susan did not know or interact with anyone with autism. She described the learning curve in the marriage:

Like we just learned how to communicate with each other, it wasn't always easy at first. There's definitely a learning curve of, um, of how she perceives things. And how her brain works. And I learned that you can be very literal....you know normal conversation where something you might seem inappropriately blunt...it actually, that is a much better way to communicate, just say how it is, you don't need to do all maybe the social niceties I guess. Um, so I think we are learning, you know we definitely have a curve of learning but I think that it was very easy, it just came naturally.

The presence of romantic experiences or relationships was introduced by the participants as a element of their social interactions with peers, on campus and off. The impact of learning how to communicate, understanding social cues, and becoming aware of communication preferences is important in understanding the relationships of the participants.

### **Theme #7 – Peers as Mentors**

The seventh and final theme explores peers as mentors and the cultural capital that peer relationships can provide. As the lone first year student amongst the participants, Norris, talked admirably about the father figure type relationship that he has with his Resident Assistant. Purposefully focused on academic success, with concern for being able to incorporate co-curricular activities without failure, Norris looks to his Resident Assistant for guidance and invitation to participate in specific extra curricular

opportunities on campus. Accepting an invitation to join an engineering club, Norris works side by side with his Resident Assistant, learning the club, its project, and how to engage with other students on campus.

“...I guess because I worked on a little bit of the engine and stuff, he, he kind of showed me around. He was like a mentor, basically.” This description of how Norris views his relationship with his Resident Assistant highlights a type of peer to peer social capital that exists between an upperclassman and first year student, encouraging persistence. A similar relationship exists between Norris and a second Resident Assistant, also an upperclassman, and with whom Norris has specifically disclosed his autism identity, doing so by sharing an essay assignment where he wrote about how he has changed over the years. The second Resident Assistant is characterized as a confidant and sounding board, someone that is also respected and valued.

As the only participant living in on campus housing, as well as the youngest participant, Norris’s experiences provide insight into the experiences of traditional aged first year students. Self-determination and navigating new social environments is a central theme that is supported by a peer mentor, Resident Assistant, whom Norris is developing a genuine and supportive relationship with.

Table I

Research Participants



Participant	Gender	Race/Ethnicity	Age	Diagnosis	Accommodations	Classification	Prior Attendance
Mary	F	White	35	33yrs old	None	Alumni	2yr & 4yr Colleges
John	M	White	26	1 <sup>st</sup> Grade	Extended Time & Recording Rights	Sophomore	2yr College
Gary	M	Hispanic/Latino & Biracial/Multiracial	20	9 or 10yrs old	Extended Time & Quiet Testing Room	Sophomore	None
Norris	M	Asian American	19	7yrs old	Extended Time	Freshmen	None
Don	M	White	36	32yrs old	None	Alumni	None

### Case Summaries

#### “Mary’s” Case Summary

##### Interview #1: 96:00 minutes, In Person

...if you tell me it’s pouring outside, I’ll understand it’s raining. If you tell me that it’s, raining cats and dogs, well who’s flinging them out the window. It sounds simple but at the same time, it’s a hindrance to understanding people who speak in, in these phrases...because people assume that intent is understood...

Formally diagnosed with autism as an adult at the age of 31, the diagnosis co-exists with a number of competing diagnosis that beg of Mary’s time management: PTSD, High Functioning Autism or HFA, and a speech impairment. Due to a physical impairment and existing disability accommodations, Mary decided not to use accommodations that were granted specifically for her autism diagnosis. It is the same

physical impairment that initially led her to not consider living on campus when she first transferred to the sample institution, unwilling to be housed with a younger student because she was afraid that they would be unable to manage self-control around access to her prescription medicines. Living off campus proved to be the better decision for her as it allowed her to manage her living environment.

Reflecting on her transition and persistence from community college to a private four year institution, to a public four year institution, Mary shared that although college was essentially what she expected it to be, she was initially terrified when leaving her smaller private campus of less than 3,000 students, with an average class size of 11 students, to attend the much larger public four year institution with over 24,000 students. However, the cost of obtaining an education prohibited her from continuing her studies at the smaller private institution. After an eight-year part-time journey she successfully completed her undergraduate degree last spring. In the face of multiple personal hurdles Mary is the epitome of persistence.

Keenly aware of her own environmental needs, Mary typically wears headphones to buffer outside noises, avoids campus events where crowds of people will be present, and generally prefers to minimize socializing to a small and intentional circle of friends. Most of her social engagement is done with her spouse, including any rarely attended campus events, as most excursions that she chooses are off campus and in less populated venues like cemeteries. As a history buff she really enjoys the ornate details about local and regional spaces. As a student this did not translate into attending many campus events or participating in many campus organizations, "...there's all of these expectations to participate in all of these things and attend a football game, attend, uh, uh, attend here,

attend...I'm like noise, noise is bad, no way." She did however, find comfort in a campus student ministry group that she would attend:

I attended the masses, um...but that was about it and I did I to help quiet down my mind. It's always all over the place...It's always active and thinking and everything so the, the routine of, of the sacraments and the prayers and the meditation stuff. It pushes a whole lot of the noise.

The demand for social interactions from college students is not an expectation that she had any interest in satisfying, "When I was 18, I attended an Aerosmith concert that was, uh, ungodly assault on my senses...never again." She recalled a very similar experience at her college graduation in May.

Graduation was horrible by the way. And you have to walk...and walk...in a line for almost an hour and the noise the cause of noise, the endless noise, the noise doesn't end and then all the hooting and the hollering and the flashing of the lights. I have, um...I've got this sensory sensitive something I don't know about that...what that thing is called.

And just I was going nuts. I was like, "help help help, get me out of here."

Mary spoke candidly about the need for higher education to be more inclusive in educating the campus community about the diversity that exists on campus beyond sexual orientation. Given the attention to diversity and inclusion in higher education, this inclusion could be instrumental in broadening the stakeholders for current campus initiatives and programming that seeks to support the persistence and retention of under-served communities.

...all these seminars here exist somehow to interact with LGBTQI LMNOP people. Whatever that is. I'm like, "Why all the categorization? Oh my God..." But there's, um, there's seminars on, cultured differences, on this and that, but there's nothing about autistics. If they are taking the funding and the time to educate about people's orientation...identity, ethnicity...why not something as huge as autism?

### **"John's" Case Summary**

**Interview #1: 27:00 minutes, In Person**

**Interview #2: 34:10 minutes, Skype Chat**

Researcher: Can you remind me again where you fall on the spectrum. How do you identify, how do you self-identify? Just autism in general? High functioning? Aspie? Asperger's....?

John: What do I prefer?

Researcher: Yeah

John: I don't care.

Researcher: Okay

John: I really don't care. <Shrugs>

I had the pleasure of meeting with John twice and the exchange above is a perfect illustration of his easygoing demeanor. He does not wear autism as a diagnosis. He is not autism. He is an upper class STEM major, who began his undergraduate studies at a regional community college that has a longstanding reputation in the local community. Taking a year off after high school graduation, a decision that he now questions, he is

unsure about the efficacy of the year off because he is not sure that he has anything to show for the time out of school. John is a college student who happens to have Asperger's Syndrome.

Misdiagnosed with ADD in the first grade, the correct diagnosis for Asperger's was identified shortly after, while he was also enrolled in elementary school. John has persisted through k-12 education and now post-secondary education with disability accommodations. As a college student currently registered with disability services, his accommodations include extended test time and permission to record lectures. Yet, he does not use his accommodations because he does not find them helpful. As a physics major, with a number of online classes he believes modifications to the amount of homework required in his classes would be a more suitable accommodation. In spite of this caveat he has found it relatively easy to develop relationships with faculty:

I generally have a social relationship with most of my instructors...I walk and stay after and ask my instructor questions and sometimes that will lead to conversation that are related to the question and we kinda just get to know each other that way.

As a community college student it was easy to meet and talk with other students. In particular there was a dance class that he recalled where "...it was kinda hard to not make a social connection with everyone in class. And you just spend an hour and a half dancing with everyone. You talk." The same opportunities however, do not exist at the 4-yr institution. In particular John recommends

A social group. A...ah, kind of like a club...not one on one like. Group for socialization, because socialization can be scary for some. For autistic people.

‘Cause you never know one of the common traits of Asperger’s and autism is that you don’t understand social cues and social acceptances. When you’re with other people who are like that it’s not as scary. ‘Cause you know they have, or likely have, and understand what you have.

Reflecting on his transfer experience from community college, the wisdom he would offer himself in hindsight would be to improve his poor homework habits. Although by his own admission, “old habits die hard,” he believes that his grades would be better if he focused on improving his homework habits. John’s lesson to other college students, “Do your damn homework.”

On living at home versus living on campus and being engaged with campus activities:

If I lived on campus, and was exposed to it more, and had interacted with it on a daily basis. I probably would be more attentive to it. As it is...I go, I come here to learn. I don’t care about the sports. Never have never will. Even if I lived on campus I wouldn’t care about the sports. Unless I was on them.

### **“Susan’s” Case Summary**

#### **Interview #1: 34 minutes, In Person**

Offering perspective about Mary’s college experience from the lens of a spouse, Susan shed light on valuable experiences that Mary did not discuss in our initial conversation. New to the world of cognitive disabilities and autism, Susan did not know anything about autism prior to marriage. In the six months that they have been married, learning about noise sensitivities, eye contact avoidance and communication preferences has helped eliminate the learning curve that existed.

Eliminating the learning curve has also influenced Susan's interactions with others as well. After meeting her spouse she also had the opportunity to work with a gentlemen at her job that also has autism. Many of her coworkers were mystified and fearful even of their coworker's social presentation, specifically his extensive knowledge of guns, however, she was able to advocate for his unique ability to spend inordinate amounts of time talking about guns in intricate detail because her spouse has a similar gift as it relates to mid-evil history.

Understanding the uniqueness of Mary's social experiences as a student and a student employee is one of the scenarios that Susan recalled fondly:

And this is one of my favorite stories, uh, her boss is like, uh, she said, "Oh, you are really go-getter," she's just like, "I don't understand I have to go and get up, what does this mean?" I love that story, I really do <laughter> and she says, "I've never understood that phrase," and it makes me laugh every time.

On educating the campus community on autism, especially faculty:

I think probably, um, I don't know how much they really educate professors about autism but probably education is your greatest asset when it comes to autism. If you know that the student may need to get up and leave the class because of the noise or can't, or won't be able to do as well as somebody else in a presentation. Or you know their lack of eye contact...they need to be more educated about what it really is and, I just say the attributes of autism...they probably need to talk to somebody who is autistic to really understand them...it's hard, you know you can read all the pamphlets that you want about it, until you actually interact with somebody, you know that's what actually, that's what makes it real and how you

figure out, how you need to interact with them you know. It's not, they need to change, it's that you need to change to facilitate their growth.

By her own admission Susan does not think that she nor Mary are very connected to or engaged with the campus community, in part because as a couple they are not particularly social and when they do engage socially it is typically as a couple or in a small intentional group. Noise and crowd sensitivity make attending large social events difficult. Susan often acts as a physical buffer in crowds, however, the couple typically avoids well-populated events altogether. There are few places that recognize the unique needs of persons who have autism, the Christmas Town display at Busch Gardens is one that the couple takes advantage of because persons with autism are able to secure a front line pass that allows them to avoid the bustle of amusement park crowds, while still providing access to all of the Christmas Town activities. This is a significant social experience win for Mary and Susan.

Fiercely proud, one of Susan's vivid memories of her spouse is her completion of a speech disfluency program:

Susan: Let's say if she started, uh, I don't know like 5% disfluency...and like by the end of her program she's down all the way to .3 where you barely notice it in conversation.

Researcher: Wow, that's huge.

Susan: It is <emphatically>, and, um. It helps her go with her eye contact and that kind of stuff, learning how to, get better talking on the phone, and uh...

Researcher: That's huge.



Susan: I mean she did excellent and really, no – I saw it improve as time went on in our relationship...you know where she would get, she would stutter a lot then as time goes on she got a lot better. It was really cool...it was awesome when she complete, completed the program. Um, and how, especially it helped her with job interviews...

I think it's really been great to see her be successful at her job, you know having her boss be like, "Oh, you know she told me I did so good in this that and the other." And, uh, I think it's funny when she jokes with her boss at ---- and just like, "How do you have all these organized?" she's like, "autism awareness." <laughter> That always makes me laugh.

### **“Gary’s” Case Summary**

#### **Interview #1: 40 minutes, In Person**

An upper-class student who enrolled immediately after high school, Gary is studio art major who identifies:

...somewhere in the autism spectrum...me and my family they took me to see some doctors to see what it was and they said that it's some form of autism that they haven't really heard of, that's what they said...well I think it's a blend of those two, autism and Asperger's. I don't, I'm not sure.

Medical assessments began at an early age in part because as a child he was often distracted, would daydream frequently and with the exception of his artwork was disorganized. His passion for art is prevalent in his academic studies as a studio art major. Although he has used charcoal when sketching, he prefers mechanical pencil, as the sounds of wooden pencil and charcoal are bothersome to the ear.

Gary lives off campus with his family and commutes daily. Although commuting to campus has its challenges during rush hour, inclement weather, and fighting to find a parking space, saving money by living at home is an undeniable benefit that is worth the compromise. Commuting to campus does not have an impact on campus engagement; instead Gary sees his engagement with campus similar to having a job:

No, I mean to me it's just like getting to work on time, you know, I don't really feel like it plays a part in me being here for certain social events....I'm not really like a social type of person, I can be, if there's let's say there's a young lady that I find attractive I will actually be social, I will try to be social. And that's it, or if there's like a friend, like a person in class that actually knows what's going on I will be social and say, "Hey, um, you seem like you got a handle on this can you see if you can fill me in on what's going on?"...other than that I just stick to myself...I prefer to live by the rule me, myself and I, you know, just look out for number one.

When asked about what if any impact autism has on his academic life as a college student, Gary was somewhat evasive but did share that he uses his extended test time and access to quiet testing space accommodations as needed, not for each class nor each assignment, primarily for major assignments. When talking with faculty he shares:

Hey there's this big assignment coming up and I had trouble starting it do you think I can have an extra day after due date that I can work on this so that I can turn it into you?" because even if I turn it into that day it might not be as good if I get that extra day.

In high school, confidence in his ability to be a successful college student was a palpable concern for Gary. Being transparent he shared:

Sometimes there are days where I'm like, "Man I don't feel confident enough to do this", you know, "What if I don't", there's always that think in the back of my mind, "What if I don't make it to college"... "What if I'm a screw up..."

Now that he is enrolled he is doing well and improving his grades from his first year to the second year. His inspiration and affirmations that he is on the right track come from his mother:

You know, my mom, she did nursing school and she did very well, she was like, I don't know, she might have been the top of her class. Yeah, and she tells me, you know, you have it, you can do it, you know, you just need to want to do it that's it. And, um, the affirmation that's where the affirmation comes from, I get like, "Oh so if my mom can do it so can I, you know.

Additionally he also has an academic and social support network with some other students that he attended high school with who are also college students now. Although they all have different majors, and live separately, they study together, troubleshoot academic issues for each other, and sometimes work out at the gym together. In hindsight, and academic wisdom for his younger self, Gary shared the following:

Um, don't always rely on the professor...just do what you feel you need to do. Because sometimes what, you know, this might be a little off, might but I feel it relates to the professor student thing, uh, a soldier can't always obey the orders of the general, you know. That's how I feel.

### **"Norris's" Case Summary**

**Interview #1: 35 minutes, In Person**

Researcher: So, I'm always curious to why people respond.

Norris: Well, I mean, it's good to talk once in a while, I mean, with, um, someone else at times. I mean, like, used to talk to, um, counselors or to, uh, uh, patient therapy.

Researcher: Okay.

Norris: Kind of thing. Um, but that's starting to decrease a lot because...it looks like I'm improving a lot significantly than, um, like ten years ago, for example.

Researcher: Okay.

P005: So, like, every once in a while, it is a good idea to talk about sometimes, so....

Researcher: Okay. When you say talk about it, do you mean, talk about having autism or....?

Norris: Yeah...because it, it kind of, it kind of helps because sometimes I'll forget why I'm having problems with so many stuff and I'll forget the real reason. Like, "Oh yeah, I have that," and stuff, so....

Diagnosed as a young child, Norris's earliest memories include receiving treatment and support for autism as a result of behavioral issues, specifically temper tantrums, followed by speech therapy in elementary school. As a high school student he decided to not use his IEP during his last two years of high school to prove, to himself, his parents and teachers perhaps, that he could achieve academically without

accommodations. He found this manageable with the absence of Advanced Placement classes.

As a first year engineering student he believes that he is navigating his first year of college well while living on campus in a STEM Living-Learning Community, this includes learning how to develop deeper relationships with his suitemates in his roommate's absence, and getting to know his Resident Assistant. In spite of only being on campus a little longer than one semester, he did not feel engaged with campus initially:

I didn't feel like that on, during first semester because, well, I had a protocol where I wanted to establish myself with firm ground with my academics first before I go out. Because if I do opposite, it could really screw myself up.

Because that's just how I function. Uh, for, since, eight years old, I guess. Um, but actually my hall RA got me involved, um, in his project, I guess, or in the group, uh, organization called, um the ---, which is the Society of -----.

Tremendous credit goes to the consistent community building efforts of Norris's Resident Assistant, and the impact that it has on his persistence. As a result of the Resident Assistant's work to include him in campus events, Norris recognizes his own growth; he attended a band performance at the student center by himself, and considers his Resident Assistant as a father figure. Incredibly self-aware, Norris recognizes that continuing to grow will open doors for him socially and professionally:

Um, because, I kinda wanna build on my resume stuff. So, keeping that in mind, that's a good motivator behind that. But, um, I also want a motivator for, you

know, social, uh, social reasons. Just to make out, go out and make new friends and stuff.

Unlike his high school tenure Norris is using his accommodations as a college student, as he recognizes that the outcome for using the accommodations supports his retention far better than not:

Right. Um, and then, I was a little hesitant about not doing it for, um, college, but, again, this is money as being paid. Money is in the process where we have to pay for our college, for our education, so I was like, “I’m not going to take any chances.” Because of my, like, test performances and stuff and how the way I’m thinking, um, it looks like I will need to use it. Um, but only for test, quizzes. Like, everything else if fine. I mean, I could take the test in the same classroom with all my other peers, but because I need more time, I, you know, can’t really do that. But, um, it’s, yeah, just more testing time because I can sometimes confuse myself with the question. The questions or directions or...I’ll know what to do. I just need more time because it’s just my brain process or something is really slower than the average person, so...

### **“Don’s” Case Summary**

#### **Interview #1: Email**

#### **Interview #2: 41:25 minutes, Skype Video**

“It does not get any easier when you’re an adult...managed to find for myself a situation that works for me....that I can survive...”

After years of bullying, tumultuous elementary and high school experiences, and working fourteen different jobs after completing college, Don was diagnosed with autism at age 32. The diagnosis itself was an arduous process, after driving over 200 miles to find a medical provider that treated adults with autism he finally received his diagnosis. Trained as a science teacher, he taught high school physics for one year before deciding that his talents were better suited in an environment that he is able to control. His life as a professional musician began shortly thereafter.

Attending college several hundred miles away from home, Don had considerable incentive to be sociable with other students. Described as a small conservative private liberal arts college with religious affiliation Don recalls his alma mater as the type of institution with a culture that encouraged students to find a spouse early on. Asking a classmate to lunch was perceived as a date, an unwanted request would be accepted yet, the attendee would show with an entourage of friends in tow, as to deflect any attempt at romance. Don found this experience to be troublesome and unnecessary, so he sought to be a popular face on campus through his disc jockey radio show. Quickly he became the voice of campus, a personality that everyone came to love and whose broadcasts were known as “Saturday Fever.” His role on campus was further cemented with his participation with Clowns for Christ, a student organization that he remained involved in for the remainder of his college career.

Although he was not aware of his autism in college, Don did find engaging with faculty rather easy. He attributes this to a campus that did not have a tenure system, which created a campus culture that was based on a “substantial amount of access to professors.” During his one year as a physics teacher, seven years after college, he was

able to call on a former professor to help problem solve a physics equation, a testament to the commitment to relationship building between faculty and students at his alma mater.

It is important to note that by Don's own admission he did not know what Asperger's was until he was 26, long after completing high school and college. "I entered college in 1998 and Asperger's wasn't in the DSM until 1994." While he felt academically prepared for college he was not prepared for the other aspects of being a college student:

The distinction is that although I had earned good enough grades to get where I wanted to go, and scored high enough on the SAT and various AP test to get lots of college credit prior to high school graduation, I was not prepared for REAL LIFE in high school.

In particular he advocates emphatically for practicum experiences for college students who have autism.

Without question, they need as much REAL LIFE EXPERIENCE as they can possibly get. We need less "sitting in class" and more "learning by real-life experience"...and by that I DO NOT mean "unpaid" real-life experience. It has to pay SOMETHING even if minimum wage or less (so that the student can survive)...or at least by "tuition-free." People with Asperger's are going to be better than average at book learning," generally speaking, but the majority of our problems come in the form of being incompatible with the type of "real life" generally chosen and pursued by neurological people. There are alternatives, but the important thing is that people with Asperger's have to be made aware of those alternatives. You don't HAVE to have an 8-to-5 job. You don't HAVE to live in



the same place for years. You are NOT necessarily limited by what you think are your personality tendencies. For example, I've never gotten along with people, en masse. I can get along with them as acquaintances but I've never had many friends, even though I've always been well liked (at least starting from age 15) because I am a "decent person." I don't generally like large crowds. Yet, I'm a musical entertainer and I love it. I'm around large crowds all the time. How is it that I enjoy that when I don't generally like large crowds? It all comes down to the mechanics of the interaction. I don't do well with the "rules of social engagement," so when I am subject to those rules, I am uncomfortable. However, when I am the entertainer, I'M IN CHARGE. I MAKE THE RULES. When I make the rules, I can be in a crowd of limitless size. Would I have ever imagined that I'd enjoy a life like this? Not in school. All they taught me in school was how to be a good employee, to an extent.

### **Chapter Summary**

In summary, this chapter presents the narratives of six participants to provide first person insight into the social experiences of college students who have autism, focusing on experiences that influence persistence and retention. Data analysis of the interviews and written responses provided responses to the two research questions that guided this study: What are the social experiences of college students who have autism? And, what role(s) do various social experiences play in the persistence and retention of college students who have autism? No participant identified as a college student with autism in isolation. Each student experienced autism in concert with co-morbid identities, for example ethnic or racial identities, sexual orientation, adult diagnosis, etc. Case reviews

of each participant are also offered to further illustrate the complex identities of each student as briefly outlined in Table I. In the final chapter, Chapter 5, limitations and implications for further research and recommendations will be introduced. Meaning for the findings will be assigned and discussed for Student Affairs practitioners, as well as Higher Education Disability Studies scholars. Lastly recommendations for further research will be presented.

## **Chapter Five: Interpretation and Recommendations**

This chapter provides a review of the study's purpose, research questions, methodology, and results. Limitations for the study, as well as contributions to existing scholarship and higher education practice are also addressed. Research and discussion on the prevalence of autism spectrum disorders in education is longstanding, albeit almost exclusive to secondary students (Connor, 2013; Moores-Abdool, 2010; Newschaffer, Falb, & Gurney, 2005). Furthermore, there is a gap in the research literature that does not capture the first person experiences of college students who have autism, limiting the basis by which colleges and universities have to create retention practices for this diverse community.

The purpose of this phenomenological study's semi structured interviews was to identify the social experiences of college students who have autism and the role(s) that social experiences play in their persistence and retention. The following research questions were a guide for this study: what are the social experiences of college students who have autism? What role(s) do various social experiences play in the persistence and retention of college students who have autism? Analysis of the participant interviews identified seven shared themes amongst the social experiences of college students who have autism: diverse experiences in campus engagement, the impact of noise on participation and campus engagement, living accommodations, faculty engagement and socialization, intentionality with peer and classmate interactions, romantic experiences and peers as mentors.

### **Summary of Results**

Analysis of the participant interviews identified seven shared themes amongst the social experiences of college students who have autism: diverse experiences in campus engagement, the impact of noise on participation and campus engagement, living accommodations, faculty engagement and socialization, intentionality with peer and classmate interactions, romantic experiences and peers as mentors.

Half of the participants shared that they are either intentionally not engaged or cautiously engaged with social events on campus. With engagement influenced by the size of the crowd, general disinterest, and anxiety associated with being spread too thin and not being able to focus appropriately on academics. Noise levels at events significantly factored in to the decision to engage socially with campus. The amount of noise present at campus events, and the lack of control over the noise presented a concern for some participants, influencing their decision to avoid attending.

All of the participants, with the exception of the lone first year student, lived off campus with family and commuted daily. The additional financial burden of on campus housing was overwhelmingly the primary reason the participants decided to reside off campus. Despite the challenges of commuting, traffic and parking can be unpredictable; each of the participants felt a better financial return on their decision. One third of the students reported that not living on campus did influence their social engagement on campus, however, they did not actively seek out alternative ways to be engaged with other peers, organizations related to their academic major, service organizations, etc. One participant particularly noted that living on campus could increase his attentiveness to events. However, he did not consider changing his living accommodations.

In contrast to campus engagement, each of the participants reported engaging with faculty without any reluctance, finding it effortless to talk with faculty about courses, their academic major, and other relevant topics that arose. Unlike being intentionally reluctant and selective to engage socially with the campus community participants recalled their relationships with faculty with fondness and admiration for supporting academic success in individual courses, as well as overall undergraduate enrollment. To some extent those positive experiences extended to peer interactions outside of the classroom, in the form of purposefully crafted friendships, with classmates from high school, residential hall mates, and the campus community as a whole. Half of the participants talked about creating friendships with purpose, i.e., to support academic achievement, or to create a social identity.

Half of the participants referenced romantic relationships during their college career in their discussion. Although none of the participants attended college with the hope or intention of meeting their significant other, sexual identity and orientation played some role in their social experience, be it positive or negative.

Lastly, unique to the sole first year student and only student living in university housing, developing a relationship with peer Resident Assistants was a salient theme for Norris. Purposefully focused on academic success, with concern for being able to incorporate co-curricular activities without failure, Norris looks to his Resident Assistant for guidance and invitation to participate in specific extra curricular opportunities on campus. Norris's relationship with his Resident Assistant was purposeful and affirming, helping him to identify the value of stepping outside of his own comfort zone to get involved with an academic club, while still doing well in his classes.

## Discussion of Findings

College students with autism spectrum disorders face a unique array of scenarios that both directly and indirectly impact their readiness and success in higher education. First person narratives from the body of diverse students provide insight into the complexities of identity based on their narration, social experiences, and relationships with others. This includes identity as a college student, as a person with autism, as a person of color, as well as identity as a member of the LGBTQIA community.

The seven themes and the individual case review for each participant will be used in this section to answer the two research questions for this study. The commonality across all of the participant data is that as individuals and collectively as a group the participants are people first. Individuals with unique talents, skills, goals, and dreams that they are working to accomplish through post-secondary education. Not one participant was their diagnosis. Their individual and collective identity transcended any cognitive construct or DSM-V diagnosis. They are musicians, budding scientists, history buffs, and artists. The participant data is presented and summarized below.

RQ #1: What are the social experiences of college students who have autism?

The participants in this study shared that in most instances they chose not to engage with campus based social experiences intentionally (Theme #1) due to challenges that noise and crowds presented at campus events (Theme #2). The unpredictability of a crowd's size, behavior and decibels discouraged attendance at events that are traditionally seen as the bedrock for the undergraduate student experience. Due to unpredictability the participants overwhelmingly avoided campus events, for example athletic events, concerts, pep rally or kick off events, and the like. Astin's (1999) work on the

intersection of environment, student identity, persistence, and student involvement can be seen in the connections that the participants made with faculty. Likewise the connection with faculty appears to build a foundation of support and affirmation that encourages persistence, personal exploration, and academic growth (Milem & Berger, 1997). And in the instance of the one participant who lived on campus, the connection he made with his Resident Assistant also fostered personal exploration and persistence. Yet, as I interpret Astin's (1999) work the participants overwhelmingly miss the true essence of what I believe is his contribution to student development theory, which is engaging with and experiencing campus life and those experiences becoming the foundation for their expanding adult identity and subsequently a primary factor in post-secondary persistence and retention. What a disservice to this population of students. Their frustration with this expectation is evident:

There's all of these expectations to participate in all of the stuff and these things and attend a football game, attend uh, uh, attend here, attend...it's almost as if social interaction is demanded at times...and if not, uh, then people think, they'll think you're just one of those people.

Yet, in a broader context, the participants' social experiences were inclusive of intentionally crafted and maintained friendships with people off campus, their almost collegial friendships with faculty, and romantic relationships. The participants were not using campus as their hub for communication, connection, nor identity, yet, were still having incredibly valuable social experiences as college students who have autism.

In Chapter 2, I shared that the environment we ask college students who have autism to adapt into needs improvement. The narratives of the participants support this.

When asked about their level of campus engagement Don shared: “I don’t generally like large crowds.” Mary offered the following, “Is there going to be a lot of noise? Okay. Am I able to manage it? If not, don’t go.” A quick glance at any undergraduate new or transfer student orientation is filled with standard welcome activities: a welcome class of 2020 pep rally complete with the university marching band and cheerleaders, a team scavenger hunt, comedy show/late night party with a special guest celebrity DJ, and last but not least an activities fair where student organizations, community partners, and critical student affairs units are on showcase to solicit new membership or volunteers for the academic year. Noise sensitivities aside, an incredibly outgoing student who draws energy from meeting new people could very well be depleted after such an intense orientation experience. Yet, we generally expect all of our students to participate in campus activities without forethought and quite foolishly demand identity development through these types of activities, much to the disservice of students who have autism. How then can institutions promote greater student success with consideration of Engstrom and Tinto’s (2008) student development theory that attributes some persistence and retention issues to institutional environments that are established without incorporating the diversity of the key stakeholders, i.e., the students? I believe that we cannot continue to maintain universal engagement expectations exclusive of our students’ neurodiversity.

RQ #2: What roles do various social experiences play in the persistence and retention of college students who have autism? As evidenced by this sample population, social experiences do not appear to influence persistence and retention. With the exception of Norris, who intentionally sought out social experiences with his Resident



Assistant and who is motivated to increase his social experiences on campus by establishing new friendships, each of the other participants' persistence and retention is influenced by other factors including: parental and familial support, the proximity of the institution from family; and the opportunity to reside at home, thereby eliminating on campus housing expenses.

None of the participants worked with their secondary educators to create a transition plan for navigating the matriculation from high school to college. There were no intentional discussions about the difference in receiving disability accommodations through an Individualized Education Plan, IEP, in high school versus self-identification and the request for accommodations as a college student. Likewise none of the students explored the autonomy and self-determination that being a college student presents, or how this can influence campus engagement, navigating social capital or linguistic idioms (Wehman et al, 2014) like the one Mary shared:

Mary: It, it's not...it's not easy to connect at all as it is. So if I just understand you, I'm happy as a clam.

Researcher: <Laughter> That's an old school saying, I'm happy as a clam.

Mary: I have no idea what that actually means happy as a clam, but it's a phrase that everybody understands. Does it mean happy, happy, joy, joy.

Researcher: Right.

Mary: So therefore, I understand how to employ it.

Researcher: Yeah

Mary: But seriously, I don't know if a clam could be happy or not.

Researcher: I, I don't under – Now that you say that I don't know that I understand the origin either. Um...

Mary: Think...but all of these nuances...

Researcher: Right.

Mary:...th-that you hear every day and don't even stop to think about because it, it just is.

Researcher: Mm-hmm (affirming).

Mary: I stopped thinking about every single one of them that I hear, like what the hell are you trying to say to me.

The diversity within the social experiences of college students who have autism is important and valuable to understand. While the persistence and retention of this study's participants does not appear to be influenced by their social experiences, it is critical nonetheless to understand what experiences students are having, what experiences they are avoiding all together on campus, and the types of experiences they are creating for themselves throughout the course of their college enrollment.

College students who have autism are not a homogenous group (Gobbo & Shmulsky, 2013). The diversity of this sample underscores this and provides an illustration of how unique the needs of the students are based on their age, co-morbid conditions, diagnosis and age of diagnosis, and previous post-secondary education experiences. The uniqueness of each student should not be a deterrent to seek further understanding of what college students who have autism experience on our campuses. Likewise an absence of transferability to other institutions or larger communities of college students who have autism due to the diversity of the participants' experiences

should not negatively influence further exploration. When asked what motivated him to respond to Mary's call for peer participants, Don shared that autism plays a significant role in his adult life (Longtin, 2014), he has had 14 different jobs after college, and felt it his duty to "be a part of the movement that seeks to understand autism."

### **Summary Statement**

In summary, uncovering rich data from five distinctly diverse college students who have autism and one spouse informed factors related to their college experience, course completion, and graduation (Wehman et al., 2014). Participants in this study shared that in most instances they intentionally chose to not engage with campus based social experiences (Theme #1) due to challenges that noise and crowds present at campus events. Instead the participants actively sought and selected social experiences with peers that they have a history with, for example former high school classmates. In conclusion, it is unknown if the intentional disconnect with campus is due in part to the complex nature of autism itself. Or if the disconnect is the product of a lifetime of being forced to engage with environments that do not take into account diverse abilities and needs (Ne'eman, 2009).

### **Implications for Further Research**

Although snowball sampling produced a diverse cross section of participants inclusive of age, gender, academic major and classification, diagnosis, and age of diagnosis the study's findings are not intended to be transferable to other post secondary institutions that enroll students who have autism spectrum disorders. Instead the study's findings present an opportunity to identify implications for further research. Additional research using quantitative methods, specifically a Likert Scale survey, to explore why,

or by what influence(s) students are maintaining college enrollment would add additional depth to the body of research. Further exploration into the role that family plays in supporting and inspiring students could be considered. Each of the students that referenced a parent in the discussion, Mary, Gary and Norris, and the two students that offered a parent for extended interviews, John and Norris, spoke specifically about their mother. While there can be any number of variables at play, research about the role of mothers, or mothering, in the persistence and retention of college students who have autism would be a valuable research extension.

The role of faculty is introduced in this study and can certainly be explored for more in depth dissection. Specifically, what role, if any, early connections to faculty play (Milem & Berger, 1997) in establishing purpose and academic identity. Does early exposure to faculty, like Norris's as a first year student, establish a rapport that complements student services staff? Or build upon the examples of scholarship that were demonstrated in high school, specifically relevant for students who were enrolled in Advanced Placement (AP) courses or completed a International Baccalaureate (IB) program. Similarly disability services staff are discussed, almost exclusive to providing accommodations, yet, their roles in the persistence and retention of college students who have autism can be explored more explicitly (Robertson, 2010). What type, if any, of case management does disabilities services staff provide students who are on the autism spectrum? Is there consistent and intentional outreach that is proactive, or does the staff engage with the students in more reactionary ways after failing grades or concerns by faculty are raised. Are the disabilities support staff intentionally collaborating with career services staff to provide mentorship and training on resume building, interviewing,

and personal communication throughout a student's collegiate career so they are competitive amongst peers for internship placement and job opportunities before graduation? Case studies on the preparation or internship/job readiness boot camp experiences would provide incredible insight into techniques that can be beneficial to a diverse body of students, with differing social abilities and academic competencies.

A mixed method approach combining a Likert Scale survey with focus groups could potentially present a unique opportunity for participant observation. Specifically analyzing the patterns of communication within a group with similar diagnosis could take learning and supporting college students who have autism to new heights. Social and communication abilities as well as deficits are well documented (CDC, n.d.; Connor, 2013; Robertson, 2010), however, there does not appear to be research that convenes focus groups amongst adults with autism as a research tool. John's recommendation for a social group on campus for students who have autism to ease the anxiety of communicating could support this type of mixed methods research.

Two of the participants identified as persons of color, yet, there is very little literature about the role within the context of autism, if any, that race plays in the matriculation of students from high school to college, and their racial identity development (Pinder-Amaker, 2014; Robertson, 2010; Shattuck et al, 2014). This is definitely an area for further research. Lastly an additional opportunity for research exists in the identification and study of peer support or social groups for college students who have autism. Do other institutions have peer-facilitated groups as a safe space for students with autism to socialize and develop friendships or explore romantic relationships? If so, how do these groups function? Are they housed within disability

services, or does diversity and inclusion staff incorporate this community into their portfolio?

### **Implications for Practice and Recommendations**

As evidenced by Kelley & Joseph (2012) and Prince-Hughes (2002) there is a gap in the literature that does not capture the first person experiences of college students who have autism. Milem & Berger (1997) explored the relationship between campus involvement and persistence within the general student body, concluding that students that are engaged and have an identity on campus, or relationships with peers and faculty are more successful at persisting. This study can be used among student affairs practitioners and disability services advocates to examine and challenge existing campus culture related to student engagement and involvement, following Milem & Berger's (1997) prior research.

Culture and presumptions that do not account for neuro-diversity can be a disservice to the entire campus community. Often times class participation and public speaking are components of course grades. Mary shared her own experience where she confidently was able to advocate for an alternative way to participate in a seminar; in spite of what she felt was the instructor's reluctance to deviate from the syllabus. Using universal design to be inclusive of different cognitive abilities and learning styles, giving diverse learners access to present their comprehension of the course's material (McKeon, Alpern, & Zager, 2013) can be implemented to encourage persistence and retention. Centers for Teaching and Learning would be a resource for existing faculty and Teaching Assistants, who are preparing to be faculty, to learn more about incorporating universal design in their courses to be responsive to diverse cognitive ability for students who do

and choose not to self- identify. It will be important to extend this professional development opportunity to faculty, adjuncts, and Teaching Assistants to increase awareness of cognitive diversity and shift the campus culture.

As recommended by John, college students who have autism may benefit from the creation of a social group where familiarity in communication styles is established, easing any apprehension (Burkhardt, 2008). Although there was an attempt to facilitate a social communications group at the sample institution, the scope, objective and delivery of the group may have missed the mark for students since no students participated. Perhaps a more organic group, created by students, supported by disability services, and guided by the perspectives of students at community colleges that feed into the sample institution, as well as students currently enrolled at the sample institution, instead of a group facilitated by faculty would be better received. Engaging students requires a delicate balance, an art of sorts, between providing an opportunity and managing an outcome.

In complement to the university's teaching mission, questions for student affairs practitioners and disability service advocates to consider include: what role, if any, does on campus residency play in campus engagement? Do opportunities exist for commuter students to engage in social activities, academic organizations, and service-learning opportunities at varied times throughout the day? That is, are events traditionally held at night with unchecked preference for residential students who do not have to travel? Lastly, are campus engagement opportunities created with universal design strategies to incorporate different abilities? Specifically the following campus events can be evaluated for inclusivity: new and transfer student orientation, student activities' night,

residential room selection process as well as student staff recruitment and selection, and alternative spring break excursions. Objective evaluation of these events with attention to location, design, and noise levels could provide new streams of engagement for college students who have autism spectrum disorders.

### **Limitations**

There are four limitations that emerged during the facilitation of this study, specifically during the recruitment of participants: low response rate, mode of participation offered, stigma, and sample site gatekeepers. Thirteen recruiting sources were identified for collaboration and to disseminate the call for participants, however, only five of the recruiting sources agreed to participate. The reluctance for gatekeepers within the sample institution, academic advising and STEM faculty, to share the announcement was unexpected and unfortunate. Although the gatekeepers encouraged partnership with disability services the missed opportunity to reach students who are not registered with disability services was an influential limitation.

It is believed that stigmas associated with autism and/or seeking support from disability services is a barrier (Shattuck et al, 2014) and proved to be the second limitation for this study. Populations reticent to research include persons who have autism (Haas et al, 2016; Lennox, 2005) in part due to the stigmas associated with having autism and self-identification. To offset this limitation and account for any anxiety that the students felt about face-to-face interviews after the second month of recruitment I incorporated two different modes of interviewing, Skype Chat and Q&A via email exchanges.



Lastly, the low response rate resulted in a smaller sample size than initially projected. Although the responses represent 14% of the population of students who have autism and are registered with the Office of Educational Accessibility and the sample is diverse, the low response rate influences the transferability of results.

### **Self Reflection**

My connection to autism pre-dates my work in higher education. Over the last decade or so I have been fortunate to have friendship with classmates and colleagues who are purposefully, courageously and openly reflective while parenting adolescents and teenagers who have autism spectrum disorders. In one particular friendship milestones, successes, medical challenges and moments of uncertainty were typically explored with a glass of wine and questions about the future. What opportunities for post-secondary education would exist after high school? It was already determined that continuing the maternal Ivy league legacy would not be an option for fear of the pressure and social culture.

The first college student to self-identity to me did so when I was serving as a university case manager, somewhere around 2010. Few resources existed for student affairs professionals at the time; *Students with Asperger Syndrome: A Guide for College Personnel* was a good resource that prompted more questions and discussions with my then supervisor and colleagues. I began to look for additional resources that would expand my practitioner's knowledge of how to meet the needs of college students who have autism spectrum disorders.

After my role as case manager, I served as an assistant dean of students at a different university and received a faculty report about a student whose after class

behavior concerned another student. On the surface it appeared that the offending student had inappropriate social and cultural boundaries or behaviors. Multiple traditional attempts to reach the student through email, voicemail, and residential life staff wellness check-ins were to no avail. However, one day the student appeared in my office and we met, seated across from each other at a small round conference table. Fleeting eye contact. No verbal communication. None. Slightly inaudible grunts. And silence. Considerable silence. Which I was used to in my case manager role. However, that time it was much different.

I have never teared up while meeting with a student. Ever. Until that day when I realized how we failed to be inclusive and accessible to all students. That day will always stand out as I realized had I not taken the time to patiently see it through no one at the university would have been any wiser as to some sort of understanding for his behavior. Even after sharing my meeting with my supervisor and colleagues in disability services there was no groundswell of interest or concern. An upperclassman, a scholar by all accounts, Dean's List multiple semesters, non-verbal, was living in our residence halls, and WE did not know he existed until someone perceived there to be a problem. That experience is the driving force for this research.

This research is necessary because we, the academy, student affairs practitioners, educators do not recognize invisible disabilities on campus. It is far easier to recognize and be actionable for a student who presents with a physical or visual impairment, in the form of a veteran with a traumatic brain injury or a student with a guiding dog. However, we are missing the opportunity to provide support and a sense of community for another diverse group of students – students who have autism. There is an astounding amount of

attention given to children with autism, in the form of intervention services, coaching for parents on how to navigate accommodations in public education, tips on securing appropriate medical care, etc. But there are glaring omissions from all of these laudable yet, shortsighted campaigns. Secondary students grow up. And they go to college. What attention is systemically drawn to their preparation for college and experiences as college students? This is the void that my research will contribute to.

### **My Role As Researcher**

Finding participants for this study proved to be more difficult than I anticipated. More difficult than recruiting for the pilot study and without any reason that I could understand. My recruitment efforts were actually more exhaustive for this study. In addition to recruiting on campus, I attempted to recruit at two other institutions, however, neither attempts were successful. Recruiting on campus through email, flyers, and campus television announcements seemed to be uneven, in part because there are so many ways that students can ignore messaging. Discouraged by slow recruitment, I did gain perspective about my numbers after learning that faculty in the Speech & Hearing Clinic were not successful recruiting any students at all for a social communications support group that they launched.

Taking a step back from all of my efforts to meet students where they are, encouraging them to respond to the call for participants, I began to shift my thinking to the bigger picture. The impact of self-identification must be acknowledged. There is disparity between the number of undergraduates and the number of students registered with the Office of Educational Accessibility (OEA). The number of students with disabilities is drastically underreported as there are less than 1,000 students registered on

a campus of almost 20,000 undergraduate students. NCES data (2015) tells us that on average eleven percent of undergraduates reported having a disability, with variations within categories like gender, race/ethnicity, age and military affiliation. Teasing out race/ethnicity, age and military affiliation alone, should increase the number of students registered with OEA as the campus is heralded as a military friendly institution with an exceptionally diverse undergraduate and graduate student population.

The reticent nature of underrepresented populations, specifically persons with intellectual and cognitive disabilities, likely compound the response rate for this study. In addition to the 6 participants that I did interview there were 4 others who expressed interest in participating in the study. Two students communicated with me via email in fairly regular intervals, yet, could not commit to an actual interview. Similarly one of the six students who did participate confided that it took him two months to express interest by completing the Qualtrics survey. I would be naïve to ignore the role that autism plays in a student's ability to express interest in participating and actually follow through with that interest. I am thankful for the participants who were eager and able to participate.

When I asked the participants why they agreed to talk to me the responses I received were heartfelt. Either they wanted to be apart of a conversation about autism because they realized how little attention adults with autism receive therefore they wanted to contribute to the good of the discussion. Or they were curious about how autism was represented on campus and met with me to find out what my perspective was. For each participant, their agreement to talk with me supported their commitment to influencing what we know about autism. Throughout the course of the interviews I learned how each student is unique. Which will allow me to share the participants

experiences with university staff to adjust service areas that are not conducive to the type of social environment that some college students who have autism may need.

### **Summary and Conclusion**

This research study was purposefully developed to capture the voices of college students who have autism spectrum disorders. To accomplish this two research questions were the guide for this study: what are the social experiences of college students who have autism, and what roles do various social experiences play in the persistence and retention of college students who have autism? The participants in this study shared that in most instances they chose not to engage with campus based social experiences intentionally due to challenges that noise and crowds presented at campus events. Yet, the students intentionally developed social connections outside of campus with friends and family. It is these social connections, those that exist outside of the campus, that appear to influence persistence and retention. It is important to note that the diversity of this sample population may be an anomaly, further influencing the transferability of this research. In spite of this limitation, uncovering rich narratives from six participants establishes a foundation for the diversity of background (Robertson, 2010) and experiences within college students who have autism, and supports the commitment to additional qualitative and quantitative research about the role(s) of family, influence of co-morbid diagnosis, and the journey of racial identity development within the context of autism. In closing, this study is successful in filling the literature gap by capturing the first person experiences of college students who have autism by recording that narratives of six diverse participants.

## References

- Astin, A. (1999). Student involvement: A developmental theory for higher education. *Journal of College Student Development, 40*(5), 518-529.
- Baron-Cohen, S., Wheelwright, S., Burtenshaw, A., & Hobson, E. (2007). Mathematical talent is linked to autism. *Human Nature, 18*(2), 125-131.
- Burkhardt, S. (2008). The challenge of social competence for students with autism spectrum disorders (ASDs). *Autism and Developmental Disabilities: Current Practices and Issues, 8*, 1-24.
- Centers for Disease Control and Prevention. (2014). Community Report on Autism. Division of Birth Defects and Developmental Disabilities. National Center on Birth Defects and Developmental Disabilities.
- Chiang, H., Cheung, Y., Hickson, L., Xiang, R., & Tsai, L. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal Of Autism & Developmental Disorders, 42*(5), 685-696.
- Chown, N., & Beaven, N. (2012). Intellectually capable but socially excluded? A review of the literature and research on students with autism in further education. *Journal of Further and Higher Education, 36*(4), 47-493.
- Colclough, M. (2015). *Understanding the experiences of college students who have autism: Executive summary*. Unpublished manuscript, Old Dominion University.
- Connor, D., (2013). Kiss my Asperger's: turning tables of knowledge. *International Journal of Inclusive Education, 17*(2), 111-129.
- Couzens, D., Poed, S., Katoaka, M., Brandon, A., Hartley, J., & Keen, D. (2015).

Support for students with hidden disabilities in universities: A case study.

*International Journal of Disability, Development, and Education*, 62(1), 24-41.

Creswell, J., & Miller, D. (2000). Determining validity in qualitative inquiry. *Theory Into Practice*, 39(3), 124-130.

Cullen, J. (2015). The needs of college students with autism spectrum disorders and Asperger's Syndrome. *Journal of Postsecondary Education and Disability*, 28, 89-101.

Definition of Intellectual Disability. (n.d.). Retrieved from

<http://aaidd.org/intellectual-disability/definition#.Vb7A8c627PA>

Denzin, N., & Giardina, M. (2015). Qualitative inquiry and the politics of research. Retrieved from <http://www.ebib.com>

Disability Documentation Guidelines. (n.d.). Retrieved from

<https://www.ahead.org/affiliates/connecticut/documentation#E>

Ditterline, J., Banner, D., Oakland, T., & Becton, D. (2008). Adaptive behavior profiles of students with disabilities. *Journal of Applied School Psychology*, 24(2), 191-208.

Eckes, S., & Ochoa, T. (2005). Students with disabilities: Transitioning from high school to higher education. *American Secondary Education*, 33(3), 6-20.

Elliott, J.M. (1995, March 16). Edward V. Roberts, champion of the disabled. *The New York Times*. Retrieved from

<http://www.nytimes.com/1995/03/16/obituaries/edward-v-roberts-56-champion-of-the-disabled.html>

- Engstrom, C., & Tinto, V. (2008). Access without support is not opportunity. *Change: The magazine of higher learning*, 40(1), 46-50.
- Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, 33, 2177-2192.
- Gardiner, E., & Iarocci, G. (2014). Students with autism spectrum disorder in the university context: peer acceptance predicts intention to volunteer. *Journal of Autism Developmental Disorders*, 44(5), 1008-1017.
- Gobbo, K. & Schmulsky, S. (2012). Classroom needs of community college students with Asperger's disorder and autism spectrum disorders. *Community College Journal of Research and Practice*, 36(1), 40-46.
- Gobbo, K., & Shmulsky, S. (2013). Faculty experience with college students with autism spectrum disorders: A qualitative study of challenges and solutions. *Focus on Autism and Other Developmental Disabilities*, 29(1), 13-22.
- Gordon, M. & Keiser, S. (Eds.) (1998). Accommodations in higher education under the Americans with Disabilities Act (ADA). GSI Publications, NY. Guilford Press, NY.
- Haas, K., Costley, D., Falkmer, M., Richdale, A., Sofronoff, K. (2016). Factors influencing the research participation of adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 1-13.
- Hammond, L. (2015). Meeting their needs: Transition to college with an autism spectrum disorder. *The Vermont Connection*, 35(6), 47-54.



- Hart, D., Grigal, M., & Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorders and intellectual disabilities. *Focus On Autism And Other Developmental Disabilities, 25*(3), 134-150.
- Hays, D., & Wood, C. (2011). Infusing qualitative traditions in counseling research designs. *Journal of Counseling & Development, 89*, 288–295.
- Hays, D., & Singh, A. (2012). *Qualitative inquiry in clinical and educational settings*. New York, NY: Guilford.
- Henderson, C. (2001). College freshmen with disabilities, 2001: A biennial statistical profile. *American Council on Education*. Washington, DC.
- Hock, R., & Ahmedani, B. (2012). Parent perceptions of autism severity: Exploring the social ecological context. *Disability and Health Journal, 5*, 298-304.
- Hughes, C., & Smith, J. (1990). Cognitive and academic performance of college students with learning disabilities: A synthesis of the literature. *Learning Disability Quarterly, 13*(1), 66-79.
- Hughes, J. (2009). Supporting college students with Asperger Syndrome: Possible strategies for academic advisors to use. *The Mentor*. Retrieved from <https://dus.psu.edu/mentor/>
- Kelley, L., & Joseph, B. (2012). Rethinking higher education for students with autism spectrum disorders: The importance of adult transitions. Retrieved from [http://www.cscconline.org/files/6713/3097/9778/Rethinking\\_Higher\\_Education\\_for\\_Students\\_with\\_Autism\\_Spectrum\\_Disorders\\_APA.pdf](http://www.cscconline.org/files/6713/3097/9778/Rethinking_Higher_Education_for_Students_with_Autism_Spectrum_Disorders_APA.pdf)
- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D., & Boyle, F. (2005).

- Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, 49(4), 296-305.
- Longtin, S. (2014). Using the college infrastructure to support students on the autism spectrum. *The Journal of Postsecondary Education and Disability*, 27(1), 63-72.
- Lounds, T., Dove, D., Veenstra-VanderWeele, J., Sathe, N., McPhetters, M., Jerome, R., & Warrenz, Z. (2012). Interventions for adolescents and young adults with autism spectrum disorders. Agency for Healthcare Research and Quality. *Comparative Effectiveness Reviews*, 65. Executive Summary. Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK107268/>
- Matson, J., Wilkins, J., & Ancona, M. (2008). Autism in adults with severe intellectual disability: An empirical study of symptom presentation. *Journal of Intellectual and Developmental Disability*, 33(1), 36-42. doi: 10.1080/13668250701829837
- Matson, J., Rivet, T., Fodtsad, J., Dempsey, T., & Boisjoli, J. (2009). Examination of adaptive behavior differences in adults with autism spectrum disorders and intellectual disability. *Research in Developmental Disabilities*, 30, 1317-1325.
- Matson, J., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, 30, 1107-1114.
- McMahon, D., Cihak, D., & Wright, R. (2015). Augmented reality as a navigation tool to employment opportunities for postsecondary education students with intellectual disabilities and autism. *Journal of Research on Technology in Education*, 47(3), 157-172.
- McKeon, B., Alpern, C., & Zager, D. (2013). Promoting academic engagement for

- college students with autism spectrum disorder. *AHEAD Association*, 26(4), 353.
- Milem, J., & Berger, J. (1997). A modified model of college student persistence: Exploring the relationship between Astin's theory of involvement and Tinto's theory of student departure. Center for International Education Faculty Publications. Paper 11.
- Miller, D., & Salkind, N. (2002). *Handbook of research design & social measurement* (6<sup>th</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Moores-Abdool, W. (2010). Included students with autism and access to general curriculum: What is being provided? *Issues in Teacher Education*, 19(2), 153-169.
- Ne'eman, A. (2009). The future (and the past) of autism advocacy, or why the ASA's magazine, the advocate, wouldn't publish this. *Disability Studies Quarterly*, 30(10).
- Newman, L. (2007). *Facts from NLTS2: Secondary school experiences of students with Autism*. Retrieved from the National Center for Special Education Research website: <http://ies.ed.gov/ncser/pubs/20073005/>
- Newschaffer, C., Falb, M., & Gurney, J. (2005). National autism prevalence trends from United States special education data. *Pediatrics*, 115(3), e277-e282.
- ODU Factbook, (n.d.). Retrieved from <http://www.odu.edu/content/odu/about/facts-and-figures/factbook.html>
- Pelka, F. (2012). *What we have done: An oral history of the disability rights movement*. University of Massachusetts Press, MA.
- Pillay, Y., & Bhat, C. (2012). Facilitating support for students with Asperger's

- Syndrome. *Journal of College Student Psychotherapy*, 26, 140-154.
- Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22(2), 125-137.
- Prince-Hughes, D. (2002). *Aquamarine blue 5: Personal stories of college students with Autism*. Athens: Swallow Press/Ohio University Press.
- Reis, S., Neu, T., McGuire, J. (1997). Case studies of high-ability students with learning disabilities who have achieved. *Exceptional Children*, 63(4), 463-79.
- Remy, C., & Seaman, P. (2014). Evolving from disability to diversity: How to better serve high-functioning autistic students. *Reference and User Services Quarterly*, 54(1), 24-28.
- Robertson, S., & Ne'eman, A. (2008). Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly*, 28(4), 14.
- Robertson, S. (2010). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, 30(10).
- Rubin, H., & Rubin, I. (2012). *Qualitative interviewing: The art of hearing data* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Sappok, T., Budczies, J., Bolte, S., Dziobek, I., Dosen, A., & Diefenbacher, A. (2013). Emotional development in adults with autism and intellectual disabilities: A retrospective, clinical analysis. *Plos One*, 8(9).
- Schalock, R., & Luckasson, R. (2004). American Association on Mental Retardation's definition, classification, and system of supports and its relation to international

- trends and issues in the field of intellectual disabilities. *Journal of Policy & Practice in Intellectual Disabilities*, 1(3/4), 136-146.
- Schwitzer, A. (2005). Self-development, social support, and student help-seeking: Research summary and implications for college psychotherapists. *Journal of College Student Psychotherapy*, 20(2), 29-52.
- Shattuck, P., Narendorf, S., Cooper, B., Sterzing, P., Wagner, M., & Taylor, J. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129(6), 1042-1049.
- Shattuck, P., Steinberg, J., Yu, J., Xin, W., Cooper, B., Newman, L., & Roux, A. (2014). Disability Identification and Self-Efficacy Among College Students on the Autism Spectrum. *Autism Research and Treatment*, Volume 2014, Article ID 924182. doi: 10.1155/2014/924182
- Tamura, E. (Eds.) (2008). *The history of discrimination in U.S. education: Marginality, agency, and power*. Retrieved from Google Play
- Taylor, R. (1997). *Assessment of exceptional students: Educational and psychological procedures*. Needham Heights, MA: Allyn & Bacon.
- Tinto, V. (2006-2007). Research and practice of student retention: What next? *Journal of College Student Retention: Research, Theory, & Practice*, 8(1), 1-19.
- U.S. Centers for Disease Control and Prevention. Autism spectrum disorders fact sheet. (n.d.). Retrieved from [http://www.arnionline.org/images/stories/pdf/AutismFactSheet\\_Spanish.pdf](http://www.arnionline.org/images/stories/pdf/AutismFactSheet_Spanish.pdf)
- U.S. Department of Education, National Center for Education Statistics. (2011). *Students*

*with disabilities at degree granting postsecondary institutions.* Retrieved from <http://nces.ed.gov/pubs2011/2011018.pdf>

U.S. Department of Education, National Center for Education Statistics. (2015). *Digest of Education Statistics, 2013* (2015-011), Chapter 3. Fast Facts, Retrieved from <https://nces.ed.gov/fastfacts/display.asp?id=60>

Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G. (2014). Transition from school to adulthood for youth with autism spectrum disorder: What we know and what we need to know. *Journal Of Disability Policy Studies, 25*(1), 30-40.

Wenzel, C., & Rowley, L. (2010). Teaching social skills and academic strategies to college students with Asperger's Syndrome. *Teaching Exceptional Children, 42*(5), 44-50.

Wessel, R. D., Jones, J. A., Markle, L., & Westfall, C. (2009). Retention and graduation of students with disabilities: Facilitating student success. *Journal of Postsecondary Education and Disability, 21*(3), 116-125.

White, S., Ollendick, T., & Bray, B. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism, 15*(6), 683-701.

Zager, D., Alpern, C., McKeon, B., Mulvey, J., Maxam, S. (2012). *Educating college students with autism spectrum disorders.* New York: Routledge, Taylor and Francis.

Appendix A  
Educational Accessibility Participants Call

Recruitment Announcement:

Are you an ODU student who identifies on the autism spectrum?

If you are interested in sharing your social experiences as a college student with autism and/or Asperger's Syndrome please complete a short sign up form with your name and email address, and I will be in touch with you to schedule a 45-minute conversation. Sign up here:

<http://tinyurl.com/ConversationsWithMonique>

Thank you for your help!

For more information please contact, Monique N. Colclough at [Mcolc001@odu.edu](mailto:Mcolc001@odu.edu)  
IRB Project # TBD

Appendix B  
University Announcements

Navigating College with Autism

Are you an ODU student who identifies on the autism spectrum?

If you are interested in sharing your social experiences as a college student with autism and/or Asperger's Syndrome please complete a short sign up form with your name and email address, and I will be in touch with you to schedule a 45-minute conversation. Sign up here:

<http://tinyurl.com/ConversationsWithMonique>

For more information please contact, Monique N. Colclough at [Mcolc001@odu.edu](mailto:Mcolc001@odu.edu)  
IRB Project # TBD



Appendix C  
Email to Pilot Participants

Hi -----,

I hope that you are doing well!

I am emailing you to see you if you would be interested and available for a follow-up interview after the Thanksgiving holiday? I am working on my dissertation now and would like the opportunity to talk in more detail about your social experiences as a college student. If you are interested and still in the Hampton Roads area please let me know! Thank you so much.

Monique

Appendix D  
STEM Participants Call

Dear ---:

I am Monique N. Colclough an ODU doctoral candidate, in the Darden College of Education, working to capture the social experiences of college students who have autism and/or Asperger's Syndrome, as a part of my dissertation work. Related to success and retention in higher education there is a gap in the research literature about the experiences of college students who have autism. Specifically, I am looking to schedule individual conversations/informal interviews with ODU students who are interested in sharing about their college experiences. I've already been connected with students who are registered with the Office of Educational Accessibility, and as a result met with a student in your college. The literature tells us that college students who have autism and/or Asperger's Syndrome are often pursuing majors in STEM areas (Baron-Cohen, Wheelwright, Burtenshaw, & Hobson, 2007) and may also not be registered with disability services on campus. In an attempt to reach more ODU students would you be willing to include my call for participants in any communiqué that you send to College of Sciences students?

I am happy to answer any questions that you may have about my research and IRB approval. In addition to communicating via email I can also meet with you in person if your schedule allows.

Regards,  
Monique N. Colclough

Appendix E  
Qualtrics Snapshot

Navigating College with Autism

Are you an college student who identifies on the Autism Spectrum?

If you are interested in sharing about your academic and campus experiences as a college student with autism and/or Asperger's, please complete a short signup form with your name and email address, and I will be in touch with you to schedule a 45 minute conversation.

Sign up here: <http://tinyurl.com/ConversationsWithMonique>

For more information please contact:  
Monique N. Colclough at [Mcolc001@odu.edu](mailto:Mcolc001@odu.edu).  
IRB Project #704413-1

## Appendix F Contact Summary Sheet

Interviewee ID: P00-  
Interviewed by: Monique N. Colclough

Interview Date: --/201-  
Contact Sheet Date: --/201-

### Contact Summary Sheet

*Understanding the Social Experiences of College Students Who Have Autism*

- 1. What were the main issues or themes that stuck out for you in this contact?**
- 2. What discrepancies, if any, did you note in the interviewee's response?**
- 3. Anything else that stuck out as salient, interesting, or important in this contact?**
- 4. General comments about how this interviewee's responses compared with the other interviewee?**

Appendix G  
Participant Demographic Questionnaire

**Participant Demographic Questionnaire**

**Gender Identity:** Male      Female      Transgender

**Race/Ethnicity:** African American, Asian American, Hispanic/Latino(a), Native American, White/European American, Biracial/Multiracial, Other Not Specified: \_\_\_\_\_

**Age:**

**Classification:**

**Have you attended any colleges or universities prior to your current one? If so, how many since high school:**

**Types of institutions attended (2yr, 4yr, technical, etc.):**

**Anticipated Highest Degree:** Associates, Bachelors, Masters, Educational Specialist, Doctorate

**Living Situation (On campus, Off Campus Alone/Roommate/Family):**

**IEP/Accommodations in high school:** Yes      No

**What activities: school, community, and/or faith based were you involved in, in high school?**

**Registered/Accommodations in College:** Yes      No

**What activities: school, community, and/or faith based are you involved in as a college student?**

## Appendix H Interview Protocol & Questions

### Interview Protocol:

Thank you for agreeing to meet with me today. Prior to beginning the discussion today I would like to go over a few housekeeping items: the informed consent and demographic form. You had an opportunity to review the informed consent before today; do you have any questions or comments?

<PAUSE, allow participants to complete form or ask questions >

If not, I would like to capture a few elements of demographic data, would you mind reviewing and filling out this form? As I continue to study and do research I would like to be informed of the demographics of college students who have ASD and/or Asperger's.

<PAUSE, allow participants to complete form or ask questions>

Ok, let's go ahead and get started. I am going to ask some questions about your general background and your experiences in high school to learn a little about you as well as your perceptions about the experiences you've had.

### Self-Identity

1. Where do you identify on the autism spectrum?

### High School Experience

1. When did you begin to think about attending college?
2. Were there any transition plans or programs that you participated in prior to, enrolling in college courses?

### College Experience

1. Are you registered with the Office of Educational Accessibility at ODU?
  - a. If so, are there any accommodations that you use?
2. Thinking back to your high school experience and your present college experiences, do you think that you were prepared for college?
  - a. Why, or why not? Please explain.
3. In your opinion, what type of academic or in-class support do you think college students with may ASD/Asperger's need?
4. Are the other areas that you think college students with ASD/Asperger's could use support in, if any?
  - a. For example communicating with faculty, navigating campus or administrative tasks (financial aid, registration, etc.), preparing for a career after college.
  - b. How do you get support in the areas you just identified, now?
5. How do you describe your social experiences as a college student?
  - a. Do you feel connected or engaged with peers, classmates, and faculty?
6. Do you feel engaged with the social events/offerings on and off campus?
  - a. Please explain why or why not.

7. Have you attended any events/activities on campus?
  - a. If you haven't attended any campus events or activities, is there anything that has prevented you from doing so?
8. Do you live on campus, off campus with roommates, at home with family?
  - a. How did you make the decision to live there?
9. Are there any significant successes or lessons that you've learned as a college student? How would you describe them?
  - a. What were the factors/who influenced your success or lesson?
10. Are there any things about your college experience that you wish were different?
11. Is there anything else that you would like to add that I might have not asked?

Appendix I  
Informed Consent

**Informed Consent**

**PROJECT TITLE:** Understanding the Social Experiences of College Students Who Have Autism

**INTRODUCTION:**

The purposes of this form are to give you information that may affect your decision whether to say YES or NO to participation in this research, and to record the consent of those who say YES. This qualitative study's purpose is to gain knowledge of the social experiences of college students with Autism Spectrum Disorders (ASD).

**RESEARCHERS:**

This research is being conducted as a part of FOUN 899 Dissertation:

Dr. Chris Glass, RPI

Phone: (757) 683-4118

Email: [Crglass@odu.edu](mailto:Crglass@odu.edu)

Doctoral student in Higher Education that is in charge of and conducting research:

Monique N. Colclough, MPA, MEd

Phone: (757) 645-7323

Email: [Mcolc001@odu.edu](mailto:Mcolc001@odu.edu)

**DESCRIPTION OF RESEARCH STUDY:**

Literature exists on the experiences of students with disabilities in higher education, but little research has been done in the area of students with Autism Spectrum Disorders (ASD) and their experiences in higher education.

If you decide to participate, then you will join a study involving research of your social experiences as a college student who has an Autism Spectrum Disorder. If you say YES, then your participation will likely involve one audio-recorded interview session located in a private meeting space on campus. The interview may last from 30 to 60 minutes. There may be a need to follow-up to clarify your statements.

**EXCLUSIONARY CRITERIA:**

Enrollment in college course(s) within the last academic year.

**RISKS AND BENEFITS:**

**RISKS:** If you decide to participate in this study, then you face the risk of discussing potentially uncomfortable topics. The researcher will reduce these risks by allowing the participant to choose not to answer any question that they do not feel



comfortable answering. As with any research, there is some possibility that you may be subject to risks that have not yet been identified.

**BENEFITS:** Your participation in this research is a valued part of this process, however there are no direct known benefits for participation in this study. Upon completion of participation in the study you will receive one (1) \$15 gift card for vendor TBD.

**NEW INFORMATION:**

If the researchers find new information during this study that would reasonably change your decision about participating, then they will give it to you.

**CONFIDENTIALITY:**

The researchers will take reasonable steps to keep identifying information confidential. The results of this study may be used in reports, presentations, and publications; but the researcher will not identify you. Of course, your records may be subpoenaed by court order or inspected by government bodies with oversight authority.

**WITHDRAWAL PRIVILEGE:**

It is OK for you to say NO. Even if you say YES now, you are free to say NO later, and walk away or withdraw from the study – at any time. Your decision will not affect your relationship with Old Dominion University, or otherwise cause a loss of benefits to which you might otherwise be entitled. The researchers reserve the right to withdraw your participation in this study, at any time, if they observe potential problems with your continued participation.

**COMPENSATION FOR ILLNESS AND INJURY:**

If you say YES, then your consent in this document does not waive any of your legal rights. However, in the event of harm arising from this study, neither Old Dominion University, nor the researcher are able to give you any money, insurance coverage, free medical care, or any other compensation for such injury. In the event that you suffer injury as a result of participation in any research project, you may contact Monique N. Colclough (757) 645-7323 or Dr. Ed Gomez, HSRC Chair at [egomez@odu.edu](mailto:egomez@odu.edu), who will be glad to review the matter with you.

**VOLUNTARY CONSENT:**

By signing this form, you are saying several things. You are saying that you have read this form or have had it read to you, that you are satisfied that you understand this form, the research study, and its risks and benefits. You are also saying that you consent to audio recording of the interview. The researcher should have answered any questions you may have had about the research. If you have any questions later on, then the researcher should be able to answer them:

Monique N. Colclough

Phone: (757) 645-7323

Email: [Mcolc001@odu.edu](mailto:Mcolc001@odu.edu)

If at any time you feel pressure to participate or if you have any questions about your rights or this form, then you should contact Dr. Ed Gomez, HSRC Chair, or the Old Dominion University Office of Research, at 757-693-3460.

And importantly, by signing below, you are telling the researcher YES, that you agree to participate in this study. The researcher should give you a copy of this form for your records.

Subject's Printed Name & Signature	Date
Witness' Printed Name & Signature (If Applicable)	Date

**INVESTIGATOR'S STATEMENT:**

I certify that I have explained to this subject the nature and purpose of this research, including benefits, risks, costs, and any experimental procedures. I have described the rights and protections afforded to human subjects and have done nothing to pressure, coerce, or falsely entice this subject into participating. I am aware of my obligations under state and federal laws, and promise compliance. I have answered the subject's questions and have encouraged him/her to ask additional questions at any time during the course of this study. I have witnessed the above signature(s) on this consent form.

Investigator's Printed Name & Signature	Date
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## Appendix J A Priori Codes

ASD & Self Determination	Communication	Adaptive Behaviors
<ul style="list-style-type: none"><li>• Accommodations</li><li>• Abilities/Disabilities</li><li>• Engagement: Campus Involvement &amp; Friendships</li><li>• Identity: Goals &amp; Relationships</li></ul>	<ul style="list-style-type: none"><li>• Face to Face</li><li>• Distance Learning</li><li>• Job Search/ Interviews</li></ul>	<ul style="list-style-type: none"><li>• Role Modeling</li><li>• Education/Peer Coach</li><li>• College Techniques for Success</li></ul>

## VITA

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### **EDUCATION**

#### **Doctor of Philosophy, 2016**

Higher Education, Old Dominion University  
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#### **Master of Education, 2006**

Counselor Education, Clemson University  
Clemson, South Carolina

#### **Master of Public Administration, 2002**

Public Management, Troy University  
Troy, Alabama

#### **Bachelor of Arts, 1999**

History, University of Delaware  
Newark, Delaware

### **PRESENTATIONS & PUBLICATIONS *in brief***

**American Educational Research Association** Spring 2016  
Community College Discipline Faculty Perceptions of Role as Literacy Educators

**Southern Association for College Student Affairs** Fall 2015  
College Students Who Have Autism: The Ability Community We Don't Discuss

**National Conference on Race & Ethnicity in American Higher Education** Spring 2015  
Understanding the Experiences of College Students Who Have Autism

### **PROFESSIONAL AFFILIATIONS**

American Educational Research Association

National Women's Studies Association, Women of Color Leadership Project

Old Dominion University, Preparing Future Faculty Program

Southern Association for College Student Affairs