

A GROUNDED THEORY INVESTIGATION OF
PROGRESSING THROUGH COLLEGE WITH AN
AUTISM SPECTRUM DISORDER
A DISSERTATION
SUBMITTED TO THE FACULTY
OF
THE GRADUATE SCHOOL OF APPLIED AND PROFESSIONAL PSYCHOLOGY
OF
RUTGERS
THE STATE UNIVERSITY OF NEW JERSEY
BY
LAUREN POLEYEFF
IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY

NEW BRUNSWICK, NEW JERSEY

May 2015

APPROVED:

Kenneth Schneider, Ph.D.

Sandra Harris, Ph.D.

DEAN:

Stanley Messer, Ph.D.

Abstract

This qualitative research study provided an in-depth exploration of a sample of college students with autism spectrum disorders (ASD) from two different institutions of higher education in the northeast region of the United States. Five students from a large, public university with a supplemental support program for students with autism spectrum disorders, and four students from a private science, technology, engineering, and math college completed semi-structured interviews containing questions about their experiences managing their ASD related challenges while in college. Research about the experiences of young adults with ASD in higher education has been limited. The purpose of this study was to gain an understanding of the experiences of students with ASD in higher education from the students' perspectives. A qualitative study was appropriate as independent and dependent variables were not readily apparent and theories did not exist to explain the behavior of these participants. The strategy of inquiry used was grounded theory as the goal was to derive an abstract framework of a process that was grounded in the views of the participants in the study. Through analysis of the data - patterns, categories, and subcategories emerged consistently across participants. An integrated story developed that accounted for the variables that affected the students' likelihood of progressing through college and obtaining a degree. A model for progressing through college was created with four subgroups: students who manage ASD related challenges under conditions of on-course, low stress context; on-course, high stress context; off course, non- critical context; and off course, critical context. It became apparent that students who planned in advance and had supports arranged prior to starting college, whether the supports were provided through the university or privately, experienced less overall stress. However, social challenges had less of an impact on academic success than executive functioning challenges, and when a student experienced both

social and executive functioning challenges, academic progress was at greatest risk. Ultimately, intervening conditions of motivation to graduate, assessing the need for help, parental involvement, and comorbid conditions had the largest impact on service utilization and outcome. Recommendations for recognizing and better supporting the needs of students with ASD in higher education were discussed.

Dedication

Dedicated to my children,

Jenna and Callie

Acknowledgements

I would like to express my sincere appreciation for all those who have supported and encouraged me throughout the process of the dissertation. I would like to thank Kenneth Schneider, my dissertation chair and supervisor, for guiding and mentoring me through the dissertation process and for his sensitivity in accompanying me on the journey. I feel privileged to have benefited from his deep compassion and wisdom. I am very grateful to Dr. Sandra Harris, committee member and advisor, for her wisdom, advice and guidance during the dissertation process. I am honored to have had her support. I would like to thank Pamela Lubbers from the College Support Program for her help in recruiting participants. Finally, I would like to thank Dr. Jodi Streich for her support and encouragement and for allowing me to work on dissertation during work hours.

I would also like to express a very special thanks to my family and friends for their support, encouragement, and love. My deepest appreciation goes to my husband Jacob for his love, support and understanding throughout the dissertation process. I could not have done this without him.

Finally and most importantly, I want to express my gratitude and admiration to the students who openly and honestly shared their stories and experiences with me for this study. Without their participation this research would not have been possible. It has been an honor and a privilege getting to know each participant.

Table of Contents

	PAGE
ABSTRACT.....	ii
DEDICATION.....	iv
ACKNOWLEDGEMENTS.....	v
LIST OF TABLES.....	x
LIST OF FIGURES.....	xi
CHAPTER	
I. INTRODUCTION.....	1
Statement of the Problem.....	1
Significance of the Problem.....	3
Background - Autism Spectrum Disorder.....	4
Postsecondary Education.....	8
Purpose of the Study.....	12
Summary.....	13
II. LITERATURE REVIEW.....	15
Prevalence of ASD in Higher Education.....	16
Transition to Higher Education.....	18
Self- Awareness and Self-Advocacy.....	20
Programs and Supports.....	22
Summary.....	31

III.	METHODS	32
	Qualitative Paradigm	32
	Qualitative Method	32
	Constructivism	33
	Researcher’s Role	35
	Ethical Considerations	37
	Data Sources	38
	Data Collection	39
	Survey Questions	41
	Data Analysis	43
	Strauss and Corbin’s Model of Grounded Theory	44
	Verification	45
	Summary	47
IV.	RESULTS	48
	Axial Coding.....	49
	Central Phenomenon.....	50
	Causal Conditions	54
	Action/Interaction Strategies	55
	Stress Context	59
	Intervening Conditions.....	66

	Consequences.....	72
	Negative Case Study.....	75
	Selective Coding.....	80
	Summary.....	88
Chapter V.	DISCUSSION.....	89
	Summary of the Study.....	89
	Problem.....	89
	Purpose.....	89
	Method.....	90
	Research Questions.....	92
	Findings.....	92
	Discussion of Findings.....	97
	Comorbidity.....	97
	Emerging Adulthood.....	100
	Parental Involvement and Self-Determination.....	101
	Intrinsic and Extrinsic Motivation.....	103
	Implications.....	104
	Limitations.....	107
	Future Directions.....	110
	Recommendations.....	111
	Summary.....	115
	Conclusion.....	115

References.....	116
Appendices	
A. Informed Consent Agreement.....	126
B. Interview Protocol.....	130
Tables	
1. Summary of Participant Demographics.....	132
2. Categories and Subcategories.....	133
Figures	
1. Grounded Theory Coding Paradigm.....	134

List of Tables

	Page
Table 1 Summary of participant demographics	133
Table 2 Categories and Subcategories	134

List of Figures

Page

Figure 1. Grounded Theory Coding Paradigm

Chapter I

Introduction

This qualitative research study explores the experiences of students with autism spectrum (ASD) disorders as they progress through higher education. The problem of increasing numbers of students with ASD entering colleges and universities is discussed in this chapter as well as background on autism spectrum disorders and the laws that have influenced changes at the post-secondary level. A preliminary literature review of students with ASD in higher education is presented in chapter two. The methods section and an explanation of the format of the study are provided in chapter three. The results of the study are presented in chapter four. Finally, a discussion of the findings, implications for future research, limitations, and recommendations for stakeholders are provided in chapter five.

Statement of the Problem

It is estimated (U.S. Government Accountability Office, 2005) that there are over 1.5 million individuals diagnosed with ASD and that this includes over 100,000 school-aged children classified with autism served under the Individuals with Disabilities Education Improvement Act (IDEIA), the primary federal legislation that addresses the educational needs of children with disabilities. The number of individuals diagnosed with autism spectrum disorders (ASD) has dramatically increased over the last decade (VanBergeijk, Klin, and Volkmar, 2008).

Approximately 50,000 individuals with autism spectrum disorders (ASD) turn 18 each year in the United States (2012. <http://www.autismspeaks.org/science/science-news/top-ten->

lists). Many of these students are entering college and university. There is little objective information available on the needs of individuals with autism spectrum disorders entering higher education and the colleges and universities preparing to receive them. Research on treatment and support services for people with ASD has long focused on early childhood (2012. <http://www.autismspeaks.org/science/science-news/top-ten-lists>). One reason for the emphasis on early intervention and elementary education is that ASD is typically first diagnosed when a child is between the ages of two and five (Johnson, 2004) and because early intervention has been shown to be a critical service for individuals with ASD. Furthermore, public schools are mandated by IDEIA to provide services to all children who meet criteria for special education (IDEA.ed.gov). Accommodations which have been made available as a result of national legislation have enabled students with high functioning ASD to succeed in increasing numbers at the primary and secondary school levels (Lyman, 2008). Many of these students are now going to colleges and universities, and while some are academically gifted, many of these college students are challenged by deficits in social and interpersonal skills, organization and self-advocacy -- the very skills that are essential for success in college and beyond (Wolf, Thierfeld Brown, Bork, and Shore, 2009).

Individuals with ASD are often isolated from their chronological peers. This is partly due to the social skill deficits that accompany an ASD. Many of these individuals have difficulty adapting their behavior to the changing demands of the college environment. Verbal expression and receptive ability to interpret non-verbal signals is not automatic for individuals with ASD (Zagar and Alpern, 2010). These students are often literal in their understanding of words and do not easily grasp verbal and nonverbal cues for communicating. In a social context, individuals with ASD have difficulty understanding the intentions or the motives of others (Zagar and

Alpern, 2010). This places them at risk of failure in the complex social environment of a college or university.

Despite the academic skills that some students with ASD possess, many face difficulties maintaining themselves in an educational setting, and the dropout rate for these students is high as compared with students without disabilities (Wolf, Thierfeld Brown, and Kukiela Bork, 2009). Not only do the students with ASD face challenges when they go to college, but the colleges themselves may have challenges because they have not had to provide appropriate services for students diagnosed with ASD in the past

Students with ASD pose a challenge to the higher education system because their deficits are incongruent with the traditions, customs, mores, and social interactions of a college (Farrell, 2004). As the population of individuals diagnosed with ASD who are entering institutes of higher education is rapidly growing, these same institutions must be prepared to understand this disorder and how to address the needs of this population of students.

Significance of the Problem

College students with autism spectrum disorders have different daily and life trajectories from typical college students (Wolf, et al., 2009). Most adults on the spectrum realize suboptimal outcomes with respect to employment, social relationships, and education (Cederlund, Hagberg, Billstedt, Gillberg, I., and Gillberg, C., 2008). Only about 35 percent of young adults with ASD attend college and only 55 percent had a job during the first six years after high school. Overall, these individuals faced a greater than 50 percent chance of being unemployed or not attending college when compared to those with other disabilities (www.health.usnews.com/2012/05/14). The lack of research emphasis in this area presents a considerable cost in terms of unmet human potential and loss of productivity.

Unfortunately, the evidence base about how best to facilitate success for these students is poorly developed (Hart, Grigal, and Weir, 2010). Their needs are diverse and the presence of psychiatric comorbidities and academic / life dissatisfaction are also potential concerns (White, Ollendick, and Bray, 2011). Although the number of colleges and universities providing opportunities for young adults with ASD has been growing in recent years, the types of programs and supports that are intended to foster integration into college life, the services offered, as well as intensity and quality vary greatly among these programs (Camarena and Sarigiani, 2009). There is a need for research examining the effectiveness of programs and resources that support young adults with ASD in college (Hart, Grigal, and Weir, 2010). There is also a need for wider adoption of research supported programs and resources to aid young adults with ASD as they transition into and from college (VanBergeijk et al., 2008).

The consequences of not developing and implementing effective programs to help promote success in postsecondary education may result in overeducated but unemployed adults with ASD, or partially educated students who cannot complete a college degree. An important goal is to develop support services for the ASD community that could increase the likelihood of positive outcomes.

Background – Autism Spectrum Disorder

Children began being officially diagnosed with ASD based upon the criteria set forth in the Diagnostic and Statistical Manual (DSM – IV). In the DSM – IV, several disorders fell under the rubric of Pervasive Developmental Disorders. These included Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Autistic Disorder was the most widely recognized pervasive developmental disorder

(American Psychiatric Association, 1994, p 66). One of the distinguishing features of autistic disorder as it presents in infancy is the delay or total lack of language development. In terms of IQ testing, individuals with autistic disorder are described as having stronger nonverbal or performance skills as compared to their verbal skills (VanBergeijk et al., p. 1360). This holds true for both those on the autism spectrum who are more impaired and those who are higher functioning. The term high functioning autism is a colloquial one used by clinicians to describe individuals on the autism spectrum who score above a 70 on standardized IQ tests and would be considered in the normal range of intelligence (VanBergeijk et al). However, there is no agreed upon definition of “high functioning” and anecdotal comments seem to base the term “high functioning” on at least average IQ levels.

For the past twenty years, the diagnosis of Asperger’s disorder (AD) had been commonly used; it was characterized by severe and sustained impairment in social interaction, and the development of restricted, patterns of behavior, interests and activities (VanBergeijk, et al., p. 1360). Asperger’s disorder has a later onset than autism (Klin et al. 2000) and there is no clinically significant delay in either receptive or expressive language development. Students with Asperger’s disorder may have excellent vocabularies - although, their communication can be quite impaired. Their difficulties often reflect the semantics and pragmatics of speech (VanBergeijk et al., 2008). Also, there are no clinically significant delays in adaptive functioning, and cognitive abilities. Their IQ profile is the reverse of students with autistic disorder, i.e., typically students with Asperger’s disorder have a deficit in their nonverbal skills. Their IQ scores on the performance portions of standardized IQ tests are markedly poor as compared to their scores on the verbal portions of these tests (Volkmar and Klin, 2001). A

diagnosis of PDD-NOS had been used in clinical situations where the individual's presenting symptomatology is either atypical or sub-threshold (VanBergeijk, et al., 2008).

In the most recent edition of the Diagnostic Statistical Manual (DSM-5, 2013), the distinct conditions have been merged into one category called autism spectrum disorder (ASD). As this is the current edition in use, this dissertation will refer to all students who were diagnosed with various spectrum disorders in the past, as ASD, although it should be noted that all the participants in this study reported that their diagnosis was Asperger's disorder (AD). The present study focuses on students with ASD who have average or above average IQ scores.

Autism Spectrum Disorder (ASD) is a lifelong, non-progressive neurodevelopmental disorder. The term Autism Spectrum Disorder (ASD) refers to a single diagnostic category that includes two core-defining features: impairments in (a) social communication and (b) restricted and repetitive behaviors and interests (American Psychiatric Association, 2013). There is however, marked variability in the severity of symptomatology and the need for support across individuals with ASD. Symptom expression falls on a continuum and will vary from significant to mild impairment (White, Ollendick, and Bray, 2011). Although ASD is often associated with cognitive impairment, ASD may occur without significant intellectual disability (Center for Disease Control, 2009). Fombonne's (2005) review of epidemiological studies of autistic samples found a median proportion of subjects without intellectual impairment to be 29.6%. However, the literature suggests that approximately 70% - 80% (Fombonne, 2005) of individuals diagnosed with an ASD during childhood will continue to demonstrate marked social impairment in adolescence and adulthood.

In 2014 the Centers for Disease Control and Prevention revised its estimate of the ASD prevalence to 1 in 68 (www.cdc.gov/ncbddd/autism.html). This statistic was determined by an evaluation of the health and education records of all eight year olds in 11 states. ASD is still found to be more common among boys (1 in 42) than among girls (1 in 89) (www.cdc.gov/ncbddd/autism.html). The state that the present study was conducted in has one of the highest rates of occurrence at 1 in 45 (www.cnn.com/2014.03/27/health/cdc-autism). ASD reportedly occurs in all racial, ethnic, and socioeconomic groups. While the causes remain unclear, it is clear that public education systems in the United States are facing increased numbers of students with an ASD diagnosis. Consequently, colleges and universities nationwide are also seeing a marked increase in the numbers of students who carry autism spectrum diagnoses (Wolf, et al. 2001).

In 2006 an informal survey of 42 colleges found an average of only 4.28 students with ASD at four-year institutions and only 8.9 students at community and technical colleges in the United States. The recent prevalence by the CDC suggests that these numbers will continue to grow. Many suspect that the increase in numbers reflects, in part, the inclusion of more individuals at the boundaries of ASD who would not have been previously diagnosed. In fact, the largest increase in children in the CDC study was found in those who have average to above average intelligence with nearly half of the children having an IQ score of 85 or above as compared to a decade ago (www.cnn.com/2014.03/27/health/cdc-autism). It is these young people with milder symptoms who may make up the incoming population of college students in the future.

Unfortunately, many intellectually capable adolescents and young adults either do not seek or gain entry into college, or drop out prematurely (Glennon, 2001) due to social isolation,

difficulty with changing routines, and new schedules, problems living independently, and lack of external supports and guidance (Howlin, Goode, Hutton, and Rutter, 2004; Jobe and White, 2007). Although young adults on the autism spectrum may qualify academically for college, they often have difficulty managing these other aspects of college life. The rates of post-secondary educational participation for youth with ASD are substantially lower than the general population, with previous studies indicating 40% or fewer ever attending college and very few of whom receive a degree (Shattuck, Narendorf, Cooper, Sterzing, Wagner, and Taylor, 2012).

Postsecondary Education

Historically, students with disabilities have counted for a very small minority population on college and university campuses (Russo-Jameson, 2007); however, with the advent of federal legislation aimed at providing non-discrimination and equal access for people with disabilities, young adults with disabilities have been exploring postsecondary education as a realistic goal when planning for their futures (Hawke, 2004; Russo Jameson, 2007).

Autism was first listed as a disability category for special education in the Individuals with Disabilities Education Act (IDEA) of 1990. Since then, there have been marked increases in the classification of ASD (Graetz and Spampinato, 2008) in schools. Many of the children originally classified, having become young adults, have chosen to pursue higher education. The increase in K-12 students receiving special education services has been thought to be another major contributor to the increase in this population (Szentmiklosi, 2002).

Most of the children who received K-12 special education services come from a very structured and accommodating academic environment (Hawke, 2004). Since its inception in the mid-1970s, students with disabilities in the K-12 environment have been served under the

Individuals with Disabilities Education Act (IDEA) (Eckes and Ochoa, 2005; Hawke, Madaus and Shaw, 2006). Under IDEA, (and later IDEIA, 2005) schools have been required to, not only serve these students but, actively seek out, identify, and assess students with possible disabilities using a thorough and nondiscriminatory evaluation process (Hawke, 2004; Madaus and Shaw, 2006). Once identified and evaluated, school districts are required to develop and implement an Individualized Education Plan (IEP) for each student with a disability. IEPs have been used to assess students' progress which is closely monitored by IEP team members who work together to meet students' needs. This level of structure and support decreases significantly after high school (Eckes and Ochoa 2005; Hawke, 2004).

At the postsecondary level, IDEA/IDEIA does not govern disability access. Rather, students have been protected under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990. (Eckes and Ochoa, 2005; Madaus and Shaw, 2006). The ADA established that any program receiving federal funding may not discriminate against individuals with disabilities. The law emphasized equal treatment in federally funded programs, whereas IDEIA emphasized adequate access to a free and appropriate education (FAPE) (Walker, 2006). The Americans with Disabilities Act shapes how universities provide services to students with ASD. In contrast to the IDEA/IDEIA focus on ensuring the success of students with disabilities, Section 504 and the ADA have shifted to a focus on access through the removal of barriers and the provision of accommodations. In higher education, there has been no assurance of success. In reference to higher education, both Section 504 and the ADA have provided examples of reasonable accommodations for qualified students with disabilities; however, the typical accommodations may only address academic barriers and not help with

social/relationship or emotional issues common to students with ASD (Graetz and Spampinato, 2008).

At the postsecondary level, students with ASD, along with other students with disabilities who transition from high school to the postsecondary level, have faced a multitude of challenges associated with changes in their rights and responsibilities, procedures to receive disability services, and the overall learning environment (Eckes and Ochoa, 2005; Hawke, 2004; Madaus and Shaw, 2006). There has been an ongoing debate about what actually constitutes a “reasonable accommodation,” and college administrators have struggled to determine when ASD students might benefit more from behavioral coaching than from specific academic accommodations (Farrell, 2004). However, it is unclear who would be responsible for providing that type of service.

The needs of students with ASD differ from other populations of students with disabilities who have traditionally been seen by disability service professionals and higher education administrators (VanBergijk et al., 2008). Accommodating students whose disabilities may include social and self-regulatory areas present a particular challenge for service providers who are not accustomed to supporting so many areas of student life. The extra supports that learners with ASD can require to succeed may be difficult to provide in the postsecondary campus setting because of the required physical space and human supports necessary for success (Hart, Grigal, and Weir, 2010).

The support systems within the college environment can potentially help these students work toward gaining independence and becoming functional, gainfully employed adults. However, to support students toward these goals requires education and training, as most

professionals and staff who interact with students with ASD know little about the disorder and how it affects daily life (Camarena et al., 2009). A common concern of disability support staff is that many higher education faculty members are not trained in ways to serve students with ASD. Most professors have mastered their subjects yet may not have the skills to relay the information in order to meet the learning styles of the diverse student population.

Instructors may not know that a student has a disability because the individual may be hesitant to share his or her diagnosis. It is at the discretion of the student to disclose their disability and seek support from their instructors. Disclosure of a disability enables the support staff and professors to understand more clearly the student's needs for academic support and accommodations.

ASD is known as an invisible disability and is not obvious as is blindness or a hearing impairment (Taylor, 2005). Taylor (2005) states that since very little is known about ASD, it may be difficult for higher education personnel to understand why it is necessary to incorporate adjustments to academic practices to accommodate ASD students. Taylor (2005) argues that it may be difficult for both faculty and students to truly appreciate the struggles of an ASD student transitioning to the college setting and also learning to cope with his or her disability. Taylor (2005) also asserts that because of this there may be difficulties making appropriate adjustments to academic practices for students with ASD.

Many campuses are working to improve programming to support students with ASD (Roberts, 2010). In order to respond to the increasing enrollment of students with disabilities entering higher education, colleges and universities have established an office on campus,

sometimes called the Office of Disability Services (ODS), which serves as a liaison and advocate between students with disabilities and faculty.

Many Offices of Disability Services within institutes of higher education simply provide academic accommodations. Accommodations are defined as adjustments to an academic program or environment intended to mitigate the impact of the functional limitations of a disability on participation in that environment (Wolf, et al., 2009). Known for “leveling the playing field,” accommodations make the academic environment manageable without fundamentally altering the curriculum (Wolf, et al., 2009).

Accommodations must not provide students with ASD an unfair advantage over other students. ADA Title II defines an accommodation as a modification of the institutions’ rules, policies, or practices; environmental adjustments, such as the removal of architectural or communicative barriers; or providing auxiliary aids and services (Macurdy and Geetter, 2008). Accommodations may be considered either reasonable or unreasonable. However, the interpretation of this distinction is not straight forward. Universities may determine what is reasonable and appropriate and select among effective alternatives.

Every student with ASD is different; therefore, it is impossible to offer a range of reasonable and unreasonable accommodations for all students with ASD. Successful accommodations stem from understanding the diagnosis and should be individualized for the student.

Purpose of the Present Study

Research about young adults with ASD and their experiences in the realm of higher education is somewhat limited. When the experience of college aged students with ASD have

been investigated, it has often been from the perspective of educators, parents, and service providers with little being written about the experience of living with the disorder from the perspective of someone who has it (Szentmiklosi, 2009). The purpose of this qualitative study was to gain a better understanding of the experience of students with autism spectrum disorders in higher education from the students' perspective. The study explored how individuals diagnosed with ASD manage the challenges that the disorder presents to them while attending college. It also examined the students' use of various services and supports and their beliefs about the effectiveness of these resources and of their own internal coping skills. The primary investigator interviewed students from a private science, technology, engineering, and math (STEM) college and a large state university in the northeastern region of the United States in order to better understand and compare the students' experiences. Each institute of higher education offer different types of supports. The data were intended to inform families of college age students with ASD as well as institutions of higher education about how to better meet the needs of this growing ASD population, whether through academic accommodations or more nontraditional supports and services. Additionally, this research was designed to contribute to the growing body of literature about students with ASD participating in higher education.

The primary purpose of this study was to present a framework exploring the phenomenological experience for college students with ASD and the services they utilized. It was based upon research guided by several main questions which the primary investigator developed through personal experiences with students with ASD and an initial literature review.

Summary

This chapter introduced the problems associated with the phenomenon of students with ASD entering institutions of higher education at dramatically increasing rates. It also discussed

the significance of the problem. Some history of Autism Spectrum Disorder and policies that have shaped the provision of services at the post- secondary educational level were provided. Finally supports, services, and academic accommodations were discussed. The purpose of the study was introduced at the end of the chapter.

Chapter II

Literature Review

This qualitative research study used a grounded theory paradigm in its approach to data collection and analysis. The intent of a grounded theory study is to generate a theory, or an abstract analytical schema of a phenomenon, that relates to a particular situation (Creswell, 1998). In contrast to an a priori theoretical orientation, grounded theory methods are grounded in data from the field. Different methods of conducting grounded theory have been proposed since its conception in the 1960s.

Divergent opinions exist regarding the use and timing of conducting the literature review within the grounded theory camps. The classic grounded theorists (Glaser and Strauss, 1967; Glaser, 1978) advocate delaying the literature review until after completing the data analysis. The purpose of delaying the literature review is to avoid using preconceived ideas and forcing one's data into pre-existing categories (Charmaz, 2006). Delaying the review is thought to encourage the researcher to articulate his/her own ideas. Strauss and Corbin (1990, p. 49) in contrast recognize that most researchers come to the field with some background in the technical literature, and encourage the researcher to recognize and use it, however they do not believe it is necessary to review all of the literature before the data collection. The hope is that if the researcher is effective in the analysis, then new categories will emerge that no one has thought of previously. Strauss and Corbin (1990) advise making oneself aware of the concepts that repeatedly turn up in the literature and appear to be significant in an effort to stimulate theoretical sensitivity or "an awareness of the subtleties of meaning of data" (Strauss and Corbin, 1990). As Strauss and Corbin's method provided the main model for the research design and analysis used in this study, their approach to the literature was also followed.

In a pre-data collection review of the literature, the researcher located qualitative studies that were conducted on experiences with transition to higher education, self-advocacy, and programs and supports for students with ASD in higher education. Additionally, several studies focusing on the prevalence of ASD within higher education were reviewed. It became apparent that there exists a lack of insight into the reality of attending college for these students, and the coping mechanisms and supports utilized, from these students' perspectives, which became the focus of this research study.

Prevalence of ASD (and broader ASD phenotype) in Higher Education

White, Ollendick, and Bray (2011) examined the prevalence of higher functioning students with ASD at a single university, and surveyed students on the characteristics, problems, and risks associated with ASD. Researchers found that between 0.7% and 1.9% of a large sample of students (n=667) in a single university met the criteria for ASD, and they stated that the true prevalence likely falls somewhere between these two estimates. This suggests that symptoms of ASD were fairly common among college students in their sample. An important finding was that none of the students who met the formal criteria for receiving a diagnosis of ASD had been diagnosed previously. Those students who scored above the clinical threshold for symptoms of autism (n = 13) self-reported more problems with social anxiety than a matched comparison group of students with lower autism severity scores. In addition, symptoms of high functioning ASD were significantly correlated with symptoms of social anxiety, as well as depression and aggression. According to these researchers, in the future colleges and universities may expect to enroll an increasing number of students who have been diagnosed with ASD, students who meet criteria for the disorder but who have not been identified, and students who would fall in the category of the broad autism phenotype.

Jobe and Williams-White (2007) investigated a possible relationship between social functioning and a broader sample of non-clinical undergraduate students from a large urban university (N = 97 mean age 19.4). Characteristics associated with autism were measured including friendship and dating history, feelings of loneliness, and social motivation. Results showed that individuals with a stronger autism phenotype reported significantly more loneliness and fewer and shorter duration of friendships. Findings supported the view that individuals with characteristics of autism and related conditions do not necessarily prefer being alone, but experience increased levels of loneliness related to lack of social skill and understanding. Similar to the White, Ollendick, and Bray's study, these findings also suggest that there is evidence for a broader autism phenotype, or set of symptoms associated with ASD, observable in the general population.

Recognizing the link between social skills and academic success, some colleges have begun to offer students with ASD guidance on interpersonal skills, such as lessons in etiquette and social norms (Farrell, 2004). Bauminger's (2002) work on social skills training with adolescents with ASD supported the idea that training in social and emotional understanding can increase quality of social interactions. Jobe and Williams-White's (2007) findings highlighted the importance of assistance for non-diagnosed college age students in areas such as friendship maintenance, social communication, and dating strategies through group or individual coaching or therapies (Jobe and White, 2007). If as this research suggests, students who possess features of ASD would benefit from social skills training, clearly students with diagnoses of ASD would profit from the support as well.

Transition

The transition to college from high school is a particularly stressful period. (Baker, McNeil, and Siryk, 1985). College students, with or without disabilities, are faced with numerous stressful situations within the university environment (Glennon, 2001, p. 183). Living apart from one's parents for the first time, making decisions about one's day to day functioning and future direction may cause anxiety and stress for any college student. For students on the autism spectrum the anxiety may be magnified. According to a 2001 study by Glennon, individuals diagnosed with Asperger's syndrome, required non-traditional supports to find success at this level. University staff -- who often have limited knowledge of autism spectrum disorders (Glennon, 2001), were frequently unaware of these students' limitations and needs, and did not recognize the additional supports that were required for success (Glennon, 2001).

Roberts (2010) reported that college students with ASD may require extensive planning and ongoing support because of underlying issues directly related to the individuals' disabilities – specifically delays in communication, social interaction, and behavior. The transition from high school to life after high school leaves many individuals with ASD without any support (Osborne, and Reed, 2009). The authors suggested this may be because of the lack of a functional and informed plan to guide the students through the transition process.

Roberts (2010) observed that as an individual prepares to transition from secondary to postsecondary education, educators need to know what supports the student requires for optimal transition and success in postsecondary education. The author stated that a comprehensive transition plan should include up-to-date information on the individual as a whole, not just assessments based on psycho-educational tests. Roberts argued that transition plans should

identify services to be provided, specify timelines and persons responsible for implementing services, state the intended outcomes, and provide a plan for monitoring and following up on the implementation of activities. Also, the transition plan should take into account the student's personal goals and aspirations and be based on the student's individual strengths, "not the strengths of specific systems or agencies" (Roberts, 2010). Topic areas to consider when developing a transition plan include career exploration, academic goal setting and preparation, assessing and knowing learning styles, self-advocacy skills, reasonable accommodations, academic supports, interagency collaboration, technology, and time management skills (Roberts, 2010).

The transition from school services to adulthood may be particularly difficult for many adolescents with autism spectrum disorders (deFur and Patton, 1999; Schall and Wehman, 2008). According to Hendricks and Wehman (2009), although some individuals with ASD are able to successfully transition from high school to college, most are faced with significant obstacles in multiple areas as they attempt to negotiate their way into college, work, community participation, and independent living. With appropriate training and education, Hendricks and Wehman believe that individuals with ASD can integrate meaningfully into the community and work competitively. Given the heterogeneity of the disorder however, young adults require a wide range of services and supports that are individualized and needs driven.

Federal measures have been put in place to ensure that public schools plan for transition from high school to post-secondary experiences (IDEA, 2004); however, the transition planning and implementation is falling short of what the federal government intended for many with ASD (Certo, Mautz, Pumpian, Sax, Smalley, Wade, 2003). Students often do not receive the services and supports needed to address their complex set of needs (Hendricks and Wehman, 2009). It is

essential that professionals carefully plan for this transition to ensure young adults are equipped with the appropriate skills and supports needed for success. Individuals with ASD spend much more of their lifetime outside of the educational system than in the system; therefore, efforts to maximize this critical period are pivotal to improving outcomes.

Lyman (2008) examined the narrative statements of individuals with Asperger's Syndrome concerning their recollections of the transition from high school to college. Nine male college students were interviewed, starting with their experiences in high school, to the initial stages of preparing for college life, and ending with current experiences in college. Analysis of the data focused on the factors that have an impact on this transition. Themes were developed using techniques based on grounded theory (Strauss and Corbin, 1990). Four themes emerged from the data including academic functioning, social functioning, independent functioning, and personal issues. Within each of these major themes the words of the respondents with AS told what it was like to make the journey from high school to college. Each person experienced varying degrees of success in his transition in these thematic areas. A limitation of the study was that none of the participants were female.

Self- Awareness and Self- Advocacy

As individuals with disabilities enter postsecondary education, they are encouraged to disclose their disability to staff at the campus disability services office, provide documentation of their disabilities, and express their accommodation needs. For many students this change is a significant and challenging adjustment (Roberts, 2010). Roberts reported that becoming an effective self- advocate, including disclosing one's disability is necessary for success in postsecondary education.

Carmarena and Sarigiani (2009) administered and analyzed academic and social rating scales to college age youth with ASD and their parents. On every item the youth rated the severity of the problem lower than their parents which may have been due to a lack of awareness about their unique challenges. This was viewed as a potential obstacle to success for these students. Complicating this issue is the fact that for some students, a lack of acknowledgement of their disability may stem from the fact that they may not view themselves as having a disability. In Camarena and Sarigianis' study, some students were struggling with self-acceptance or had not been provided with an adequate alternatives for how to frame the nature of their exceptionality (Camarena and Sarigiani, 2004). Previous research on successful adaptation of young adults with learning disabilities found that those who were doing well, had an awareness, acceptance, and understanding of their disability, but at the same time, their disability did not define their identity (Spekman, Goldberg, and Herman, 1992).

Szentmiklosi (2002) investigated the self-determination of community college students diagnosed with Asperger's syndrome. Five students were interviewed. Varying levels of self-determination were displayed by each of the five participants. Five major and two minor themes related to the collegial experiences of these students were revealed. The major themes highlighted were that community college students with AS (a) enjoyed academic success, (b) found disability services and accommodations important, (c) chose majors based on personal interests, (d) relied on family members for support, and (e) had difficulty developing social connections on campus.

Ciccantelli (2011) examined the perspectives of students with Autism Spectrum Disorder, their parents, and Office of Accessibility (OA) staff at the institution of higher education attended by the student. Ciccantelli's study used a multi-case qualitative research design aimed

at developing grounded theory. She identified critical factors for successful navigation of the academic, social, and independent living demands of institutions of higher education for students with ASD. The participants included three male students with ASD, three mothers of the students, and three female OA staff members from the participating institutions of higher education currently attended by the student.

Findings of this study revealed students and parents belief that parents' continuing active participation was central to the student's successful navigation of higher education; however OA staff placed greater emphasis on the need for students with ASD to increase their level of personal independence as is the expectation when any student transitions to college. Outcomes of this study were consistent with research that confirms the need for students with ASD to be autonomous from their parents in order to gain a sense of identify and develop self-governing behaviors such as independent decision making (Hoffman, 1984; Kenyon and Koerner, 2009; Lapsley, Rice, and Shadid 1989; Palmer, 2006). Moreover, findings were also consistent with additional research (Fullerton, 1995; Halpern, 1985; Hendricks and Wehman, 2009) that validates the need for students to demonstrate not only academic skill, but also competence in other areas such as social, communication, self-management, self-determination, independent living, community, and employment skills to be successful in college.

Student Desires, Concerns, and Perceptions of Programs and Supports

Camarena and Sarigiani (2009) conducted individual interviews with 21 adolescents diagnosed with an autism spectrum disorder and their parents to assess postsecondary educational aspirations and thoughts concerning obstacles and resources that influence educational achievement of this group. In an earlier study by Hitichings, Retish, and Horvath

(2005), the authors found that in 10th grade, 77% of their sample were interested in attending postsecondary education, however, the percentage of youth with this aspiration declined over time. A substantial proportion of youth with disabilities aspired to postsecondary education. However, these youth were often derailed along the way and were unable to successfully meet their aspirations (Carmarena and Sarigiani, 2009). Carmarena and Sarigiani recommended that both public schools and post - secondary institutions do more to nurture the postsecondary aspirations of youth with disabilities.

More individuals with ASD than members of the general population have IQ scores measuring in the superior to very superior ranges (Barnhioo, Hagiwara, Myles, and Simpson, 2000). These authors recommended that institutions of higher education tap into the strengths of these individuals and help to nurture their “islands of competence” (Brooks and Goldstein, 2001) in order to increase the chances of achieving more positive lifelong outcomes. For these talented youth with ASD, Carmarena and Sarigiani found that their intellectual capabilities are an important domain that relates to their feelings of self- worth. However, social challenges may negatively affect educational achievement (Carmarena and Sarigiani, 2009).

Carmarena and Sargiani continue to state that parent and self – reports revealed that concerns about the capacity to function or be accepted socially outweighed concerns related to academic accommodations and resources (Carmarena and Sarigiani, 2009). Parents recommended mentors, a buddy system, and an identified professional available at all times to provide a listening ear and helping hand to students with ASD. Campus disability awareness was a category frequently mentioned by parents as a requested program element. Other suggestions included that students with ASD be introduced to similar students or “understanding roommates.” Although the specifics of parents’ desires varied according to the goals and needs

of the adolescent, several themes for support were noted: a) key staff members must be trained and clearly identified as a resource for students, and b) specific social supports need to be built into the lives of students with ASD (Carmarena and Sarigiani, 2009).

The nature of available resources may vary significantly with many postsecondary institutions focusing more narrowly on “reasonable accommodations” directly tied to academic functioning (Carmarena and Sarigiani, 2009). The results from these semi-structured interviews revealed that both the adolescents and their parents have clear postsecondary educational goals but have significant concerns about the readiness of postsecondary institutions to meet the adolescents' needs.

The majority of students and parents agreed that a “program” to help this population of students succeed would be very important, but there was disagreement about what the term “program” might mean. Several issues were noted including: a) Does a program have to be formalized or could training and supports just be infused through campus? b) Do students need to self-identify or be identified to somehow benefit from a formal program? c) Is there a value in bringing students with similar needs together (in residence halls, in support groups, etc.) (Carmarena and Sarigiani, 2009).

Recommendations for Programs and Supports

Hart, Grigal, and Weir (2010) provided an overview of postsecondary education options for students with Autism Spectrum Disorder (ASD) and other Intellectual Disabilities (ID). The authors noted that the human service field must begin to develop evidence based practices that support young adults with ASD in postsecondary education as there currently is a dearth of evidence based interventions and services adapted for this age group.

In the past 10 years, opportunities for access to post- secondary education for students with ASD have grown through a variety of approaches and with varying degrees of inclusiveness in typical college life (Hart, et al., 2010). Some colleges have created support groups, offer peer-mentoring programs, or provide access to counseling services. The need for nontraditional supports has led to the creation of for-profit and private community organizations which provide fee-based services to university students with ASD (Hart et al., 2010).

Research supports the view that when elementary and secondary students are included in typical classrooms, with high expectations and the appropriate supports, they can be successful in those environments (Jorgenson, McSheehan, and Sonnenmeier, 2009). Participation by young adults with ASD in inclusive post- secondary education settings can result in similarly positive results in academic and social success (Uditsky and Hughson, 2006). The authors emphasized however that the level of academic rigor of a class should not be altered to meet the needs of students with ASD.

Several features that authors mentioned that may help students with ASD negotiate the social environments of college include: a) peer mentors who can model appropriate social behaviors, and increase the students' social circles; b) an educational coach who can work to "even the playing field" for students with ASD (Attwood, 2006; Hart et al., 2001). However, coaches are not typically provided by colleges and universities and may need to be obtained via an external source. C) Post -secondary education initiatives for students with ASD should include a strong employment component (Briel and Getzel, 2009) which supports students to participate in career-related courses in order to gain critical work experiences, and to secure competitive employment. As policies and programs continue to broaden the access of students

with ASD to post-secondary education, the authors asserted that there needs to be a parallel focus on evaluating the activities and outcomes of such efforts.

VanBergeijk, Klin, and Volkmar (2008) provided specific recommendations regarding the academic, independent living, social, vocational, and counseling needs of college students who are on the autism spectrum. The limited research available addressing the psychosocial profiles of young adults with ASD suggested that these individuals continue to struggle with the developmental tasks of their age (Billstedt, Gillberg, and Gillberg, 2010). Howlin et al. (2004) examined the adult outcomes of individuals diagnosed with an ASD as children. They found that while some of these individuals were able to live independently, the majority were unable to transition fully to an adult life that embraced work, personal relationships and independent living. Most of these individuals remained dependent upon their families and were socially isolated (VanBergeijk et al., 2008). The authors contended that the majority of these individuals will experience difficulty in undertaking adult social roles although they may be cognitively capable of meaningful employment.

With a carefully planned transition, appropriate accommodations and support, VanBergeijk et al. found that students with ASD can be successful academically and socially in college. They stressed the importance of “fit” of the student to the institution, as small schools may offer a more personalized learning environment and decrease the chance that the student will feel over stimulated in the environment. However smaller schools “may not be familiar with the unique needs of students on the autism spectrum. They may approach the student as though he or she has a specific learning disability and provide academic based interventions only” (VanBergeijk et al., 2008). The authors argued that in large universities students on the autism spectrum may have a better chance of “finding their niche both socially and vocationally.” A

large university may offer a curriculum that is more diverse than what is offered at a smaller college. Whether the student with ASD and their parents select a small college or larger university, VanBergeijk et al. (2008) stated it should be based upon their assessment of how supportive the college community is of people with different abilities.

Most colleges and universities are familiar with the learning needs of students with specific learning disabilities and ADHD (VanBergeijk et al., 2008). These students typically need specific supports and modifications in the academic realm. However, students on the autism spectrum require modifications and supports in social, organizational, and communicative realms in addition to traditional academic supports (VanBergeijk et al., 2008). In terms of counseling, VanBergeijk et al. state that students on the autism spectrum require directive, explicit guidance and counseling. Because these students will have difficulty making inferences, drawing conclusions and making connections, social situations in particular must be broken down and analyzed (VanBergeijk et al., 2008). Each step the student is expected to take should be clearly stated and rehearsed prior to the student attempting the behavior. Role-plays with explicit feedback are critical (VanBergeijk et al., 2008). Because many students on the autism spectrum have difficulty generalizing skills across situations, practicing new behaviors should ideally be practiced in vivo (VanBergeijk et al., 2008). Social skills groups with students on the spectrum in which explicit teaching and role play are utilized may be an effective way to help this population generalize new skills.

Issues of sexuality are particularly difficult for people with ASD. Many of these students do not know how to negotiate a simple dating situation let alone a far more complex social situation (e.g., negotiating a sexual relationship). Students on the autism spectrum must be

explicitly taught what is appropriate to say to a person he or she may find attractive (Volkmar, 2004).

VanBergeijk et al. (2008) stated that an important role of colleges and universities is to prepare students to become productive members of the labor force. Neurotypical students are trained in college to think about a problem based upon the academic discipline they are pursuing. The process of job training is secondary to teaching the student how to think about life. For the student on the autism spectrum, VanBergeijk et al. emphasized that preparing the student for work must be a deliberate and planned effort. Direct connections should be made between what he or she is learning in college and the world of work. Completing the job search and application process is a skill that needs to be practiced with students on the autism spectrum. Teaching students on the spectrum how to conduct themselves during a job interview through role-playing is key. It should be broken down into discrete tasks. Because much of a job interview is unscripted, student on the autism spectrum may have to practice a variety of scenarios in reference to how to introduce themselves, make small talk, whether or not to shake someone's hand, and where to sit (VanBergeijk, et al., 2008).

Considerations for college-based programming for students with autism spectrum disorders (ASD) were addressed by Zagar and Alpern (2010), with particular attention to social communication supports necessary to facilitate student success. One specific communication area that often present challenges to students with ASD at the postsecondary level is conversational skills (Bellon-Harn and Harn, 2006). Deficits in joint attention and symbol use may underlay these conversational problems. Adults with ASD frequently report miscommunication with others that result from their inability to understand idioms, double meanings, and body language (Zagar and Alpern, 2010); another issue is voice and prosody

(Church, Alisanski, Amanullah, 2000). Deficits in voice and prosody include speaking with appropriate volume and inflection. Sensitivity to the listener's needs is also important (Colle, Baron-Cohen, Wheelwright, and van der Lely, 2008). Adults with ASD may demonstrate continued inability to keep the listener's perspective in mind (Zagar and Alpern 2010).

Zagar and Alpern(2010) recommended the Campus Based Inclusion Model (CBIM) for students with ASD in post-secondary education. The mission of the CBIM is to educate students with autism alongside their peers to provide an age appropriate postsecondary option that will prepare them for adult living. To help ameliorate social challenges confronted by young adults with ASD, a key component of the CBIM is the facilitation of social communication skills. Weekly group and individual sessions were provided to students in the CBIM by speech-language pathology majors. Scripted role-playing activities were conducted in therapy sessions, and social communication skills were incorporated and reinforced in academic and social settings on campus. Students role-played both the speaker and the listener roles in reciprocal conversation to help develop more appropriate responses in various settings. Role-playing activities were used to elicit requests for more information, or for more time, or simply to convey their confusion with statements such as "I don't understand." Therapists reported that the students' successfully learned to communicate their need for information to be repeated or clarified in another way. Zagar and Alpern reported that over a five year period the provision of appropriate social - communication support services helped to foster student success in academic, social, and vocational domains.

Effectiveness of Programs and Supports

Using the framework of a logic model Ford (2009) examined two support programs in higher education for college students who were diagnosed with ASD. Ford made suggestions about the type of culture and supports needed to provide a successful atmosphere for high functioning students, and raised questions about college policies regarding disability support and accommodations systems. She advised that institutions of higher education develop programs that bring these students to campus prior to the transition from high school to help prepare these students for the expectations and norms of college life.

Tarallo (2012) found that there may not be sufficient support within institutions of higher education for students with ASD who wish to pursue advanced education; her study explored the experience of students with ASD attending an institution of higher education. A key element of the study focused on understanding the experience of students with ASD as they accessed support services. She conducted a phenomenological study of six students with ASD in the university setting. Analysis through the lens of disability theory and achievement ideology enabled a deeper understanding of the students' experience of being a college student with an ASD. Her recommendations included: 1. Continued, clear communication about services available to students with ASD and other disabilities, 2. Accessibility of appropriate support, 3. Provision of volunteer peer tutors or academic peer support, 4. Disability awareness and training for university staff, and 5. Connections with specialists at universities to strengthen resources.

Ellison's doctoral dissertation (2013) explored the ability of higher education to effectively educate and support college students diagnosed with Asperger's Disorder. Emerging research details specific service systems and resources necessary to effectively educate and

support college students with Asperger's Disorder. Public, four year institutions of higher education were surveyed to assess their current readiness to use identified best-practice methods of support with this student population. Participants (n = 230) reported traditional on-campus disability service programs served as the primary provider of academic, social /communication, and independent living supports for college students with Asperger's Disorder. A minority of institutions reported specialized services developed to meet the unique needs of this student population. Ellison reported that institutions of higher education were currently unprepared to meet the needs of this growing population of students.

Summary

This chapter serves as a pre data collection literature review for a qualitative study based on grounded theory methodology. This literature review included the findings of several studies that examined the prevalence of ASD among samples of non-diagnosed students in the higher education. The literature review then covered the topics of transition to college for students with ASD, self- awareness and self- advocacy for students with ASD. Finally it examined numerous examples of studies conducted that explored student and parent perceptions of needs in terms of supports and programs, program recommendations, and an examination of what the majority of colleges and universities are actually currently providing these students.

Chapter III

Qualitative Paradigm

This study used a qualitative research method to gather and examine accounts given by individuals with autism spectrum disorders who spent at least half of one semester in the past three years in college or university. Qualitative research methods are useful when exploring topics that have not yet been thoroughly researched (Creswell, 2003). As the topic of students with autism spectrum disorder in higher education is only beginning to receive scientific attention, qualitative methods were appropriate as they provided a detailed view of the problem from the participants' perspectives. Independent or dependent variables could not be easily identified and theories were not available to explain behavior of participants. Qualitative research focuses on the process that is occurring as well as the product or outcome (Creswell, 2003).

The aim was to capture the “lived experience” from the perspective of those who live it and create meaning from it and potentially develop a framework of a theory to explain the process of progressing through college with an Autism Spectrum Disorder. Another reason that qualitative methods were suitable is that this was a potentially sensitive topic. The data that emerged were descriptive and reported in words rather than in numbers. The objective was to understand and explain multiple realities.

Qualitative Method

The strategy of inquiry employed in this qualitative study was grounded theory, as the goal was to derive a general, abstract framework from a process that was grounded in the views of participants in the study. According to Creswell (1998), grounded theory is a theory

generated from data systematically obtained and analyzed through the constant comparative method. The process involved using multiple stages of data collection and refinement and interrelationship of categories of information (Strauss and Corbin, 1990). Two primary characteristics of this design are the constant comparison of data with emerging categories and theoretical sampling of different groups to maximize the similarities and the differences of information (Cresswell, 2003). Theoretical sampling means that the researcher purposefully interviews participants who can contribute to the evolving theory. Initially a homogenous sample is interviewed, and as the theory begins to develop, a more heterogeneous sample who can confirm or disconfirm the conditions under which the model is maintained is interviewed (Creswell, 1998).

Grounded theory can be described as an inductive-deductive feedback loop in which hypotheses are tested as the conceptual model is built (Padgett, 2008). Deductively, statements of relationships are proposed and then verification of deductions against data occurs as incidents are compared with similar incidents. This process of verifying data is an inductive process. Thus, there is a constant interplay between proposing and checking. This back and forth movement is what makes theory grounded. Proposed relationships have to be supported over and over again in the data (Strauss and Corbin, 1990).

Constructivism

Constructivist grounded theory is part of the interpretive tradition which emphasizes understanding rather than explanation. Interpretive theories allow for “indeterminacy rather than seeking causality” and gives precedence to showing patterns and connections rather than linear reasoning (Charmaz, 2006). This type of theory assumes emergent, multiple realities.

Constructivists study how participants construct meanings and actions in specific situations. It acknowledges that the resulting theory is an interpretation (Charmaz, 2006). The theory depends on the researcher's view. Constructivists attempt to become aware of their assumptions and to understand how they affect the research. According to Strauss (1987) who was a symbolic interactionist, researchers' biographies exert influence over their use of grounded theory methods which needs to be accounted for during the research process. Birks and Mills (2011) also contend that critically analyzing the "flashes of understanding" that occur during grounded theory data analysis need to be done in light of the researcher's own history, context, and culture.

The social constructivist tradition that the primary investigator (PI) positioned herself in as a researcher assumes that individuals seek understanding of the world in which they live and function. They develop subjective meanings of their experiences which are varied and multiple; this philosophical frame enabled the PI to look for a complexity of views rather than narrowing meanings into a few categories (Creswell, 2003). The goal of the research was to rely as much as possible on the participants' views of the challenges they face in college and their use of internal and external support strategies. These subjective meanings were negotiated socially and historically. They were formed through interaction with others and through historical and cultural norms that operated in individuals' lives (Charmaz, 2006). Hence, the experience of students with ASD attending college / university today is quite different from the experience of someone who attended college ten or twenty years ago.

Researcher's Role

Sensitivity of the subject matter made rapport building important for successful interviews. The PI hoped that her experience over the years working with individuals with ASD and other developmental disabilities had given her some insight into the worlds of these individuals, and enabled her to be an empathic listener.

Qualitative researchers are often encouraged to disclose their personal perspectives on the groups they study so that readers can be conscious of potential bias in the work. Prior to beginning this research, the primary investigator worked at a public elementary school and a private pre- school for students with developmental disabilities including autism spectrum disorders, where she assisted in IEP development, facilitated support groups for parents, and social skills groups for children on the autism spectrum. The PI also completed a psychology externship at a diagnostic clinic affiliated with a university based medical center, where she assessed and made treatment recommendations for children ages 0-5 with ASD and other developmental disabilities.

While working on this dissertation, the PI began a pre-doctoral psychology internship at the college for science, technology, engineering, and math majors, in the student counseling and disabilities office. Upon completion of the internship, she was hired as the Disability Services Coordinator and Staff Clinician at the college. As a staff clinician, the PI facilitated a group called "Building Social Confidence" for the college students; some, but not all of the members had diagnoses of ASD. As the disability services coordinator, the PI evaluated diagnostic reports and made recommendations for academic accommodations based on these documents. At times

her job required her to decline requests for supports due to the lack of available resources or the unreasonableness of the request.

In addition, the PI is the parent of a child with a developmental disability, although not an ASD. As a result of personal and professional experiences, the PI has been exposed to a wide range of chronological and developmental ages, levels of functioning, and services and supports for individuals with ASD and other disabilities.

As the parent of a child with a developmental disability, the PI considers herself to be particularly sensitive to the demands placed on parents -- including pressure from professionals on parents to actively participate in their child's interventions and treatment plan when they are young. As a college counselor and disabilities coordinator, the PI appreciates professionals' concern that parents take on less of a managerial role in relation to their sons/daughters with ASD in order to facilitate the students' autonomous functioning. However, the means to enable parents and their children with ASD to shift in this direction are unclear.

This researcher supports community building for students with disabilities (and their families) in an effort to empower students and enhance self-determination efforts. At the post-secondary level, the PI favors social skills groups, peer mentor programs, executive functioning coaches and psycho-educational counseling for college students with ASD. While this compendium of services may represent the ideal, it is understood that most colleges do not offer this array of services, and many families are not in the position to hire outside supports. The PI's perspective may have affected her interpretation of events and discussion during the course of her research. However, she has attempted to remain open to other ideas and approaches.

The hope is that by continuing to read accounts of the wide variation in ways that social problems are dealt with, and by maintaining a critical stance toward her own work in the field, the PI was able to see beyond her own ideological and practice assumptions. The PI was interested in as wide a range as possible of the students' experiences of programs and supports. The lived experience of the participant remained central to the analysis.

Ethical Considerations

The research process began by obtaining approval from the Office of Human Subject's Institutional Review Boards (IRB) from the two institutions of higher education that the participants attended. IRBs require that researchers submit detailed descriptions of their research plans and complete instruments for review. This process is inherently at odds with the emergent nature of grounded theory methods (Charmaz, 2006). Theoretical sampling posed obstacles because it was impossible to anticipate what the core category or central phenomenon would be at the outset of the study. As new questions arose as the categories developed and story integration began, amendments to the proposals were submitted to the IRBs. Additionally, the committee had to be convinced throughout the process that no harm would befall the participants as a result of responding to the interview questions. This was accomplished by emphasizing the participants' comfort level over obtaining sensational data. Close attention was paid as to when to probe for further information.

Another consideration was that the researcher was promoted to the position of Disability Services Coordinator at the STEM college during the data collection stage of this research study. This posed a potential ethical dilemma involving the dual nature of the relationships with disability students and potential volunteers for the study. The researcher shared this predicament

with the IRB and informed them that she would state her new position in the recruitment letter and inform potential participants that their participation in the study would in no way affect their receipt of academic accommodations or other services through the Office of Disability Services.

Data Sources

Once the IRB approvals were received, emails were sent to individuals on the autism spectrum who had registered through the office of disability services at both institutions. An informal meeting was also conducted with the program director of the College Support Program (CSP) at the state university. The PI explained the research, and the CSP director agreed to provide help with recruitment. The CSP director encouraged students who utilized the program to contact the primary investigator to participate in this research. Five students from the CSP program at the state university contacted the PI and they were all interviewed for the study. Additionally, a graduate of the STEM college who had attended an ASPEN (an adult autism support group) meeting and heard about the research project contacted the PI requesting to volunteer. Gaining entrée into the sites and to the students did not represent a significant challenge. The bigger potential challenge was in finding enough participants who were able to communicate with a degree of insight, in order to provide meaningful information to aid in finding patterns in the data. As initially no students from the STEM college responded to recruitment letters, additional letters were sent in the middle of the fall semester with an increased financial incentive for participation. Three currently enrolled freshman at the STEM college eventually offered to participate.

Interviews were conducted with nine individuals who had diagnoses of autism spectrum disorders that currently attended college, or had attended at least half of a semester of college

within the past three years, and were at least 18 years of age. The interviews explored participants' thoughts about their coping strategies in dealing with the challenges presented in college due to their disability, their use of supports and services, and their belief about the usefulness of various supports.

The participants consisted of five students from the state university – four male, and one female student. One of the students transferred into the university from another college. He was considered a sophomore, despite having been in college for three years. Two other students were considered sophomores although they also had been in school for more than two years; one student was a junior, and one student was a senior. Four students identified as Caucasian and one identified as Chinese American. From the STEM college three current freshman and one former undergraduate / graduate student participated in the study. They were all males who identified as Caucasian.

The literature indicated that there is not always a good correlation between the individuals with ASD' self-report of their experiences and their parents' descriptions of their experiences. The students' stories were thus considered to be representations of the participants' college experience, rather than as verbatim depictions of reality.

Data Collection

Purposeful and theoretical sampling were employed in this study rather than random sampling procedures. Initially a sample of individuals from a large state university with a supplemental support program for students on the autism spectrum, were interviewed; these students contributed to the evolving theory. Then, after developing the framework for a theory, a group of students on the autism spectrum who attended a small, private STEM (science-

technology-engineering – math) college were sampled. This college provides academic accommodations to students with disabilities, which often consists of additional time and a distraction free room for testing. The study focused on participants from these two different post- secondary institutions. This allowed an opportunity for some comparison of services and programs utilized and the specific aspects of supports found beneficial by the students themselves.

A substantial amount of the data gathering was conducted by semi- structured interviews with individuals “in situ.” This means being with college students with ASD diagnoses in some way that allowed the PI both intimate observation of certain aspects of participants’ behavior and enabled reporting to be done in ways useful to social science and yet not harmful to participants. Research settings were conducted in locations where observation, interviewing, and casual interaction with college students with ASD, could occur and in which there would be little risk of a perceived threat to them. An initial set of interviews occurred at a library on the state university campus. An interview protocol was used that had key research questions and sub-questions that were used as probes. Prior to interviews, consent to participate in the study was obtained from the interviewees.

“Sensitizing concepts” that were found in the literature helped this researcher decide where to look while gathering and analyzing data initially (Smith, 2005). Some concepts that this researcher wished to explore as the data collection began included the notion of how the students understood their disorders, and the challenges they presented in college, and the interaction of students’ internal coping mechanisms and the external supports utilized. The emergent nature of the process required researcher to be flexible in her use of interviews as data generation. What the researcher asked a participant and how it was asked varied both between

and within interviews (Birks and Mill, 2011). It required being attuned to what each participant was saying, and being theoretically sensitive to what it meant for the developing theory and directing the interview accordingly.

As an understanding of concepts developed and a general sense of the information and its overall meaning began to be formed, the PI was better able to focus and test assumptions and inquire about meanings with individuals. A second set of interview questions were developed to be used with theoretical sampling. These questions were constructed based on the developing insights, for use in interviews with individuals, at the STEM college.

SURVEY QUESTIONS

Main Questions

1. What have been the biggest challenges for you in college?
2. How have you managed these challenges?
3. What do you as a student with an ASD want/need in terms of supports and services?
4. What, if any, supports/services have you used?
5. How have they been helpful /unhelpful?

The following sub-questions were used as probes to gather additional information and encourage further discussion. Not every question was asked of all participants.

Sub-questions

Academic and Career Goals

1. How and why did you decide to go to college?
2. What is your major/minor? Why did you choose to study this?
3. What are your career goals?

Accommodations/ Use of Disability Services

1. What factors influenced whether or not you disclosed your diagnosis of ASD while in college?
2. What accommodations and supports do disability services provide?
3. How have professors responded to your need for accommodations in class?

4. What can professors do to better support your academic needs?

Academic Functioning

1. Describe how having an ASD impacts your learning
2. Describe your experience managing your coursework
3. Describe how peers have been helpful/unhelpful in classes
4. How has having ASD been of benefit to you as a student?

Social Functioning

1. Describe your social life as a college student.
2. Have you ever felt isolated/ lonely while at college? Describe what that has been like for you.
3. Have you been involved in any romantic relationships while in college? Describe the nature and quality of romantic relationship (s).
4. What activities or organizations are you involved with in school?

Self-Awareness

1. In what ways do you think the diagnosis of ASD most impacts you?
2. What have been your greatest challenges during your time in college so far?
3. What have been your greatest successes so far in college?
4. What would improve your college experience and increase your chance for success?

Additional Questions for Theoretical Sampling

Theoretical sampling is unique to grounded theory and is an essential element in making the process emergent (Glaser and Strauss, 1967). After initial data was collected, the PI analyzed that data, and the questions about concepts that emerged during analysis determined what kind of data needed to be collected next. As it became apparent that the constructs of managing challenges and obtaining support needed to be more fully developed, the following questions were added to the initial questions and probes for the subsequent interviews.

1. What does it mean to you to have challenges?
2. What does it mean to you to manage challenges?
3. What does it mean to you to ask for supports?
4. When do you most typically experience challenges?
5. What do you do to obtain support?

6. Who provides support?
7. What happens if you don't get support?
8. What happens if you do get support?
9. How much stress do you experience before asking for support?
10. How much does your desire for obtaining a college degree influence use of supports?

Data Analysis

Data analysis and data collection were done sequentially with preliminary data analysis informing future data collection. Early in the data collection process, theoretical notes were written in which the PI played with the data, relating observations to one another, developing new concepts, and linking these to ones in the literature. Gradually these theoretical notes were integrated into longer analytic memos that helped further focus the study. Memos are written records of the researcher's thinking throughout the grounded theory development process (Charmaz, 2004). This data analysis process continued during and after data collection until some kind of overall pattern for data analysis emerged that accounted for the phenomenon observed.

In addition to the use of memos, the ongoing process of coding interview transcripts was central to the data analysis. This required reading and rereading the data to highlight and label important, descriptive, or informative issues that emerged, for later sorting and categorization. Rereading the data enabled the PI to identify and discover processes and the properties and dimensions that characterized them. The ultimate goal was to develop a theoretical framework that accounted for the phenomenological experience for the student with ASD while in college; although, rich description that depicted the experience and the meanings attributed to supports and programs for the college students would, in itself be a significant contribution to the literature. A grounded theory generally provides a comprehensive explanation of a process in

relation to particular phenomenon. It is comprehensive because it includes variation rather than assuming there is a “one size fits all” answer to a research question (Birks and Mills, 2011).

The categories were considered ‘saturated’ when it was apparent that no new ideas or concepts seemed to be emerging, and when no additional negative cases were found that disconfirmed or invalidated the proposed framework for analysis. Studies with relatively homogenous domains and/or sampling strategies are likely to reach this endpoint faster than those with broader reach and ambition (Padgett, 2008). However, Morse (1995) asserts that researchers actually cease data collection when they have enough data to build a comprehensive and convincing theory.

Analysis of the data included examination of the variances in students’ experiences from two different college/university settings, students’ use of various supports, as well as a comparison between students whose college experiences were considered successful versus those whose experiences were considered less successful.

Strauss and Corbin’s (1990) coding paradigm

Open coding is the first step in data analysis of a grounded theory framework. As defined by Strauss and Corbin (1990), open coding involves “breaking down, examining, comparing, conceptualizing, and categorizing data.” In open coding, the researcher forms initial impressions of information about the phenomenon being studied -- in this case, ASD related challenges -- and codes or labels the data (Strauss and Corbin, 2008). “Codes are used to identify conceptual reoccurrences and similarities in the patterns of participants’ experience” (Birks and Mills, 2011). Similar concepts are then grouped together or categorized. Categories are given more abstract names relative to codes. The narrowing of focus that naturally

accompanies initial coding gives direction to further data collection and aids progression of the analysis (Birks and Mills, p.97).

In axial coding, data are put back together in new ways, by making connections between categories, while elevating the level of conceptual analysis (Strauss and Corbin, 1990).

Subcategories are related to their categories through the paradigm model or a set of relationships that denote causal conditions, phenomenon, context, intervening conditions, action/interaction strategies, and consequences.

Finally during selective coding the core category is selected and related to other categories. A story or descriptive narrative about the central phenomenon of the study is developed. It is through this process that the framework emerges as concrete aspects of managing ASD related challenges are refined and integrated into conceptual and abstract ideas.

For ease of compiling information, the researcher developed six main categories and 18 subcategories, as recommended by Creswell (2003). The categories and subcategories are presented to illustrate development of the framework throughout the data analysis process. While some initial categories became subcategories, others were integrated into different categories, or were dropped as they were deemed less influential on the process of managing ASD related challenges and progressing through college.

Verification

Validity does not carry the same meaning in qualitative research as it does in quantitative research (Creswell, 2003). In qualitative research, validity is used to determine whether the findings are accurate from the standpoint of the researcher, the participant, or the readers of an

account (Creswell and Miller, 2000). Some strategies that this researcher used to check the accuracy of the findings included:

Member checking – At the end of the interviews the researcher summarized what had been said and asked if it accurately represented the participant’s experience.

Clarifying researcher’s bias – The researcher attempted to be self-reflective in order to create an honest narrative regarding her own pre-conceived ideas and how they might impact interpretation of findings.

Presenting negative findings – The researcher provided an account of an individual’s narrative that ran counter to the proposed themes. Real life is comprised of different perspectives and discussing this example openly added to the variation and credibility of the developing story.

An important step in grounded theory research is to develop open coding categories and then, through axial coding to interrelate these categories. An important verification step takes place through this process (Creswell, 1998). The researcher posed questions that related the categories and then returned to the data and looked for evidence or incidents that supported, or refuted the questions, thereby verifying the data (Creswell, 1998). After the researcher wrote the framework of the theory, the literature was used for “supplemental validation;” the researcher referenced the literature to give validation for the accuracy of the findings or provided examples of how the findings differed from the published literature.

Summary

This chapter provides an explanation of the reasons for using a qualitative paradigm in this research study. It discusses the specific qualitative method used, in this case, grounded theory. Additionally, the researcher's role and background are revealed to enable readers to understand potential researcher bias in this study. Information about the data sources and ethical considerations are provided and methods of data collection and analysis are described. Finally the means of verifying data were explained.

Chapter IV

Results

The purpose of this grounded theory study was to generate a framework that accounts for the phenomenological experience of students with ASD at two institutions of higher education: a large state university with a supplemental support program for students on the autism spectrum, and a small, private STEM college that provides traditional academic accommodations. Both institutions were in the northeastern part of the U.S. Additionally, this study assessed the meanings attributed to utilizing supports and services for these college students.

The results section is organized in conjunction with the process of data analysis as described by Strauss and Corbin (1990). Emphasis is placed on axial and selective coding.

The axial coding model is presented through a process in which the central phenomenon (ASD related challenges) is identified. After the central phenomenon is discussed, the causal condition is explored (the event that leads to the need for managing ASD related challenges) and strategies used to manage the challenges are discussed. The causal conditions and strategies will lend themselves to a discussion of the stress context and intervening conditions involved in accessing and utilizing supports. Finally, the consequences, or outcomes of these strategies are discussed. This coding paradigm for grounded theory data analysis is reciprocal in nature. While this coding paradigm served to guide the data analysis and presentation of results, it also demonstrates how each element involved in managing ASD related challenges in higher education are interconnected and influential. Results are presented in terms of this coding paradigm to keep within Strauss and Corbin's model of data analysis within the grounded theory tradition.

After the central phenomenon, causal conditions, strategies, context, intervening conditions and consequences of managing ASD related challenges are discussed, a supplemental section focusing on a former undergraduate and graduate student of the STEM college, who was unaware of his diagnosis of ASD while he was an undergraduate is presented. This section highlights distinct differences between students who utilize supports during college vs. the experience of someone who did not.

After a thorough discussion of each of the facets of axial coding, a conditional proposition or hypothesis about the process of progressing through college with an ASD is presented. In the final coding process, selective coding, the framework is refined and integrated (Strauss and Corbin, 2008). In this way, all of the steps in the process and results of the grounded theory coding paradigm affect one another in a temporal progression.

Axial Coding

Axial Coding involves a “set of procedures in which data are put back together in new ways after open coding, by making connections between categories. This is done by using a coding paradigm which includes conditions, context, action/interactional strategies and consequences,” (Strauss and Corbin, p. 96). The initial codes and subsequent categories naturally fit into this schema and enabled the story to easily develop from the data.

The central phenomenon that emerged from the initial codes was *ASD related challenges*. This phenomenon was broken down into two main subcategories – *social challenges* and *executive functioning challenges*. The subcategory *social challenges* developed from three initial codes which emerged during the open coding phase: *peer relationships*, *romantic relationships*, and *roommate relationships*. The subcategory *executive functioning challenges* developed from

the codes *organizing work, managing time, and prioritizing responsibilities*. As the participants' own words best represent the development of codes and categories, many direct quotes are provided throughout the chapter. Samples of the participants' quotes are included below to illustrate the creation of the central phenomenon and its subcategories: Social Challenges and Executive Functioning Challenges.

Category (Central Phenomenon) - ASD Related Challenges

Subcategory: Social Challenges

Code	Example Quote
Peer Relationships	“There were people from sororities and fraternities who teased me and bullied me at times.” S1
Romantic Relationships	“I had a big crush on a girl in my class and I didn't realize that my actions at the time were like needy or more like stalker. When it was explained to me I felt really ashamed of myself.” R1
Roommate R-ships	“Starting in my freshman year, my biggest problem was getting along with my roommate, because we were absolutely incompatible. He was the social butterfly and I was the quiet person, who was always on my computer. He thought I was wasting my life.” I applied for a single because whenever you have a roommate, you sort of become camera conscious. When I got a single, the cameras were taken away and I was relieved.” R1

Strauss and Corbin (1990) state that when developing a category you do so in terms of its properties, which can then be dimensionalized, or located along a continuum. After labeling each subcategory, the participants were given a score (from 1-5) indicating the level of intensity in which the participant emphasized the subcategory as being problematic for him/her during

their interview -- 1 being least problematic and 5 being most problematic. For example, participant S2 was given a 4.5 for social challenges based on the following statements:

“I’ve had challenges with social. I feel like this is kind of the crux of my disorder. I feel like I’m being a jerk and I don’t mean to be...I try not to be as much as I can and I really don’t wanna be in any way, but sometimes I feel like I’m doing it by accident or maybe it’s an outlet when I have those short outbursts.”

“It’s the social aspect because the definition of Asperger’s -- it’s harder to understand people’s body gestures for the most part and nonverbal cues. I very much do feel like sometimes I’m in the dark unintentionally with regards to other people and how they feel; I just can’t quite tell how (people) are feeling and I feel like I should be able to.” **S2 – 4.5**

In contrast, participant R4 was rated a 2.5 for social challenges based on his comments:

“Socially, I’ve never really had too much (trouble) at all. I could say that I’ve been a little socially awkward. I’ve always been fairly good at making friends and interacting with people. I have had some trouble with some missed signals here and there, and sometimes misinterpreting things. But it’s not as often as you would think it would be.” **R4 – 2.5**

It should be emphasized that the dimensional scores were based on participants’ perceptions of their situations, which may not have been completely accurate representations of reality. Participant R3 received the lowest score of 1 based upon his comments:

“My social skills aren’t a problem for me. One of the least of my worries when it comes to my disability is socially.” **R3 - 1**

An example from participant R1 who received the score of 4 was based on the following comments:

“Most of the time, I do generally want to develop relationships, but a lot of other times, I just can’t see the point of being social. It’s very mentally taxing for me to try to keep up a façade of being a regular social person.”

“It used to be when it came to people outside of my family, I couldn’t get along with them.” **R1 - 4**

Participant R2 was a challenge to score in this category because she reported having some close friends, but also having social challenges. She ultimately received a score of 3 based on the following statement:

“I have social challenges, just having friends and knowing the right things to say and navigating the social and romantic world. As far as friendships -- it’s just maintaining them and keeping in touch that is hard, especially if you’re in a bad mindset.” **R2 - 3**

All of the nine participants received a score for the category of social challenges as they all referred to it in terms of the level of challenge and stress it creates for them. For several participants, it was a lesser concern, while for others, it was more problematic and for one participant in particular, it was extremely problematic.

The category of Executive Functioning Challenges was also mentioned by all participants and each participant was ranked according to the level of challenge it presented for him/her.

Category (Central Phenomenon) -- ASD Related Challenges

Subcategory: Executive Functioning Challenges

Codes	Example Quote
Organizing Work	I think my greatest challenge has been the organization and planning. If I get behind I feel like I’ll get into a hole.” R3 – 3.5
Managing Time	“It’s more mentally taxing for me to keep track of what exactly I should and shouldn’t be doing at a certain time.” R1 - 3
Prioritizing	“Balancing work and different types of relationships whether it was romantic or friendship, just making the time for the person but also it was making the time for myself to get stuff done. Just like knowing when to study versus when to do homework and I’m still struggling with that to this day.” R2 - 4.5

Again, the participants in the study were ranked on a 1-5 scale based on the intensity of their responses to the category and subcategories. Quotes from several of the participants that represent the subcategory executive functioning challenges are presented below, along with their dimensional score.

“My biggest challenge has been adjusting to the lifestyle, learning to push myself to do my own things, learning for me to push myself to do my work because in high school, it was very much an organized schedule. There were always parents and teachers encouraging me and telling me to do the work. When I came here to

college I needed to figure out how to push myself to get my own work done and to be the one in charge.” **R4 – 4.5**

“I get all of the work done. Whether I am time efficient, that’s debatable.” **S4 - 2**

“Time planning I think was a big challenge because I tried to study a lot but I don’t think I organized my time efficiently.” **S1 - 3**

Causal Conditions

Causal conditions refer to the event that leads to the occurrence of the central phenomenon (Strauss and Corbin, 1990). In the case of this study, the causal condition was attending college or university which triggered the perceived ASD related challenges. The properties of this category were broken down into size -- a large, state university, versus a small, private, STEM college; distance from home-- short versus long distance from home; commuting versus living on campus; and attending a college with a built- in support program versus attending a college that just provided traditional academic accommodations.

All but two of the participants were raised in the same state as the institutes of higher education; the other two were from a neighboring state. One of the two who grew up in the neighboring state currently lived with his father who resided near the university. None of the participants’ families lived more than 1 ½ hours from their school. One participant commuted to school. The eight others lived on campus for all or part of their time in college with one student having taken a temporary leave of absence, who was taking one course as a part-time student and living with his father at the time of his interview. Five of the students were attending the large, state university at the time of the interviews; three were currently attending the small, private,

STEM college, and an additional participant had attended the STEM college as an undergraduate and graduate student and received his master's degree two years prior.

This participant discussed his experience attending the STEM college as such:

“S was a small school and part of the social difficulty was that everyone knows almost everyone else. So me having a bad reputation filtered out to the entire school. At a large school, I probably would have felt more invisible.” S1

However, he also spoke about his experience at this school in positive terms:

“I still have very negative feelings against all the people that wronged me at (college). But on the other hand they gave me a good education and they really prepared me for the mentality of an engineer. And whenever I send out my resume it gets instantly noticed. I never have a shortage of interviews or job offers.”

Action/Interaction Strategies

In grounded theory, action/interaction strategies are directed at managing or responding to a phenomenon as it exists under a set of perceived conditions (Strauss and Corbin, 1990). It typically occurs through strategies. “Controlling” became the term for strategies use to manage the challenges associated with college life for these students. Below is a list of the most frequently mentioned strategies that participants used to manage their ASD related challenges.

Category: Controlling Strategies

Subcategory	Example Quote
CSP Support	(CSP supports) are there to “help me learn to manage stuff on my own.” R4
Accommodations	“I’m allowed extra time on exams, but I usually finish exams way before time is up.” R5
Outside Support	“My mother has hired another student to help me become organized.” S3
Join Campus Activities	“The only things that I really interact with are clubs, which I go to once a week. I go to anime club or videogame club. A lot of people in the CSP I know have the same interests and attend those clubs.” R5

Academic Accommodations

As with any process, not just managing ASD related challenges, there are specific strategies that are used to achieve the desired result. The dimensional scores denote the level of help perceived from the controlling strategy: 1 represents the lowest amount of help; 5 indicates the highest perceived level of help. One of the main strategies used by these participants was academic accommodations. All but one of the students interviewed had provided the Office of Disability Services at their college with documentation of their disorder and were receiving academic accommodations. The quote presented above was fairly representative of the students’ sentiments. Participant R1 similarly stated:

“I used to use accommodations in my early years at R; I found as time went by I was gradually needing them less and less.” **R1 - 2**

Participant R4 commented:

“For accommodations, I have extended time on tests, permission to have a note-taker...and I’m allowed to take tests in a low distraction environment. I don’t need the extended time unless it’s something that I’m really having trouble with. Usually I end up finishing it around the same time most of the other people will. And I rarely use the note-taking because I keep trying to teach myself to take notes because I don’t want to rely on someone else to take notes for me.” **R4- 3**

In general, participants commented that professors were supportive of their need for academic accommodations. However one student, participant R2 commented:

“Sometimes teaching assistants don’t listen to me (that I need support) even though I tell them I have accommodations.”

Teaching assistants are often not included on correspondences sent to professors acknowledging the student’s approved accommodations, which can lead to misunderstandings and frustration.

CSP Support

This program was instituted at the university in 2009. The CSP offers individualized support to students who are on the autism spectrum. The services are funded by a per semester fee which is billed through the university health service office and is independent of tuition and fees at the university. After a student is accepted to the university, he/she may apply to the CSP for services.

All five of the participants from the state university were utilizing some CSP services which include social skills groups, peer mentors, executive functioning coaching, and interview

preparation. Comments from all five students relating to their use and the effectiveness of CSP services were extremely positive. The dimensional scores represent the degree of perceived helpfulness (5 being the highest level of perceived helpfulness.) Several representative comments include:

“CSP keeps me on track with academics and helps me talk with my teachers and deans.” **R2 - 5**

“Having mentors means I have an assured person to talk to. I get practice talking to people in a regular conversation. Also, social skills group gets me to interact with students.” **R1 - 5**

“CSP has been really, really helpful. My two mentors – I’m very close with the both of them. They’re both very kind.” **R3 - 5**

“CSP is not over supporting me in terms of doing everything for me or getting to the point where I’m leaning too much on the support. It’s there to help me overcome the problems and the issues that I’ve been having with time management and other things.” **R4 - 5**

“I went to social skills group at CSP for higher functioning kids and we’re focusing on higher functioning things such as dating as opposed to recognizing non-verbal signals and things like that.” **R4 - 5**

Outside Supports

Two out of the three students from the private, STEM college utilized outside supports including therapists, and an executive functioning coach. The third current student from the

STEM college uses services provided by the college's counseling center, including individual counseling and a social skills group. Two students who were utilizing CSP supports at the state university also utilized outside supports including academic coaching and therapy. Services provided through the college counseling center are included in the cost of tuition; outside supports require additional fees. Participant S2 describes his therapist as such:

“I had a lot of fears about a year or two ago about how this transition (to college) was going to go. And I thought this was going to be awful like maybe not even survivable. Then I switched therapists about one year ago and she's made a very large difference in my life. She's mostly helped me with my depression.”

Without my therapist, “I probably wouldn't be here right now. I feel like I would come here then I would have to leave because I just wouldn't be able to handle it.” **S2 – 5**

“Freshman year was the hardest for me...I sent a text to my mom that just said, ‘Help!’ Then I talked about my difficulties with my therapist. I felt like I was going insane. He gave me advice on how to get help and not long after that I joined the CSP.” **R1 - 5**

Stress Context

According to Strauss and Corbin (1990) context “refers to the particular set of conditions within which action/interaction strategies are taken to manage or respond to a phenomenon.”

Students' circumstances and the degree to which they perceived them as intensifying their ASD related challenges varied. But, perceived stressors existed for every participant and influenced their use of strategies. For every subcategory within the category stress context, each participant

was again scored along a dimensional range from 1-5 (1 being the least intense and 5 the most intense experience).

Context for ASD Related Challenges

Category: Stress Context

Subcategory	Example Quote
Peer Rejection	With peers – “It’s been a mixed bag. Not everyone understands me. They’ll be grateful for the homework help, but I don’t feel as included as everyone else.” R2 – 3.5
Academic Problems	Academically, I have had some troubles. I was on academic probation. My third year I ended up withdrawing at the end of last semester because I was having a lot of trouble. R4 - 4
Isolation	“I don’t really hang out with people that much. I only like talking to people who like anime and video games. I usually pretend my roommates aren’t there unless they’re doing something fun...like playing videogames.” R5 – 3.5
Poor Choices	“I made a lot of dumb choices. This might’ve been because of the Asperger’s, so naivete. First there was this girl who seemed to like me and she was part of ROTC and she smiled and would say a couple of words. So I thought there was an attraction when I didn’t know she was just being nice to me. And out of naivete I joined ROTC. That was a big mistake.” S1 - 5
Negative Self-Concept	“I just thought I was an extreme nerd.” S1 - 5

Academic Problems

Six out of the nine participants noted academic problems as a significant issue for them which played some part in their help seeking. Several examples with their dimensional scores are included below:

“Everyone thinks I’m a senior, but according to my credits I’m between sophomore and junior year.” A better way to support my (academic) needs would have been if someone “at least tried to help me study better; not everyone’s brains work the same way. Using slides repetitively does not always help.” **R2**

“It’s really hard to do material science engineering. You have to do four calculus courses. And physics was not kind either.” “I try to do memorization but – and this semester just wasn’t good. I am withdrawing (from school) tomorrow.” **R2 – 5.**

“I should be a senior, but credit wise, I’m a sophomore.” Math isn’t great, only because it’s not just stuff I can memorize like history. I mean when it comes to numbers, and dates – I was awesome at that.” **R3**

“I don’t think high school ever prepared me for college. I didn’t really learn how to study because my memory is so good. I relied on my memory and when I got to college I was like ‘what!’” **R3- 3**

“I am currently in my third year here. I do not have the credits of my third year. I am technically based off of my credits, I am a sophomore.” I decided that this semester I would take some time off to refocus, and figure out how to deal with some of the issues that I’ve been having in procrastination through therapy.” **R4 - 4.**

“If I’m able to completely understand the topic and form the patterns and connections in memory, then it’s not that hard for me to study.” **R1 – 1.5**

Peer Rejection

Only two out of the nine participants mentioned peer rejection at college being a problem that led to their need for support. But both students’ reports of peer rejection were significant enough to warrant mention in the study.

“Some of the people that I had made friends with, they began to become more isolated because that time I probably was unaware of the autistic quirks I was giving off and before they probably thought I was an eccentric. I was growing up and when I didn’t grow up according to their expectations, they began to distance themselves more from me. **S1**

“At S I tried to hang out with some of the gaming people. One of the reasons I got isolated was I tried to imitate them but I came across to people as annoying. When I felt loose, then people got freaked out and backed away because I probably did things in extremes and didn’t know when to stop. I somehow went past the boundaries so they thought there was something wrong with me.” **S1**

“I told this guy that I had been isolated in high school and he mercilessly picked on me after that. He nicknamed me Bill Tower after that University of Texas student who in 1996 went up to the Bill Tower and started shooting people at random. He nicknamed me that and he spread that to other people and then other people behind my back started calling me Bill Tower.” **S1 – 5.**

“I don’t know if it was bullying, but he (ex-boyfriend) would always say it was a joke. It’s like he would do verbal put downs. “ **R2**

The upper class and lower classmen in my major were fine but the ones that were my year were not always kind. They seemed more frat boyish. They did not understand me and like some of them were like, ‘oh, I can’t really give you that data or everything or I don’t feel comfortable with it,’ like of bunch of excuses. It’s like anytime I help them, they would be totally happy but if I ask for help or like something to verify my data like I just was thought of as the annoying kid for the last two years.” **R2 – 3.5.**

Isolation

Isolation is often the result of peer rejection, and frequently both concepts appear within the same passage. However, isolation receives its own subcategory here because most participants reportedly did not experience direct peer rejection in college, yet isolation was common. Some of the participants preferred the seclusion, while others complained of feelings of loneliness and wished for more social connections. Some participants expressed both sentiments.

“I went to the TV Club and I initially made some good friends there until I got into a bit of drama with one or two people in which I got humiliated and I felt no one was standing up for me. So I started spending less time at the club and we gradually got alienated from each other. And after one row I tried to confront the guy. He tried to brush me off saying this little (bleep) is not worth my time and I

got so mad that I threw a cup at him and he got so pissed off, he left and all the other members of the TV club left. So I just felt isolated. **S1 – 4.5**

“There have been times where I really have enjoyed the quiet, just being able to sit down, rest, do my own thing, listen to music, play my games frequently, read my fanfiction, ‘ cause I think being an introvert and being an Aspergian, like they are generally mutually exclusive.” **R1**

“I take solace going online.” **R1 – 2.5**

“Sometimes I get lonely if I see a peer mentor and her roommates all bonding and everything. At the same time I’m like what if I had a bad habit moment like how am I going to deal with the girl not being grossed out by that because I’ve dealt with stereotypical crap like with them being like Ew!” **R2 – 3**

Poor Choices

Poor Choices refer to decisions that were made in the social or academic realm which lead to negative consequences. This negative experience contributed to the participants’ perception of the need for supports. Five of the participants directly mentioned, or referred to poor choices that they made in college.

“Considering I have trouble with word problems, (majoring in material science engineering) was probably not the smartest choice.” **R2 – 3.5**

“I thought I could get along with any type of person and I chose a roommate which turned out to be a very poor choice of this jock type of person and it turned out we didn’t get along so well. **S1**

“So I made a lot of mistakes. I started to do a master’s degree in math...because I had a friend who was also doing a master’s in math. So I thought I could do what he did as well. But I didn’t do so well in the graduate math courses, and I eventually had to change my major.” **S1 – 4.5**

Negative Self Perception

Self- perception is the idea that a person has about the kind of person they are. One’s self - perception may or may not be different than the way others perceive the person. Six of the participants spoke in negative terms about themselves. Their reflections often indicated a degree of insight that people often don’t realize that individuals with ASDs possess.

“Part of me was upset feeling that life was going by and I was missing it because I could see people going out with girls. I saw people having a good time with each other, and I felt outside of that. I seemed to feel I would never have the ability to be doing what other people did.” **S1 – 4.5**

“I am looking for a job that is high task, low people. When it comes to social interaction, I can do short conversations or long conversations about topics that I have a vested interest in, but when it comes to topics that I have absolutely no interest at all, it’s mentally more taxing for me than most people in order to keep it up.” **R1**

“It just feels frustrating that a lot of students can have relationships and it comes naturally, but I can do the academics just fine, but, and I consider myself a nice

guy most of the time, but when it comes to relationships...well you get the idea.”

R1 – 4.5

“I feel socially awkward half the time.” **R2 – 3.**

Intervening Conditions

Intervening conditions are broad and general conditions that act to either facilitate or constrain the action/interactional strategies taken within a specific context (Strauss and Corbin, 1990). Again, these conditions varied for each participant, but several themes were consistently mentioned. The themes that occurred with the most frequency became subcategories. Every participant who mentioned the subcategory was scored along the dimension of 1 – 5. Examples and scores are included below.

Category: Intervening Conditions

Subcategory

Example Quote

Comorbid Conditions

“My thoughts started going into loops about what could have gone wrong; the OCD went into regular thought loops and I had to use Prozac and other techniques to control it.” **R1**

Parental Involvement

“I talk to my parents almost every day, so I mean they do stay close by.” **R3 – 4**

Category: Intervening Conditions (cont.)

Subcategory	Example Quote
Motivation to Graduate	“I realized at some point that I needed to make my way through college in order to be able to do the kind of job that I wanted to do.” R4 - 4
Assessing Need for Help	“Asking for help in an area of strength – I’d say my stress level would have to get pretty high.” S4 – 4.

Parental Involvement

Parental involvement refers to the assistance – either physical or emotional that parents provided the student while they were in college. In many cases, it was the parents’ encouragement that influenced the student to obtain help, while in other instances parents remained neutral or actively dissuaded their child from learning about their diagnosis and seeking support. Eight of the participants mentioned their parents as playing a role in their management of ASD related challenges. Higher dimensional scores indicated a greater degree of perceived help from parental involvement.

“My parents told me I can learn history by studying myself, but it’s better to get a practical degree. That time I was more passive. I didn’t question my parents openly.” **S1**

“My family provided some support, but not to the extent that I hoped because in the old days my father would actively confront the bullies and they would stop for a while. I subconsciously thought they would come and they would give a dressing down but at this stage they couldn’t do that.” **S1 – 3**

“I don’t know where I’d be if it wasn’t for my mom and sister and, I think my dad as well. I go home more than most people, over the weekends. I miss the familiar setting.” **R1 – 5**

“My parents have helped me with academics and after a breakup with a guy I was dating they tried to make sure I wasn’t suicidal for the next couple of months.” **R2 – 4**

“My family understands the differences in the way I learn and they try to help me to figure out how to balance my schedule to make it so that I can take classes that I’m not necessarily interested in and still manage to invest time and energy in those classes in order to succeed in them.” **R4 – 4**

“It’s been a really long time...a long time my mom really like, bless her heart, she did so much, like she basically researched my disability to death.” **S2 – 4.**

Motivation to Graduate

Motivation to graduate was determined through statements participants made that indicated the degree to which attending college and obtaining a degree was their decision versus their parents’ choice or based upon a societal expectation. Six people mentioned it in their

narratives. Dimensional scores were based upon the degree to which college was internally motivated (scores of 4-5) versus externally motivated (scores 1-2).

“College was really my decision because I knew what I wanted to do and I had to obviously get a higher education degree.” **R3 – 5**

“College had been drilled into our heads since, I wanna say, elementary school, but it’s necessary if you wanna get a job to have a bachelor’s degree at this point. I think I did come to college to learn.” **S2 - 3**

“The reason I came to college was that I wanted to learn more about sciences and technology and I wanted to get a job where I can solve scientific and technological problems.” **S3 – 5.**

“I always wanted to go to college. I thought college would be a fresh start.” **R2 – 3.**

Assessing Need for Help

Assessing the need for help refers to the cognitive process that influenced participants’ decision to obtain support versus choosing to function independently. Participants continually evaluated their situation throughout college and determined their stress level at that point in time and the need for supports. It was indicated in some manner in seven of the participant’s interviews. Dimensional scores were determined based on the negative perceptions of asking for support (higher score) as compared to the neutral or positive feelings associated with seeking support (lower score).

“I never even went for mental health (counseling) because I thought it would be like a sign of defeat...that it would be an acknowledgement that I am screwed up or something like that.” **S1**

“I guess I didn’t report (bullying) for two reasons: I couldn’t really verbalize what was happening to me and two, I was afraid of being perceived as a sissy.” **S1**

“I was embarrassed to go for support initially. I felt to go for support was like admitting defeat that I hadn’t done well in life.” **S1**

I eventually sought help because - “I felt things were at rock bottom because I graduated but I was feeling so depressed.” **S1 - 5**

“It took me until the end of the first semester to realize that I could lean on my parents. I basically had been trying to deal with everything on my own and I hadn’t really been talking to them much about what I needed to do in class. Toward the end of the year I ended up crashing and they suggested that I join the CSP. It was only once I crashed that I realized it was okay to ask for help.” **R4**

“I had trouble asking for help in the past because I felt a need to be able to do something on my own, to become independent, and because sometimes I have the problem that I think too much before I act or speak. I overanalyze what will happen and I think “well maybe this could happen.” **R4**

“I have come to the realization that it was very important to be able to ask for help because that had been something that I had a lot of trouble with in the past.” **R4 –**

4.5

“If I had challenges socially I would come here (counseling center) or go to my therapist back home.” **S2 – 2.**

“It makes me kind of anxious asking for support. It’s like having to explain my situation to another person. Communicating my challenges to another person is going to be pretty stressful.” **S3 - 4**

“I’d have to experience an awful amount of stress before asking for support.” **S3 – 4**

Comorbid Conditions

All but one of the participants mentioned co-occurring disorders that affected their functioning. Of those eight students, six of them mentioned one other disorder, and two mentioned two co-occurring disorders. Two of the students knew of their diagnosis of ADHD before they learned that they also had an ASD. The responses for this subcategory did not receive dimensional scores.

“By my fourth year I was suffering from bouts of anger and depression; anger that I felt I was being constantly humiliated all the time and no one seemed to be standing up for me and depression because it seemed like no matter what I do, I was stuck in the same rut again.” **S1**

“I take medication to keep my mood the same. The other one is to help with my picking and other bad habits. My mood is getting in the way of my academics now. I was also told that I have ADHD.” **R2.**

“I was diagnosed with ASD halfway through my freshman year at college. I can clearly see if I take my meds (vivanse for ADHD) one day and if I don’t the next. It’s like I’m two completely different people.” **R3**.

“I actually found out about my diagnosis of Asperger’s sometime at the very end of my first year or at the very beginning of my second year at college. It was just more information as to what I had and a way to explain some of the things that I might do that didn’t necessarily fall under the ADHD umbrella.” **R4**

“I’ve been a bit anxious lately and I think that it’s been interfering with my college experience.” **S3**

Consequences

Consequences are the outcomes of the action/interaction strategies taken to manage a phenomenon. For the large part, the outcomes were positive; occasionally despite receiving support, positive outcomes were not achieved.

Category: Consequences of Support

Subcategory

Example Quote

Social Success

“My greatest success has been my club where I met people I can really talk to.” **R5**

Improved Executive Functioning

(At CSP) “there is actual support, like helping me figure out how to organize things, helping me identify what kind of stuff needs to be done.” **R4**

Category: Consequences of Support

Subcategory

Example Quote

Identity Development

“I think my greatest success in college is realizing some of the problems that I’ve had since I don’t know when, and confronting them and learning what those problems are so that I can better deal with them in the future and change those habits.” **R4**

Social Success

Four participants mentioned the positive social outcomes that resulted from their use of supports. They all spoke in very affirmative terms about their experiences.

“I now attend support groups for people with Asperger’s. It’s been very, very helpful. It’s not been a cure all because I’ve had some unfortunate negative incidents, but in the main, it’s been very, very positive for me. It’s helped to bring me out of my shell. I’m more socially confident and aware of my flaws at times. Now if my flaws appear at a social situation, I know when to nip it in the bud so it doesn’t escalate.” **S1**

“Due to the CSP I’ve been learning to just go outside my comfort zone, and my social skills have definitely boomed from what they were back in high school. I actually initiate sending out email conversations now.” **R1**

“Most of my friends are from CSP or the anime club.” “CSP supports have been really helpful. It’s helped me develop bonds with mentors and I felt like it really helped me come out of my shell the first few years when I wasn’t sure what to do and I’ve slowly grown from that.” **R2.**

“I’ve learned to be myself but at the same time just not be totally out there. There are things I want to say to certain people but then I realize it’s either not o.k. or it’s really not their business.” “I try to make sure that I’m not – I don’t want to say a target, but not trigger anything. I try to be normal. I try to be on topic, try to talk to people. I’ve learned those skills through social skills groups.” **R2**

“I’m meeting probably new people every week with the anime club. When you find people that share the same interest, there’s already a common bond of some kind.” **S2**

Improved Executive Functioning

Five participants indicated improved ability to plan, prioritize, shift between demands, and multi-task as a result of their use of supports.

“I found a professional therapist who specializes with autism spectrum disorders for children and adults. A lot of it was focused on practical issues like money issues. At first I was hoping for a magical cure for my social ailments, but hers was more of a practical approach, like to be on time with work, not to get sidetracked by negative emotions. By getting rid of the practical aspects (of my struggles) I no longer felt as bad about myself and I could confront social aspects in my life.” **S1**

“I worked with K in disability services. We worked out some techniques to delegate different tasks at various points in my schedule.” “What’s been most helpful even though it’s a little tedious going through the motions are my sessions with P because I really needed to get it drilled into my head that it’s possible for

me to start my assignments early and I used to have a big problem with procrastination.” **R1**

“I have weekly meetings with P and we end up talking about various things that I need to do within the week – things that are most important to get done first, priority.” **R4**

Negative Case

What follows is a brief discussion of a negative case or outlying member in the sample. Participant S1 is included in the generation of the “progressing through college with an ASD” model, and his quotes can be read throughout the results section of this dissertation. However, he is an outlier as his experience in college was quite divergent from the rest of the sample population. His experience doesn’t necessarily negate the theoretical frame; rather it adds variation and depth of understanding. As a way to understand the diverse experiences within the population of college students with ASD and avoid generalizations, more detail about his particular experience is provided.

All the other participants received ASD diagnoses prior to entering or early on in their undergraduate education and utilized numerous supports and services. Although participant S1 was diagnosed as a young child with an ASD, his parents did not share this diagnosis with him until he was an adult. Due to his delay in language development, participant S1 briefly attended a pre- school for children with developmental delays, however his parents wanted him “out of the school as soon as possible because they were afraid of (me) being labeled as disabled.” He participated in regular education from kindergarten – 12th grade at several public schools in two different towns in which his family resided. He did not have an IEP or receive any supports or

services during this time. He did not learn of his ASD diagnosis until he was 25 – when it was confirmed by a psychologist who specialized in the ASD population and who conducted an extensive evaluation.

S1 explained his parents' decision to withhold the diagnosis from him as such: "My parents told me you should be glad you didn't get diagnosed until this late age because you would've been self-defeating. You would have attached labels and said 'I can't do this; I can't get a regular job because I have social awkwardness.'" He further explains his parents' reasoning: "My parents grew up in a former eastern European country that became independent after the disintegration of the Soviet Union where no kids were spoiled. They said they were trying to prepare me because whether I like it or not reality is harsh. I think because of that I was able to get through college." In this participant's situation, cultural influence was an additional intervening condition which impacted his perspective of help seeking and utilization of supports. While cultural influence may have consciously or unconsciously impacted other participants' support seeking behaviors, no one else spoke about it as having an influence and it was therefore not included as a subcategory under the intervening conditions category.

Another intervening condition in this participant's story was his history with peers prior to entering college. It presumably was a factor in the development of his cognitive schema for social relationships and may have provided a template for his behaviors in social situations. He spoke about his past with bullies throughout his interview.

"I was bullied and teased a lot and I almost had no friends (in high school). I tried to socialize with nerds but I felt even the nerds were rejecting me."

“I had such a negative expectation that people were going to laugh at me that (in college) I would be quite surprised when people would actually be friends with me.”

“When I was at (college), I actually was really angry at how I was treated in high school that it kind of became my driving mechanism at S and I did so well.”

Although several other participants mentioned experiences with bullies in their past, only this participant emphasized that it was a motivating factor for his academic achievement in college.

Participant S1 clearly demonstrated common ASD traits, particularly in the social realm, both as a child and as a young adult in college. The expression of these traits often interfered with his healthy functioning and mood, as he articulated throughout his narrative. Although he did not utilize traditional supports, he did learn his own coping strategies which helped him maintain his equilibrium for periods of time. He states, as a child “I would hang out with one person, then we would get distance from ourselves and then I would hang out with another person for a while and then when I got distanced from that person, I would go back to the original person.” He uses similar strategies as an adult. “I manage challenges by diversifying my friends and interests so in case something turns sour, I have other friends and interests to fall back on. Then I usually give the away treatment and after a couple of weeks or months, it’s usually safe for me to go back when things have cooled down.” This individual desperately wanted social interaction and connection as a college student, but lacked the skills or awareness to maintain many friendships. However, he never gave up trying.

“I met a libertarian on campus and we would debate intellectual topics. I felt the connection that I had long been lacking before. Then things started to go downhill in the third year steadily, and fourth year dramatically. In my third year, I noticed (the people) who I socialized with were more seniors. So they had graduated and moved on and I was forced to socialize with some younger people. Things declined dramatically in my fourth year and it was so bad that I felt everyone on campus was laughing behind my back.”

S1’s social challenges were not limited to peers and one of his most painful memories was regarding a relationship with a professor. “I had a professor and he actively picked on me during class. I was getting excessively intimidated by his behavior and the more intimidated I got, the more he seemed to bully on me. It’s like a shark that smelled blood in the water. It just seemed like he disliked me just because I was socially awkward.”

Another strategy this participant used to manage his stress was focusing on academics, which for him was “the only way of validating” himself. He states “I studied all the time. I neglected my social life which may have been a bit of a mistake. I loved the school work but part of it was an avoidance of having to socialize with people. I actually felt more of an emotional connection with my studies because it turned out I really loved to learn and I hated socializing because people would either be instantly agitated by me or I would make friends but then gradually they would get more and more alienated from me and I didn’t want to go through all that pain again. So that’s why I was more reluctant to socialize.”

However, he states “I never slacked off from my grades. I graduated with a 3.8.”

This participant’s experience was a stark contrast to most of the other participants, many of whom reported struggling more with academics than in the social realm. Although some other

participants also experienced social struggles, S1's experience was an extreme example of social challenges that an individual with ASD may face in higher education, particularly if they do not utilize supports or at least register as a student with a disability at the office of disability services.

After receiving his undergraduate degree, this participant obtained and was subsequently fired from several jobs. He was also arrested on one occasion when he engaged in a physical altercation with his father. This incident represented "hitting rock bottom" and was the turning point that motivated him to seek help; he found the psychologist who diagnosed him and who continues to treat him.

When asked what would have helped him in his college experience S1 responded, "someone who would have totally understood me...just someone who got me." And when discussing his reaction to learning of his diagnosis, he stated "I knew all along there was something wrong with me. It was like I was groping in the dark, not understanding why these things were happening to me. But now I have a reference point where to build on." Discovering his diagnosis of Asperger's syndrome did not make him self-defeating as his parents assumed. Rather he gained self-awareness, learned to advocate for himself, and eventually get the help he needed to succeed in graduate school and in his career. He states, "Without the help I was anxious and paranoid, feeling like I was going to be left out of a group or ostracized. I also used to have outbursts because I had so much frustration from so many failed encounters, and then the slightest thing could set me off and put me in a really negative spot in terms of other people."

However, now that he receives support he feels more socially competent and connected. "Most helpful are the support groups and my psychologist because I found people who I could relate to and a psychologist who helps me work through my issues. I'm more socially confident

and aware of my flaws. Now if my flaws appear at a social situation, I know when to nip it in the bud so it doesn't escalate." After he arranged for supports, S1 returned to college to obtain his master's degree. He has held a job in computer engineering for several years and plans to buy his own home within the next six months.

One additional important difference between this participant's college experience and the other participants' was the period of time that they attended school. S1 was 10 years older than the other research participants and in addition to his cultural influences and history with peers, attitudes around disabilities in the educational system could be considered another intervening factor. It has dramatically changed in the past decade. S1's college experience also emphasizes the differences in stress relief when stress relief measures are taken early on in the college experience, as opposed to after stress occurred. Had protective measures been taken earlier on, a lot of unnecessary pain and trauma probably could have been avoided for this student.

Selective Coding - Hypothesis

After analyzing the data through the development of categories and subcategories and working them out in terms of their dimensions and associated paradigmatic relationships, the next step was integrating the data into a story. This occurred during the selective coding phase. Through examining the codes, categories, and subcategories for a period of time, it became evident that the core category around which all the other categories became integrated, (Strauss and Corbin, p. 116) was *progressing through college*. Progressing through college with the aim of earning a degree was the ultimate goal for all the students and the reason these individuals attempted to manage their ASD related challenges.

Having an autism spectrum disorder changes the college experience for most students, adding challenges that would not normally be there. It is the interaction between the expressed traits of the ASD and the stress context embedded within the college experience that creates the challenges. Twenty to thirty years ago students with various disabilities including ASDs were unlikely to attend college as there was little support structure to help contain their challenges. Today, with many of the supports and services that are in place throughout the K-12 years, students with ASD are increasingly being accepted into and are attending college. While challenges still exist for these students, a range of programs and services are being targeted toward assisting this population to succeed in college. The more severe the ASD (and associated co-morbid) symptoms and the more difficult it is to keep symptoms under control, then the greater the associated risk of withdrawal from school. In these cases, there may be an increased need for additional supports to manage the challenges.

The present study demonstrates that college students with ASD are attempting to manage the challenges they perceive to be associated with their disorder. Students play active roles in the management process. They must make decisions about how to best contain their challenges in order to optimize their chance of success and be responsible for showing up and participating in associated appointments and interventions. Stress management is a joint function shared by the students and their support services, i.e. CPS, ODS, and/or outside supports.

Students' perceptions of their challenges tended to vary with the stress context and their manifest traits of the ASD over the course of college, and as their perceptions changed, so did their controlling strategies. They continually assessed their stress level and made adjustments to their controlling strategies in order to keep things on course. However, the outcome of the controlling strategies varied. If the stresses were contained and the academics were kept on

course then the likelihood of staying in college, and obtaining a college degree was increased. Sometimes stresses were not able to be contained. Despite the efforts of the student and the support team, stress increased, and the student needed to take time off from college. It is frequently the intervening conditions that explain why one person has a certain outcome or chooses a certain set of strategies while another person doesn't.

Each college experience could be said to be on- course, indicating that the academic and social challenges were being managed and were not interfering with college progression, and the stressors were being contained, or off-course, indicating that college was not proceeding as planned and the stressors were not being controlled. Students attempted to manage the perceived stressors in order to obtain a college degree. This desired outcome seems to be the primary force motivating them to do whatever is necessary to minimize the risks of academic failure.

Managing ASD Related Challenges Under Conditions of an On-Course Lower-Stress Context

Stresses are assessed to be relatively low, and academics are perceived to be proceeding on course because the ASD related challenges are stable. The students who fell under this grouping were S2, S3, S4, R3, and R5. Three of these students were in their first year of the STEM college; one was a recent transfer student to the state university, and the other was a third year student at the state university. Their grades were good and they had some, albeit few social connections. They received low dimensional scores in each subcategory under the stress context category. For example, they had not experienced any significant peer rejection, indicated that they made substantial poor choices, demonstrated negative self-perceptions, or exhibited academic problems. While there may have been some social isolation, it was not deemed to be too problematic. The fact that four out of five of them were in the early stages of their time at

college, may be associated with their relatively stable circumstances. However, four of the participants knew of their ASD diagnoses for a long period of time, and came to college with supports already established. The fifth, R3 learned of his ASD diagnosis during his second semester of his freshman year at a different college. When he transferred to the university, he immediately registered for CSP supports, as this was a primary reason for his decision to transfer.

Managing ASD Related Challenges Under Conditions of an On-Course, High Stress Context

There were two students in the study (S1 and R1) who fell under this category. One had already graduated from college and graduate school and the other was a graduating senior at the time of the interview. Their situations were considered “on course” because while in college they maintained their academic standing and were not at risk of academic failure. However, each experienced a number of stressors which placed them at higher risk. One of the students, S1 experienced extreme peer rejection and made numerous poor choices in college. Both students reported isolation and negative self-perceptions. Due to intervening conditions which are discussed below, the students were able to remain on course throughout college, despite their significant stressors. R1 reassessed his stressors throughout his college course and made adjustments to his supports as needed. When his stress level was particularly high, he applied for services through the CSP. As mentioned above, S1 became aware of his diagnosis after undergraduate school, reassessed his situation, and began receiving services before beginning graduate school. Although he did well academically throughout his educational training, his social struggles were dramatically decreased when supports were

added. These students did not utilize services from the start of their college careers. Had they, their perceived stressors may have been decreased. Both of the students' stressors were mainly in the social realm. They received low to moderate scores on executive functioning challenges.

Managing ASD Related Challenges Under Conditions of Off Course, Non Critical

Context

One student, R4 fell under this category. His academics were suffering and he had decided to take a semester off to obtain therapy to “refocus and deal with some of the issues” he was having with procrastination and time management. In terms of the stress context, R4 had experienced academic problems, and made some poor choices however, he had a positive self-perception, and was socially active. He did not express any experiences with peer rejection or social isolation in college. S4 was still taking a course at the university, while working, and living at home for the semester. He emphasized that he was maintaining friendships that he made at the university and was looking forward to returning to full-time study and moving back on campus the following semester.

Although he had a comorbid ADHD diagnosis, he had strong parent support, and internal motivation to graduate. These intervening conditions increased the likelihood that he would meet his goal of returning to college and completing his college degree. This student did not utilize supports from the start of his time at the university. Had he, the need to take time off may have decreased. However, his challenges were in the executive functioning realm, and students in this study who struggled with time management, organization and planning seemed to be at greater risk of academic problems and

withdrawal from school as compared to those participants who mainly struggled with social challenges.

Managing ASD Related Challenges Under Conditions of Off Course, Critical Context

One Student, R2 met the conditions for this category. She experienced numerous stressors including peer rejection, academic problems, a moderate degree of negative self-perceptions, and poor choices. She was also off course in terms of her academic progress. She expressed the belief that she made a mistake in choosing her college major, which was too academically demanding for her, but didn't seem to have another desired alternative. At the time of the interview, she was taking a leave of absence from school, with no plan to return. Her ability to succeed in college and obtain a degree seemed to be most in jeopardy as compared to the other students in the study.

For theory development, it is essential to understand how the intervening conditions and their dimensional scores facilitated or constrained the use of controlling strategies and their effectiveness for each student. Some of the intervening conditions were internal; others were external.

Motivation to graduate was an intervening condition that was mentioned by 7 out of 9 participants. The dimensional scores for this subcategory ranged from 1 – 5. The individuals who scored in the 4 and 5 range demonstrated a greater degree of internal motivation. Those who scored in the 1 and 2 range indicated that their motivation to attend college was influenced more by their parents and societal expectations. R2, who withdrew from school the day after the interview, seemed to be internally motivated to attend college as indicated by her statement, “I always wanted to go to college.”

However, her following statement, “A lot of the time people did not understand me at high school. So I thought college would be a fresh start because my high school was so small and everyone would nitpick everything,” suggests that her goals for college were social rather than for professional/academic gain. Perhaps her lack of career focus and poor grades were indicative of this ambiguous motivation. In contrast, S4 who also decided to take some time off school scored a 4 for motivation to graduate based on his comment, “I realized at some point that I needed to make my way through college in order to be able to do the kind of job that I wanted to do.” S4 had some academic struggles, but his motivation to succeed and obtain a specific job impelled him to keep trying. He seemed more likely to return to school and finish his degree.

Parental involvement can be viewed as an external and/or internal intervening condition, depending on the way it was conceptualized by the participant. It was important to understand whether the support fostered dependence or in(ter)dependence. Eight of the nine participants mentioned parental involvement as it seemed to function as an intervening condition. Their parents either encouraged them to join the CSP, set up outside supports, or came in with them to register with the ODS. Additionally, many of the participants mentioned frequent contact with their parents, either by phone or returning home on the weekends. Parents provided physical (i.e. assistance with class scheduling) and/or emotional support. In R2’s case her parents “helped me with academics and after a breakup with a guy I was dating they tried to make sure I wasn’t suicidal for the next couple of months.” Her parents apparently did provide much support, but her emotional needs may have outweighed their skills and capacities. The other participants did not reveal as extreme emotional vulnerability. Participant S1 who

had some of the highest scores on several of the stress context subcategories, had a lower score for parental involvement. This combination seems to suggest that he would be at greater risk of academic failure. However, he had a strong internal motivation to succeed (as fueled by his failed social experiences in high school), and he incorporated his parents' values based on their cultural background that he had to tough out whatever life threw at him. He did eventually hit "rock bottom" but this occurred after he earned his bachelor's degree and was out of college.

Assessing the need for help was another complex intervening condition, which in some cases supported an individual's struggles, and in other cases made them more difficult depending on the individual's conception of help seeking. Some students felt the need to remain independent, and viewed asking for help as a weakness as indicated in the following statement: "I had trouble asking for help in the past because I felt a need to be able to do something on my own, to become independent." (R4) Others felt that receiving help from parents was o.k., but were uncomfortable seeking help from outsiders. Some individuals who had received outside support for a long time were not bothered to reach out for assistance. "With support, I usually have a better idea of what to do in response to challenges." (S3)

Another important intervening condition was comorbid or co-occurring disorders with which the students were diagnosed. Five of the students had an anxiety or mood disorder (one student had both generalized anxiety and depression). Three students had a diagnosis of ADHD. One of these students (R2) had both a mood disorder and an ADHD diagnosis. It is interesting to note that there seemed to be a relationship between the students with ADHD diagnoses, and executive functioning challenges; while the students with mood/anxiety disorder (s) reported less academic challenges, but greater social

challenges. In R2's case, she discussed both executive functioning and social challenges. R2 again, was the one student who was classified as 'off course and within a critical context.' It may be surmised that the compounding effects of a mood disorder, ADHD, and ASD were too much to cope with, despite the numerous supports that she utilized through the CSP.

Based on the above data, a hypothesis is proposed, but not expressed as a null nor in operational terms: Under the condition of attending college with an autism spectrum disorder, students take protective action to manage perceived challenges, by means of assessing their need for help, which is modified by parental involvement, motivation to graduate, and co-morbid symptomatology, and using a joint management process, so that they might contain stresses and increase their chances of progressing through higher education and obtaining a college degree.

Further, it may be posited that the external supports that a student with ASD utilizes, combined with their own internal resources, and comorbid conditions indicate the likelihood that he/she will remain in college and potentially graduate.

Summary

This chapter presents a model for progressing through college with an autism spectrum disorder. It breaks down the steps of open, axial, and selective coding and provides numerous examples of quotes that were used to help form categories, and presents an integrated story to help explain the framework of the theory. It also includes a negative case example which helps build variation and depth into the framework. Finally, the intervening conditions are explored to help provide an explanation for the various outcomes.

Chapter V

Discussion of Findings

The intent of this chapter is to provide further insight into the participants' experiences managing challenges associated with ASD in college in an attempt to earn a college degree. It will reiterate the study's goals, methods, research questions and findings. Limitations of the study and implications for future research will follow. Finally recommendations will be provided, those appropriate for institutions of higher education as well as those appropriate for students and families of potential college students with ASD diagnoses.

Summary of the Study

Problem

The population of individuals diagnosed with ASD who are entering colleges and universities is rapidly increasing, and these institutions must be prepared to understand this disorder and how to address the needs of this population of students coming to their campuses. It is also necessary for families to understand the factors that enable students with ASD to successfully handle their academic and social challenges while attending college/university. College students with ASD often possess considerable intellectual strengths that when supported have the potential to make substantial contributions. However, many also have significant limitations in the realm of social and executive functioning which may hinder their success. It will ultimately benefit the individuals and society as a whole to find ways to support these students' needs while maximize their potentials.

Purpose

This study examined factors that influence students with autism spectrum disorders' healthy functioning while at an institution of higher education, and increase the likelihood that

he/she will remain in college and earn a degree. It also explored students' use of supports/services at a large state university with a supplemental support program, and at a private college without such a specialized program. This study was not designed to evaluate or compare the effectiveness of these options, but to examine the variables that facilitated or impeded success for the students.

Current research supports the need to integrate students with disabilities into college life (Ellison, 2013). Yet, with the growing number of students with ASD who will be entering colleges and universities across the country, there remains a limited amount of research regarding specific means to help foster success for this population especially from the perspectives of the individuals directly involved: students with ASD.

Methods

This study used a multi-case qualitative research design using grounded theory. The participants attended two institutions of higher education in a geographically small, but population dense northeastern state. The first institution is a public, state university with an undergraduate and graduate population of over 65,000 students; the second is a private, science, technology, engineering, and math college with an undergraduate body of 2,700 and graduate population of 3,500. Both schools maintain an ethnically and racially diverse student body. The state university is 47% male, 53 % female; the STEM college has a 72% male population, and 28% female student body.

Seven participants in the study are residents of this state, while two others reside in a neighboring state. One student commuted to the private college; three others lived on the campus. The five students who attended the public university lived on campus while they maintained full-time student status. At the time of the interview, one of the students was living

with his father as he took a temporary leave-of absence and attended one class as a part-time student. Another student was about to take time off college and move home with her family. She was the only female participant in the study.

The researcher used nonrandom, purposeful, and theoretical sampling techniques (Merriam,1998) and predetermined essential criteria to select the nine participants. The sampling was open to those participants who would potentially provide relevant data about the phenomenon under investigation. The participants included nine students with ASD, between the ages of 18 – 30, who had spent at least half of one semester in college within the past three years.

Using a grounded theory approach, participants’ responses to open ended interview questions revealed a central phenomenon, categories, and subcategories that reflected the contextual stressors and intervening conditions that influenced their use of supports, and their strategies for managing challenges. It also revealed several consequences of utilizing supports.

Data were analyzed with the goal of generating a grounded framework for a theory. Grounded theory, first introduced by Glaser and Strauss in 1967, is a specific research method that uses constant comparison among cases to develop theory based upon data, (Merriam, 1998). Constant comparison involves the ongoing and repeated process of comparing and revising segments within and across categories until saturation is reached. Saturation occurs when no new or relevant data emerges regarding a category (Strauss and Corbin, 1990). Comparisons allowed for categories, subcategories, properties, and dimensions to develop which resulted in a framework for a grounded theory. Ultimately, the categories were integrated into a story which explained the core category of progressing through college with an ASD.

Research Questions

Five research questions initially guided this study:

Main Questions

What have been the biggest challenges for you in college?

How have you managed these challenges?

What do you as a student with an ASD want/need in terms of supports and services?

What, if any, supports/services have you used?

How have they been helpful /unhelpful?

Following the first phase of data collection and analysis, additional questions were added for theoretical sampling based on the initial categories that emerged.

1. What does it mean to you to have challenges?
2. What does it mean to you to manage challenges?
3. What does it mean to you to ask for supports?
4. When do you most typically experience challenges (time of day, point in semester, in dorm/classroom, etc.)?
5. What do you do to obtain support?
6. Who provides support?
7. What happens if you don't get support?
8. What happens if you do get support?
9. How much stress do you experience before asking for support?
10. How much does your desire for obtaining a college degree influence your use of supports?

Findings

Six categories and 18 subcategories emerged as a result of the data analysis. These categories/subcategories were largely influenced by Strauss and Corbin's model for developing a coding paradigm through the initial, axial, and selective coding phases. It should be noted that other methods of grounded theory were examined, but the more prescribed approach that Strauss and Corbin developed naturally fit the emerging patterns and connections that were discovered in

the data. It was not a “framework imposed on the data” as suggested by Glaser (1992), but rather it helped the researcher integrate large fragments of data into a cohesive story.

The responses to the question “what have been your biggest challenges in college?” revealed the two subcategories that emerged from the central phenomenon -- *ASD related challenges: social and executive functioning challenges*. Every participant indicated both social and executive functioning challenges in their responses and the degree to which these areas challenged the students was hinted at throughout their narratives. These responses were largely expected as they are two core features of an ASD.

Responses to the initial question also lead to the development of the stress context category. These were more specific stressors that the participants experienced during college, which influenced their use of supports. This category also revealed some predictable and some unanticipated challenges for the participants. Predictable challenges included the subcategories *social isolation* and *academic problems* as these may be consequences of social and executive functioning challenges. *Poor choices* and *negative self-concept* were less expected. With external supports in place, one would expect the risk of making a poor decision to be decreased. Choosing a well suited college major and selecting an appropriate roommate could have been handled during the transition planning stage. These relatively straightforward decisions for neuro-typical students may be more complicated and require more joint planning for students with ASD.

Negative self-concept was also an unanticipated subcategory, as several participants shared personal and insightful feelings about themselves. Some of these perceptions were quite pessimistic and at times, difficult to hear. However, they often resonated as truthful accounts. Still sadder, were the stories of peer rejection. While it was encouraging to hear that bullying

incidents did not occur with great frequency to students with ASD in post-secondary institutions, when they were mentioned, the incidents revealed malicious treatment by peers and in one instance, by a professor. However, the most profound account of bullying was incurred by participant S1 who attended undergraduate school ten years prior. The decrease in such accounts hopefully may be due to the inclusion efforts and bullying prevention initiatives that have been instituted at the elementary and secondary school levels which may be having a positive impact at the post-secondary level of education.

The *causal condition* for experiencing ASD related challenges was *attending college* with an ASD, which again, is a fairly new phenomenon for both the students and the institutions admitting them. The *size of school*, *distance from home*, and *commuting vs. residing on campus* were conceptualized as properties of *attending college*. None of these properties were mentioned in narratives as having specific effects on student outcomes, although it may be assumed that having parents physically nearby enabled more parent involvement and possibly decreased perceived stress. Whether a post-secondary institution offered supplementary supports as opposed to just academic accommodations, may have an effect on one's college experience. However, it should be noted that none of the participants in this study only utilized academic accommodations. The three students that currently attended the STEM college, which primarily offers academic accommodations, all utilized additional supports, either on the outside, or through the college counseling center.

The answers to the question "how have you managed these challenges?" lead to the conception of the *controlling strategies* category. The most frequent responses to this question formed subcategories. These included utilizing a *college support program*, obtaining *outside services*, *joining campus groups* and receiving *academic accommodations*. All of the five

students from the state university chose to participate in the college support program. Participants from both the state university and the STEM college utilized outside services, academic accommodations, and joined campus activities. In general, while attending a university with a built-in support program was perceived as a big aid for the university students, and may have enabled some to remain in college, several participants in the study felt the need to take a leave of absence despite utilizing the services offered through this program. This study demonstrates that a college-based program is not an essential factor in enabling students to manage their challenges, and maintain themselves in higher education. Such a program may facilitate a more systemic response to the problems incurred in higher education for students with ASD. However, outside supports and services may be an equally effective, albeit more costly and less efficient option. Also, this study indicated that supports and services alone do not guarantee academic success.

Joining campus groups also served a supportive function for most of the students, particularly as it helped reduce isolation and mitigate social challenges. The following quote from a student who scored fairly high in social isolation emphasizes this, “my greatest success has been my club where I met people I can really talk to.” (R5) All but two participants mentioned involvement in groups as being helpful. The two who did not mention current participation in campus activities or groups were new students who expressed a desire to join in the future.

The controlling strategy that was used by the largest number of participants, but received the lowest dimensional scores in relation to its perceived helpfulness was academic accommodations. Several of the participants mentioned the traditional “extended time” accommodation as unnecessary and unhelpful. The non-traditional supports were perceived as

most essential in helping contain challenges for the participants. Peer mentors, executive functioning coaches, and therapists were most frequently mentioned by participants as valuable supports. Social skills groups occasionally surfaced as a helpful strategy too. Internal motivation also may have played an important role for success in college, as evidenced by the one student who did not utilize any supports in undergraduate school. Despite facing some of the greatest contextual stressors, this student largely persisted in college through self-determination and academic skill.

Broad *intervening conditions* emerged as one of the most important influencing factors in the use of services and diverse outcomes. Responses to several of the questions developed for theoretical sampling lead to the creation of this category. Subcategories that emerged included: *motivation to graduate, parental involvement, comorbid conditions, and assessing the need for help*. With the exception of *comorbid conditions* the other intervening conditions -- *motivation to graduate, parental involvement, and assessing the need for help* all indicate something about the participants' *internalized beliefs*. "Internalization involves the integration of attitudes, values, standards and the opinions of others into one's own identity or sense of self" (Wikipedia, 2014). As mentioned in the previous chapter, S1, the one negative case example was shaped by the additional intervening conditions of *cultural influence* and *history with peers*, both of which likely effected his *internalized beliefs* and influenced his *motivation to graduate, use of parental involvement, and assessment of the need for help*. The overarching category of internalized beliefs may have the largest impact on one's use of supports and ability to *progress through college* with an ASD. It is likely a factor in the model.

Finally several *consequences* of the use of supports were detailed. These included *social success, executive functioning improvement, and identity development*. The study briefly

examined consequences of supports, many of which were quite positive. But as most of the participants were early on or midway through their college trajectory, it was impossible to assert conclusions about the long-term effects of supports. It was only possible to evaluate the effects of the *controlling strategies* at the point in time that the interviews were conducted for many of the participants. However, a few of the individuals who had been in college for several years were able to reflect upon their experiences with supports and services. External supports played an important role in enabling participants to remain in college and likely earn a degree. Those who set up supports early on or prior to starting college experienced less stress as compared to those who set up supports later. However, internalized beliefs, motivations, and coping strategies, and co-morbid conditions were also key factors in participants' use of services, and success in progressing through college on the path toward earning a degree.

Discussion of Findings

As a complete literature review prior to data collection did not occur given the qualitative methodology utilized, some additional concepts that emerged during data analysis are now discussed.

Comorbid disorders

It warrants further discussion that all but one of the participants in the study mentioned having diagnoses of comorbid or co-occurring disorders along with ASD. Two students had ADHD diagnoses prior to learning of their ASD diagnosis. Five other students had co-occurring mood or anxiety disorders. And one student, R2, who was about to withdraw from the university was diagnosed with both ADHD and a mood disorder along with the ASD. It bears

consideration that comorbid disorders may also have an effect on service utilization and outcomes and should be taken into consideration when planning treatment.

Comorbid conditions such as ADHD may impact academic success. All of the three students who had co-occurring diagnoses of ADHD had high ratings for executive functioning challenges and two of these participants also reported academic problems. The same two students decided to withdraw from university for an indefinite period of time. ADHD symptoms have previously been reported to be predictors of various measures of college success. Symptoms such as hyperactivity and inattention have been found to be negatively associated with college GPA (Norvilitis and Reid, 2012). Positive social adjustment in college has also been found to be associated with fewer ADHD symptoms (Norvilitis and Reid, 2012).

According to the DSM-IV criteria, it was not possible to diagnosis ADHD in the context of ASD. However, since the DSM-5 has been instituted, clinicians have been diagnosing ASD and ADHD in the same individual. In the past there had been disagreement as to whether many psychiatric symptoms including those associated with ADHD warranted separate diagnoses or should be viewed as a symptom cluster of ASD (Matson and Nebel-Schwalm, 2005). If, as it is now assumed, diagnosing comorbid psychopathology in persons with ASD is appropriate, several problems still exist. The psychiatric symptoms for individuals with ASD may vary from those seen in the general population (Matson and Nebel-Schwalm, 2005). Also, there are currently no scales specifically designed to evaluate psychiatric comorbidity in persons with ASD; previous studies that investigated comorbid disorders in ASD either referred to the DSM criteria or tried to adapt the scales used for the general population (Matson and Nebel-Schwalm, 2005).

In addition, psychiatric comorbidity is not a well investigated cause of impairment in ASD. Delineating psychiatric comorbidity may help identify targets for specific intervention that could reduce overall impairment and improve quality of life (Matson and Nebel-Schwalm, 2005).

Comorbidity may also have meaning in terms of long-term prognosis. Ghaziuddin (2002) asserts that depression is probably the most frequent form of comorbid psychopathology with ASD. Depression can negatively impact long-term outcome. Anxiety frequently overlaps with depression and ASD (Matson and Nebel-Schwalm, 2012). In fact, the director of the CSP reported “anxiety is the one symptom common to all of the students in the program.”

In a study conducted by Simonoff et al. (2008) 70.8% of individuals with ASD had at least one comorbid psychiatric disorder. Simonoff et al. reports “for any psychiatric disorder, the majority of individuals who had at least one disorder have multiple diagnoses.” The appropriate diagnosis of psychiatric comorbidities in ASD is also important for pharmacologic treatment.

Researchers know that severity of symptoms, type of disorders and comorbidity affect outcome (Matson and Nebel-Schwalm, 2005). Prognostic factors can be helpful for determining required resources, or the individual’s ability to cope with intervention on multiple target behaviors. In addition, environment seems to considerably influence the expression of psychiatric comorbidities in individuals with ASD (Mazzone et al., 2012). More attention should therefore be focused on the interactions between these individuals and their environments in order to provide better social support and help develop coping strategies.

Emerging Adulthood

The participants' ability to *progress through college* is embedded within the larger developmental context of emerging adulthood. Emerging adulthood has been proposed as a new conception of development for the period from the late teens through the twenties, with a focus on ages 18-25 (Arnett, 2000). Emerging adulthood is a time of transition, a developmental bridge between adolescence and adulthood. Typically, as students move through the twenties they gradually become increasingly independent. However, maintaining close relationships with parents during college is positively correlated with psychosocial adjustment, academic functioning, career maturity, and autonomy (Mattanah et al., 2004).

Psychological development is not inevitable. It is either facilitated or inhibited by the relationships in which an individual is embedded. Development is fostered when the student's environment provides a balance between challenge and support (Matson and Nebel-Schwalm, 2012). College students still need parental involvement and guidance, which attuned parents gradually decrease as their child matures. Research suggests that what makes individuals feel like adults is accepting responsibility for one's self, making independent decisions, and being financially independent (Mattanah et al., 2004).

Arthur Chickering (1969) identified seven "vectors" of development during the college years. Each vector is a core developmental task of emerging adulthood. One task that relates to the current study is "moving through autonomy toward interdependence." He stated that the goal of development is interdependence, rather than independence. Interdependence means that strong ties are maintained and a balance between the need to be independent and the "longing for inclusion" has been reached.

While the period of emerging adulthood is beginning to receive attention, there is no model for how students with ASD should progress through this stage. A study by VanderVeen (2013) examining the psychosocial development of students with ASD in Higher Education examined the students' development through the lens of several of Chickering's vectors. VanderVeen's study found that development toward interdependence was mixed among the participants of this study. The present study indicated that development of partial autonomy may be possible for students with ASD, as demonstrated by S1, who has maintained employment and plans to buy his own home. But he is now 30 years old and still requires much ongoing assistance by support groups, a private therapist, and parents.

Parental involvement and Self - Determination

The present study's findings are aligned with findings from other studies on college students with ASD. Research conducted by Ciccantelli (2011) on successful navigation of the academic, social, and independent living demands of institutions of higher education for students with ASD found that for students to adapt to college, they need to separate from their parents and become more independent and less reliant on them for ongoing support and advocacy. Ciccantelli comments that "parents of students with disabilities in higher education tend to be more involved than other parents in their child's education." Parents in the present study also demonstrated a high level of both emotional and physical involvement in their children's lives in college. An implication is that students' long-term success may be contingent upon their developing greater independence and self-reliance. Parents need to provide their child with opportunities for independent decision making, and self-advocacy prior to the transition to college. Earlier research has found that planning well in advance for this greater independence is essential to college success for students with ASD (Getzel and Wehman, 2005). While at times

beneficial, parental involvement had a tendency to limit a student's ability to practice and develop self-advocacy skills (Eckes and Ochoa, 2005).

A study by Jillian Szentmiklosi (2009) that explored self-determination among community college students diagnosed with Asperger's syndrome found that the participants expressed a variety of self-determined behaviors associated with their college experience. All of the participants were registered with the office of disabilities which the researcher considered an expression of self-determination, but they were all supported by their parents in the process. However, some students were able to manage their own interaction with the office after becoming more familiar with them. Similarly, the students in the current study tended to need parent involvement to initially register for supports, but became more independent as they attended future appointments on their own. The students in the study conducted by Szentmiklosi relied "heavily on family for encouragement, support, and assistance in their pursuit of higher education." This statement is equally true for the students in the current study.

A study by Tarallo (2012), found that "students with ASD in higher education could achieve academic success with significant effort on their part, as well as with support." However, initially students in Tarallo's study wanted to try to succeed academically without seeking accommodations, either to "challenge themselves," or to "normalize the situation" for them. The reasons that these students gave were hesitancy to ask for support or hope that he/she could manage without accommodations. Tarallo also reports that students stressed the great importance of family members' support in keeping them on track academically. As with the current study, the students in Tarallo's study all had the goal of degree completion. Tarallo states that realization and determination contributed to the students' success. Reportedly, "when students with ASD came to the understanding that their own achievement would occur with

support,” they became more determined to succeed and utilize supports. Hence, realization of their own abilities effected internal motivation and use of supports, and influenced outcome.

Intrinsic and Extrinsic Motivation

To be motivated means to be moved to do something. Ryan and Deci (2000) state, “a person who is unmotivated feels no impetus to act, whereas someone who is activated toward an end is motivated.” Ryan and Deci (2000) make a distinction between intrinsic and extrinsic motivation -- intrinsic motivation refers to doing something because it is inherently interesting or enjoyable, and extrinsic motivation refers to doing something because it leads to a separate outcome. People are intrinsically motivated for some tasks and not others.

As part of their Cognitive Evaluation Theory, Deci and Ryan (1985) contend that interpersonal actions that lead toward feelings of competence can enhance intrinsic motivation; individuals must also experience their behavior to be self-determined if intrinsic motivation is to be maintained. Hence, for a high level of intrinsic motivation people must experience satisfaction of the needs for competence and autonomy (Ryan and Deci, 2000).

Choice and the opportunity for self-direction appear to enhance intrinsic motivation, as they afford a greater sense of autonomy (Ryan and Deci, 2000). For activities that do not hold an innate interest for an individual, extrinsic motivation may need to be utilized.

It may be hypothesized that the primary reason people are likely to engage in a non-inherently interesting task is that they are valued by significant others to whom they feel connected (Ryan and Deci, 2000). This suggests that providing a sense of belongingness and connectedness to a person or group may facilitate internalization.

Implications

The current study offered insight into the different modes of progression through college for students with ASD based on the perceptions of these students. It examined the different factors that influenced each college path. A college experience was considered on- course, indicating that the academic and social challenges were not interfering with college progression and the stressors were low, or off-course, indicating that college was not proceeding as planned and the stressors were not under control. Most students were on course with low stressors. These students planned ahead and had supports in place from the start of college. Several students maintained intermediate positions: They were either able to remain on course despite experiencing numerous stressors or they chose to take time off college, despite encountering relatively few stressors. These students typically did not have supports in place prior to starting college. One student experienced a high amount of stress and despite utilizing supports, chose to withdrawal from the university.

Previous research has focused on the period of transition to college for students with ASD and implied that if this period is negotiated successfully, the likelihood of student persistence is significantly increased (Eckes and Ochoa, 2005; Terenzini et al., 1994; Wolf et al., 2009). Several of the current study's participants mentioned transition as being more or less difficult than anticipated based on the level of support that they had in place at the time. If needs were anticipated in advance and supports were in place, stressors were generally decreased. Transition to college was not the focus of these students' experiences or the focus of this study. Rather, the factors that affected the likelihood that a student would remain in college as opposed to withdrawing or "taking time off" were explored. This area has not been the focus of research previously and it revealed both expected and unanticipated results. The diverse outcomes were

largely impacted by the intervening conditions: comorbidity, motivation to graduate, parent involvement, and assessing the need for help.

This researcher had not previously considered the variable of comorbidity, but this may impact student outcomes as all but one participant mentioned symptoms related to their other disorder(s) as presenting additional challenges. Comorbidity in individuals with ASD is just beginning to receive attention, but little has been written about its effect on the likelihood that a student with ASD will remain in college or their need for additional related services. It appeared that the type of co-occurring disorder may be correlated with the type of challenge (executive functioning versus social) that a student experienced. The students with co-occurring ADHD primarily complained of problems with organization, time management and multi-tasking, whereas the students with comorbid mood and/or anxiety disorder concentrated more on their social difficulties. The one student with both a mood disorder and ADHD had the most precarious hope for returning to school and earning a degree as her challenges impressed as too much to manage at the point in time that the interview occurred. Ultimately, the findings seemed to suggest that executive functioning challenges may have a more negative impact on successful progression through college than social challenges alone, but the combination of the two are potentially most damaging.

The initial title of this dissertation was Students with ASD in higher education: managing challenges; utilizing supports. The early focus was on the external supports and services that enabled students to succeed in college. However, after analyzing the data, it became apparent that internal factors also influenced participants' use of supports and success in college.

The findings of a study by Ellison (2013) that assessed the readiness of higher education to support students with Asperger's disorder determined that public institutions of higher

education are currently “unprepared to support students with average to superior intelligence but severely impaired social, communication, and independent living challenges.” The present study found that even when numerous and appropriate supports are offered and utilized, supports alone may not be enough to ensure success. Internal as well as external factors, and attention to comorbid conditions, also influence the likelihood of progressing through college.

Participants’ *motivation to graduate* was not a particularly helpful intervening condition when it was primarily driven by potential social incentive or by parental and/or societal messages. It was a beneficial condition when earning a college degree was an “instrumental” goal related to professional/career development. The drive to receive an education in order to obtain a career in an area of interest clearly motivated some participants to do whatever it took to stay in college and earn the necessary degree. In some cases, this meant accepting help, which was at times difficult for them to do. “I’d have to experience an awful amount of stress before asking for support.” (S3)

The subcategories *assessing the need for help* and *parental involvements* may be viewed as interrelated as the quality and quantity of support that parents provided may have affected the student’s assessment of needs. Responses that lead to the subcategories *parental involvement* and *assessing the need for help* revealed the participant’s tendency to obtain help from others, remain independent, or rely on parents. It also indicated something about the participants’ developing capacity for interdependence. Although reliance on parents is necessary for most college students and to probably a larger degree for students with ASD, too much dependency hampers initiative, feelings of competency, and self-reliance – important steps in progressing within the developmental stage of “emerging adulthood” (Arnett, 2000). Parents who enable their child’s dependence may decrease the student’s desire to receive outside support.

Quantifying appropriate levels of reliance on parents is difficult to do both for students with ASD and for neuro-typical college students. But helping parents to step back and assisting students in initiating help seeking may be an essential part of supporting a healthy *progression through college*.

When supports are provided appropriately, they may increase the likelihood that a student with ASD will remain in college. However, students must take the initiative to ask for help, attend appointments, and follow through with interventions. Internal motivation needs to be strengthened and comorbid conditions must be recognized and appropriately treated for a positive progression through college to occur.

Limitations

The current study is significant as it provides insight into the ways college students with ASD manage challenges in an effort to remain in college and earn a degree. However, several limitations should be considered when examining the findings from this project.

The researcher initially set out to interview five students from the state university and five students from the STEM college. There was a concern as to whether enough students would volunteer to participate. The initial five from the state university were referred through the director of the CSP. The one student who was graduated several years earlier from the STEM college contacted the researcher on his own and expressed an interest in participating. It was more difficult to encourage participation from current students at the STEM college and ultimately the three students who volunteered were offered an increased financial incentive for their time. They were all first semester freshman and their college experiences were limited. The small number of participants could be considered an area of vulnerability. A “rigorous and persuasive grounded theory” project would typically include 20-30 participants to allow for full

saturation of all the categories (Strauss, and Corbin, 1990.) College students with ASD are a hard-to-reach population who may be inhibited to speak about their disability. Perhaps a larger sample size would have produced additional subcategories that would have affected the results. However, a cohesive integrated story did emerge that included variation in experiences. The results provide information about different ways that students with ASD may or may not progress through higher education. The theoretical formulation that was developed mainly applies to the two settings, but may be used as a frame for assessing the likelihood that students with ASD will remain in other college/ university settings.

Out of the nine participants, only one was female. While there are more than twice as many males than females diagnosed with ASD, this proportion is still skewed. It would have been beneficial to have more female participants as perceptions and experiences of women with ASD may differ. The one female in the study experienced numerous stressors and withdrew from the university. She demonstrated more relational motivation than her male counterparts. It would have been useful to compare her narrative to other females with ASD in college/university. The current framework may potentially be slanted to apply more directly toward male college students. In the future, a study that explores the experiences of female students with ASD's in college would be beneficial.

Despite purposeful sampling efforts, obtaining a diverse sample of college students with ASD with regard to race and ethnicity was challenging, resulting in the sample being predominantly white, with 8 out of 9 participants identifying as Caucasian. One participant identified as Chinese American. One of the Caucasian males had parents who emigrated to the U.S. from an eastern European country. He mentioned the cultural impact on his parents' childrearing methods and his experiences provided insight into potential additional intervening

conditions that added variation. It would have been useful to have a more diverse group who could have shared their experiences with cultural forces that helped shape their identities. It is suspected that various circumstances surrounding the experiences of different ethnic/racial groups may impact the acceptance of diagnoses of disability and utilization of services.

The sample was diverse in terms of age and stage in college – ranging from first semester freshman through a post graduate student. Some students were beginning their college career, others were further along or close to graduation, and one individual had already completed graduate school. This provided a range of experiences, however it may have been too diverse a sample in terms of age and life stage to fully compare and contrast experiences. A sample of students in a similar college stage would have provided more comparable results.

The majority of the sample came from a middle class socio-economic background. Their families were able to afford the cost of college as well as additional therapies and supports. Thus, the model may not be an appropriate fit for students who come from less economically advantaged homes for whom the cost of additional services may be prohibitive.

Researcher bias effects presented another potential limitation. In the current study the researcher conducted all interviews with participants. Further, she was the primary person involved in protocol development, coding and data analysis. Throughout the interview and research process, the researcher tried to maintain a neutral role in relationship to the participants. It may be assumed that the researcher's personal beliefs and biases had a slight influence on the data collection and analysis, as it would have been difficult to avoid this in a qualitative study. There is the possibility that researcher biases influenced the proposed theoretical frame.

Additionally, there is a possibility for a self-selection bias in this research. Students in this study selected themselves into the group of college students with ASD who manage challenges and utilize supports. It is possible that those students who were less able to manage their challenge and maintain themselves in college chose not to participate. In fact, several students who withdrew from the STEM college, initially expressed interest in participating in the study, but eventually declined. Also, as the students who participated were referred through the ODS and CSP, it is likely that students who were not registered and utilizing services on campus, were not aware of the study. Their experiences were probably very different than those students who were interviewed for the study.

Finally, the current study relied in large part on in-depth interview data from each individual. Only one person conducted the interviews and the sole researcher was a white, neuro-typical female. All interview data are from an outsider perspective and all observations were made as a non-participant observer. As such, the researcher could not be immersed in the data which exposes the study to potential misinterpretation of the data (Cresswell, 2007). Thus, the resulting framework should be considered with caution, and not be used as a sweeping conclusion for all college students with ASD.

Future Direction

The current study generated a framework of how students with ASD progress through college in an attempt to earn a degree. A logical future step would be to develop an assessment instrument based on these findings. This assessment would be beneficial for use in high school settings or clinics, helping students with ASD determine if they are prepared to enter college, and deciding what additional supports could assist in a healthy adjustment to college. While such an

assessment tool may benefit all incoming college students, items that focus on internal motivation, beliefs, parental reliance, comorbid conditions, and previous supports utilized and their perceived helpfulness could provide disability professionals with information on how to best assist these students.

As several qualitative studies have been conducted in recent years exploring the transition to higher education, the effectiveness of support programs, and self-determination factors, this current study is unique in that it bridges these topics into a cohesive story that emphasizes the need for a focus on internal and external resources to best support these students. Potentially a quantitative study could be conducted which focuses on the effects of supports on successful progression through higher education while accounting for the moderators of comorbid conditions, parental involvement, internal beliefs and motivation to graduate.

Only one of the participants in the current sample was post-college/graduate school and was currently working. A lot of rich material came from his narrative as he was able to reflect back on his experiences over a period of 12 years. A longitudinal study that examines college student with ASD's experience over the course of college would provide a broader perspective. A future study of students from the two participating institutions of higher education as they move into work and careers would also be of great interest.

Recommendations

Students and Families

This study is intended to help improve the overall experience of students with ASD in higher education. It can assist parents and service providers in understanding the combination of factors that should be considered when planning for the needs of students with ASD who will be

entering post-secondary institutions. Every student with ASD is unique and an individual approach to service provision must be taken. Comorbid disorders should always be considered and if warranted, a medication evaluation with a psychiatrist should occur prior to beginning college. An individual should be monitored regularly on medication as there may be an ongoing need to follow the effects and make adjustments. In addition, individual therapy, either by an outside clinician or through the college counseling center may be helpful. A practical approach that incorporates role plays of real life situations such as social scenarios, dating, and interviewing would likely be more helpful than an insight oriented therapy. In addition, an executive functioning coach can help students who struggle with organization and planning. Peer mentors may be the most valued resource to aid in social integration on campus. If the institution doesn't provide this service, parents can attempt to locate a student to serve in this role or the ODS personnel may be able to assist in finding an interested participant.

An assessment of the student's needs should include a realistic evaluation of his/her internal motivation and coping mechanisms. Attending college may not be the best course for an adolescent who is not emotionally prepared or career oriented in his/her focus. A transitional period in a community college may help these students better adjust to the demands of higher education and recognize his/her professional goals. A trade school may be another realistic option for some students.

Investigation into support services and resources must begin prior to students' arrival at college. Students and families should be aware of the resources that an institution of higher education offers and the additional supports that may be needed before beginning college. A university with a supplemental support program may be the most efficient way for students to

receive services, but it is not the only effective means of support. Outside supports were very beneficial for some students in this study, but they may be cost prohibitive for many students.

Although academic accommodations were not reported to be the most helpful means of support, they can still provide a safety net for some students. Students should take a pro-active approach in disclosing their disability to the ODS in order have accommodations in place for use as needed. Students must be aware of and be able to communicate their strengths and weaknesses and possess an understanding of what they will need to support their limitations.

Office of Disability Services

College disability professionals are mainly responsible for providing “reasonable accommodations” for students with disabilities while “facilitating equal access to the educational experience.” Section 504 and the ADA are anti-discrimination laws that guide practice in higher education. They are largely unfunded and consequently disability service offices are often unable to offer supports beyond that which falls within the scope of the law. Providing reasonable accommodations for the infinite type of disabilities and situations that arise are the primary task for ODS personnel. Offices of Disability Services are frequently low on budget and staff. To suggest that disability personnel do more for students with ASD that is outside the scope of their “legal responsibilities” would likely be met with resistance.

At the STEM college the ODS is beginning to recognize the needs of this student population. The ODS is located within the college counseling center. A Social Confidence Building group has been instituted from this office. But only a few students with ASD have chosen to participate. Many students with ASD have previously attended social skills groups and may wish to normalize their college experience. Perhaps instead of creating new programs to specifically address their social struggles, ODS personnel could partner with other

departments on campus who are interested in facilitating programming to help all students progress in their social development.

Although a full-scale program such as the college support program instituted at the state university may not be feasible or even necessary for smaller colleges, perhaps certain elements of the program could be incorporated. Specifically, a staff member who serves as an executive functioning coach could be particularly beneficial as challenges in this realm seem to correlate with academic problems and possibly withdrawal from school. Perhaps neuro-typical students could be trained in this capacity to assist students with ASD whose deficits in planning, organization and prioritization of work impede their academic success.

Finally, it is important to recognize the emotional and financial burdens that have long been placed on parents of students with disabilities. Placing sole responsibility on parents' to ensure that their children individuate and learn to function more autonomously may not be realistic. Parents' involvement at the elementary and secondary levels is essential to ensure their child's success. Parents of children with special needs including ASD do not automatically disengage once their son/daughter enters college.

Supporting a student's autonomous functioning is a challenge that should be shared by the various stakeholders involved and should occur in stages over the course of time, beginning at the secondary level. A team approach accompanied by open, honest communication around roles and responsibilities from an early stage in the student's academic life needs to occur. Additionally, as intrinsic motivation stems from feelings of competency and autonomy, it should be enhanced by providing opportunities for independent decision making, self-advocacy and self-direction prior to entrance in post-secondary institutions.

Summary

This chapter provides additional insight into the study's findings, its relevance to the literature and its contribution to the field. Limitations of the findings are presented along with implications for future research, and recommendations for students, families, and service providers.

Conclusion

For all students, including those with ASD, successful completion of college provides confirmation that they have achieved an essential educational goal that has positive implications for their future. Student success is also important for the institutions of higher education they attend. It provides validation of the relevance of their mission and the effectiveness of their educational program and support services. Student success is also important for the students' families who have worked to support them for many years, and for the society as a whole which depends on well- educated citizens.

If students with ASD are going to be integrated into college life, and schools are going to maximize students' potentials, more information is needed delineating the influence of services and the internal resources on students' success in college. This current study may help to improve understandings of the impact of various supports, utilization of supports and internal motivation and beliefs. Efforts to coordinate outside services and internal resources may be enhanced and hopefully more students with ASD will graduate from colleges and universities and successfully maintain employment and live independently.

References

- Arnett, J. (2000). Emerging Adulthood: A Theory of Development From The Late Teens Through The Twenties. *American Psychologist*, 469-480.
- Attwood, T. (2006), Autism and Asperger syndrome: preparing for adulthood, 2nd ed. *Journal of Child Psychology and Psychiatry*, 47: 223–224.
- Baker, R.W. McNeil, O.V., and Siryk, B., Expectations and reality in freshman adjustment to college, *Journal of Counseling Psychology*, 32: 94-103.
- Barnhill, G., Hagiwara, R., Myles, B.S., and Simpson, R.L. (2000). Asperger syndrome: A study of the cognitive profiles of 37 children and adolescents. *Focus on Autism and Other Developmental Disabilities*, 15, 146—153
- Bauminger, N. (2002). The facilitation of social-emotional understanding and social interaction in high functioning children with autism: Intervention outcomes. *Journal of Autism and Developmental Disorders*, 32, 283-298.
- Baxter, A.J., Brugha, T.S., Erskine, R.W., Scheurer, T. V., and Scott, J.G. (2014). The epidemiology and global burden of autism spectrum disorders, *Psychological Medicine*, 1-13.
- Bellon-Harn, M., and Harn, W. (2006). Profiles of social communicative competence in middle school children with Asperger syndrome: Two case studies. *Child Language Teaching and Therapy*, 1-26.
- Billstedt, E., Gillberg, I., and Gillberg, C. (2010). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*, 7-20.
- Birks, M., and Mills, J. (2011). *Grounded theory: A practical guide*. Los Angeles, Calif.: Sage.

- Briel, L. W., and Getzel, E. E. (2009). Postsecondary options for students with autism. In P. Wehman, M. D. Smith and C. Schall (Eds.), *Autism and the transition to adulthood: Success beyond the classroom* (pp. 189-207). Baltimore, MD: Paul H. Brookes.
- Brooks, R., and Goldstein, S. (2001) *Raising resilient children*. New York: McGraw-Hill.
- Camarena, P. M., and Sarigiani, P.A. (2009). Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. *Focus on Autism and Other Developmental Disabilities, 24*(2), 115-128.
- Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I., and Gillberg, C. (2008). Asperger Syndrome and Autism: A Comparative Longitudinal Follow-Up Study More than 5 Years after Original Diagnosis. *Journal of Autism and Developmental Disorders, 72*-85.
- Cederlund, M., Hagberg, B., and Gillberg, C. (2010). Asperger syndrome in adolescent and young adult males. Interview, self - and parent assessment of social, emotional, and cognitive problems. *Research in Developmental Disabilities, 31*(2), 287-298.
- Certo, N. J., Mautz, D., Pumpian, I., Sax, C., Smalley, T., Wade, H., (2003). A review and discussion of a model for seamless transition to adulthood. *Education and Training in Developmental Disabilities, 38*(1), 3-18.
- Charman, T., Howlin, P., Berry, B., and Prince, E. (2004). Measuring Developmental Progress of Children with Autism Spectrum Disorder on School Entry Using Parent Report. *Autism, 89*-100.
- Chamberlain-Salaun, J., Mills, J., and Usher, K. (2013). Linking Symbolic Interactionism and Grounded Theory Methods in a Research Design: From Corbin and Strauss' Assumptions to Action. *Sage Open, 3*(3).

- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.
- Chickering, A. W. (1969). *Education and identity*. San Francisco: Jossey-Bass.
- Church, C, Alisanski, S., Amanullah, S. (2000). The Social, Behavioral, and Academic Experiences of Children with asperger's syndrome. (2000). *Focus on Autism and Other Developmental Disabilities*, 15(1), 12-20.
- Colle, L., Baron-Cohen, S., Wheelwright, S. and van der Lely, H.K.J. (2008). Narrative discourse in adults with high-functioning autism or Asperger syndrome. *Journal of Autism and Developmental Disorders*, Vol. 38, pp. 28-40
- Corbin, J., and Strauss, A., (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. (4th ed.). Thousand Oaks, Calif.: Sage Publications.
- Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, Calif.: Sage Publications.
- Creswell, J. (2003). *Research design: Qualitative, quantitative, and mixed method approaches* (2nd ed.). Thousand Oaks, Calif.: Sage Publications.
- Creswell, J. W. and Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-131.
- Lynn A. Ciccantelli (2011). Critical factors in successful navigation of higher education for students with autism spectrum disorder: a qualitative case study (Dissertation)
- Deci, E.L., and Ryan, R. M. (1985). Cognitive evaluation theory. In *Intrinsic motivation and self-determination in human behavior* (Chpt. 3, pp. 43-85). New York: Plenum.

- DeFur, and Patton. (2009). Transitioning from School to adulthood for youth with autism spectrum disorder: Review and recommendations. *Focus on Autism and Other Developmental Disabilities, 24*, 77-88.
- Eckes, S., Ochoa, T.A., (2005). Students with Disabilities: Transitioning from high school to higher education. *American Secondary Education, 33* (3).
- L. Marc Ellison (2013). Assessing the readiness of higher education to instruct and support students with Asperger's Disorder. (Dissertation) Marshal University. Marshall Digital Scholar. <http://mds.marshall.edu/etd>.
- Farrell, E. F. (2004, October 8). Asperger's confounds colleges. *Chronicle of Higher Education, 51*, A35–A36.
- Farrugia, S., and Hudson, J. (2006). Anxiety in Adolescents With Asperger Syndrome: Negative Thoughts, Behavioral Problems, and Life Interference. *Focus on Autism and Other Developmental Disabilities, 25-35*.
- Fombonne, E. (2005). The Changing Epidemiology of Autism. *Journal of Applied Research in Intellectual Disabilities, 281-294*.
- Cristi D. Ford (2009). An investigation of support programs for college students with high functioning autism or Asperger syndrome. (Dissertation)
- Fullerton, A. (1995). Promoting self-determination for adolescents and young adults with autism. *Journal of Vocational Rehabilitation, 5*, 337-346.
- Getzel, E.E. and Wehman, P. (2008) Experiences of College Students With Disabilities and the Importance of Self-Determination in Higher Education Settings. *Career Development for Exceptional Individuals August 2008 31: 77-84*

- Ghaziuddin, M. (2005). *Mental health aspects of Autism and Asperger's syndrome*. Jessica Kingsley Press: London.
- Glaser, B. G. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B., and Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Pub.
- Glennon, T. J. (2001). The stress of the university experience for students with Asperger syndrome. *Work: A Journal of Prevention, Assessment and Rehabilitation*, 17(3), 183-190.
- Graetz, J., and Spaminato, K. (2008). Asperger's Syndrome and the voyage through high school: Not the final frontier. *Journal of College Admission*, 19-24.
- Halpern, A. S. (1985). Transition: A look at the foundation. *Exceptional Children*, 51: 479-486.
- Hart, D., Grigal, M., and Weir, C. (2010). Expanding the paradigm: Postsecondary education options for individuals with autism spectrum disorder and intellectual disabilities. *Focus on Autism and Other Developmental Disabilities*, 25(3), 134-150.
- Hawke, Constance S. 2004. "Accommodating Students with Disabilities." *New Directions for Community Colleges* 125:17-27.
- www.autismnj.org/prevalence-rates. Health.usnews.com/health news/news/articles/2012/05/14/employment-prospects-dim-for-young-adults-with-autism.
- Hendricks, D. R., and Wehman, P. (2009, June). Transition from school to adulthood for youth with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88.

- Hoffman, J. A. (1984). Psychological separation of late adolescents from their parents. *Journal of Counseling Psychology*, 31, 170-178.
- Howlin, P., Goode, S., Hutton, J., and Rutter, M. (2004). Adult Outcome for Children With Autism. *Journal of Child Psychology and Psychiatry*, 212-229.
- Hughson, E., and Uditsky, B. (2007). *Inclusive post-secondary (tertiary) education for adults with Down syndrome and other developmental disabilities: A promising path to an inclusive life*. Southsea: Down Syndrome Educational Trust.
Idea.ed.gov/statute.html
- Jamieson, J. and Jamieson, C. (2007). *Managing Asperger Syndrome at College and University*
A resource for students, tutors and support services. New York: Routledge
- Jobe, L. E., Williams White, S. (2007). Loneliness, social relationships, and a broader autism phenotype in college students. *Personality and Individual Difference*, 42(8), 1-13.
- Johnson, C.P. Early Clinical Characteristics of Children with Autism, In: Gupta, V.B. ed:
Autistic Spectrum Disorders in Children. New York: Marcel Decker, Inc. 2004: 85-123.
- Jorgensen, C., and McSheehan, M. (2010). *The Beyond Access model: Promoting membership, participation, and learning for students with disabilities in the general education classroom*. Baltimore: Paul H. Brookes Pub.
- Kenyon, D. Y., and Koerner, S. (2009). Examining emerging adults' and parents' expectations about autonomy during the transition to college. *Journal of Adolescent Research*, 24(3), 293-320.
- Klin A, Volkmar FR, Sparrow SS, Cicchetti DV, Rourke BP. (1995). Validity and neuropsychological characterization of Asperger syndrome: convergence with nonverbal learning disabilities syndrome. *J. Child Psychol. Psychiatry* 36:1127-40

- Lapsley, D. K., Rice, K. G., and Shadid, G. E. (1989). Psychological separation and adjustment to college. *Journal of Counseling Psychology*, 36, 286-294
- Alan Lyman (2008). A Qualitative study of male Asperger's syndrome students: transition from high school to college.
- Madaus, J.W., and Shaw, S.F. (2006). The impact of the IDEA 2004 on transition to college for students with learning disabilities. *Learning Disabilities Research and Practice*, 21 (4), 273 – 281.
- Matson, J., and Nebel-Schwalm, M. (2005). Comorbid Psychopathology With Autism Spectrum Disorder In Children: An Overview. *Research in Developmental Disabilities*, 341-352.
- Mattanah, J., Hancock, G., and Brand, B. (2004). Parental Attachment, Separation-Individuation, And College Student Adjustment: A Structural Equation Analysis Of Mediational Effects. *Journal of Counseling Psychology*, 51(2), 213-225.
- Mazzone, L., Ruta, L., and Reale, L. (2012). Psychiatric comorbidities in asperger syndrome and high functioning autism: Diagnostic challenges. *Annals of General Psychiatry*, 11(16), 16-16.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass
- Mertens, D. (2005). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods* (2nd ed.). Thousand Oaks, Calif.: Sage Publications.
- www.cdc.gov/mmwr/preview/mmwrhtml. Monitoring Network Surveillance Year, 2008.

- www.cdc.gov/mmwr/preview/mmwrhtml. Prevalence of autism spectrum disorders. Monitoring Network, 14 sites, United States, 2008. *Surveillance Summaries*. March 30, 2012/61 (ss03); 1-19.
- Morse, Janice M. (1994). Designing funded qualitative research. In [Norman K. Denzin](#) and Yvonna S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp.220-35). Thousand Oaks, CA: Sage.
- Norvilitis, J., and Reid, H. (2012). Predictors of Academic and Social Success and Psychological Well-Being in College Students. *Education Research International*, 2012, 1-6.
- Osborne, L.A., and Reed, P. (2009). The Relationship between parenting stress and behavior problems of children with autism spectrum disorders. *Exceptional Children*, 76(1).
- Padgett, D. (2008). *Qualitative methods in social work research* (2nd ed.). Thousand Oaks, Calif.: Sage Publications.
- Palmer, A. (2006). Realizing the college dream with Autism or Asperger syndrome: A parent's guide to student success. Jessica Kingsley Publishers: London: VIC, and Philadelphia, PA.
- Roberts, K. D. (2010). Topic areas to consider when planning transition from high school to postsecondary education for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 25(3), 158-162.
- Russo-Jameson, D. (2007). Self Determination and success outcomes of two year college students with disabilities. *Journal of College Reading and Learning*, 37(2).
- Ryan, Richard M. and Deci, Edward L. (2000). Intrinsic and Extrinsic Motivations: Classic Definitions and New Directions. *Contemporary Educational Psychology*, 25, 54-67.
- Saldana, J. (2013). (2nd ed.). *The coding manual for qualitative researchers*. London: Sage.

- Schall, C., Wehman, P. and McDonough, J. (2012). Transition from school to work for students with ASD; Understanding the process and achieving better outcomes. *Pediatric Clinics of North America*, 29(1), 189-202.
- Shattuck, P., Narendorf, S., Cooper, B., Sterzing, P., Wagner, M., and Taylor, J. (2012). Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder. *Pediatrics*, 1042-1049.
- Shore, S. (2003). *Beyond the wall: Personal experiences with autism and Asperger syndrome* (2nd ed.). Shawnee Mission, Kan.: Autism Asperger Pub.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., and Baird, G. (2008). Psychiatric Disorders In Children With Autism Spectrum Disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921-929.
- Smith, M.K. (2005). 'Competence and competency: the encyclopedia of informal education', <http://www.infed.org/biblio/b-comp.htm> [retrieved 14/11/06].
- Spekman, N. J., Goldberg, R. J., and Herman, K. L. (1992). Learning disabled children grow-up: A search for factors related to success in the young adult years. *Learning Disabilities Research and Practice*, 7, 161-170.
- Strauss, A., and Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, Calif.: Sage Publications.
- Jillian M. Szentmiklosi (2002). Self-determination among community college students diagnosed with Asperger's syndrome: a qualitative study
- Amy E. Tarallo (2012). Understanding students with autism spectrum disorders in higher education.

- United States Government Accountability Office (2005). Special Education: Children with Autism. GAO-05-220, Washington: GAO.
- VanBergeijk, E., Klin, A., and Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and Beyond. *Journal of Autism and Developmental Disabilities*, 38 (7), 1359-1370.
- VanderVeen, Kathleen M., "Psychosocial Development of Students with Autism Spectrum Disorder in Higher Education" (2013). Paper 223.
- Volkmar, F. (2004). Adolescence and sexuality. In F.R. Volkmar and L.A. Wiesner (Eds). *Healthcare for children on the autism spectrum* (pp. 245-260). New York: Harbor House.
- White, S. W., Ollendick, T. H., and Bray, B. C. (2011, November). College students on the autism spectrum: Prevalence and associated problems. *Autism*, 15(6), 683-701.
- Wikipedia: The free encyclopedia. (2014, May 30). FL: Wikimedia Foundation, Inc. Retrieved Jan 2015 from <http://www.wikipedia.org>.
- Wolf, L.E., Thierfeld-Brown, J., and Kukiela-Bork G.R., (2009). Students with Asperger syndrome: a guide for college personnel. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Zagar, D., and Alpern, C.S. (2010). College-based inclusion programming for transition-age students with autism. *Focus on Autism and Other Developmental Disabilities*, 25(3), 151-157.
- Zarrett, N., and Eccles, J. (2006). The Passage To Adulthood: Challenges Of Late Adolescence. *New Directions for Youth Development*, (111), 13-28.

Appendix A

Informed Consent Form

A Grounded Theory Investigation of Progressing through College with an Autism Spectrum Disorder

You are invited to participate in a research study that is being conducted by Lauren Poleyeff, who is a doctoral student in the Graduate School of Applied and Professional Psychology at Rutgers University. The purpose of this research is to explore the needs of college students with autism spectrum disorders, their use of supports, and the helpfulness of supports and services for this population of students. Approximately 10 – 20 subjects who are at least 18 years of age will participate in this study. If you have any questions about this study you may contact the primary investigator or her advisor at:

Principle investigator:

Lauren Poleyeff, Psy.M.
Doctoral Candidate
Rutgers University
Graduate School of Applied
and Professional Psychology
(201) 960-8797

Secondary Investigator:

Kenneth Schneider, Ph.D.
Active Emeritus Professor
Rutgers University
Graduate School of Applied
and Professional Psychology
848-445-3914 x53915

Description of the Procedures

In order to participate in the study, you must be at least 18 years old, a current or recent college student with a documented diagnosis of an autism spectrum disorder (i.e. PDD-NOS, Asperger's Syndrome, high functioning Autism). Data will be collected through qualitative interviews. The interview should last approximately 60 minutes and will take place in the Busch campus library at Rutgers University. During this interview, I will ask you questions about your experiences at college as an individual with an autism spectrum disorder. A second interview may be requested to clarify statements and themes. Interviews will be audio-taped and transcribed for data analysis. I plan to interview approximately 10-20 students and use the responses to write about the themes revealed in my dissertation.

Potential Benefits

You may potentially benefit from being in this study because sharing your story may aide in your understanding of autism spectrum disorders and the ways that it affects you. The possibility exists that you may not perceive any positive benefit from participating in this study. Other people are likely to benefit from this study because the results will inform persons with autism spectrum disorders, their family members, and professionals who work with them about the challenges students with ASDs face and ways to better support such students to be successful in college. Results of research will be provided to participants upon request.

initial

Risks and Discomforts

It is possible that during the course of the interview, or after the interview you might experience some emotional upset. This may happen as the result of being asked to recall life experiences that were distressing to you at some point in the past. Because of this possibility, you will be given the names and phone numbers of two mental health professionals that you can contact should you feel the need to pursue follow-up counseling. If you already have a therapist, you are free to discuss your reactions to interview questions with this person. (See attachment for list of providers)

Confidentiality

Your responses to survey questions will remain confidential. Your real name will not be used in the written case report; instead, you and any other person and place names involved in your case will be given pseudonyms that will be used in all written records and reports. Audio recordings will be immediately uploaded to a password protected computer until October, 2015 and then will be destroyed. No one will have access to the recordings other than the investigators.

Reasons You May be Taken Out of the Study Without Your Consent

If health conditions occur that would make participating in the study interview possibly dangerous to you, or if other conditions occur that could affect you or your health, Dr. Schneider or Lauren Poleyeff may take you out of this study. In addition, the entire study may be stopped if dangerous risks or side effects occur in other people.

New Findings

If any new information develops that may affect your willingness to stay in this study, you will be told about it.

Payment

You will receive a \$20.00 gift card for participating in the study. Gift card is not contingent upon completion of study.

Costs to Participant

Uncompensated costs to the subject that may result from participation in the research may include travel expenses to interview location.

INJURY

If you are injured as a result of this study, you will be provided with immediate necessary medical care. However, you will not be reimbursed for medical care or receive other

Initial

payment. Rutgers University will not be responsible for any of your bills, including any routine medical care under this program or reimbursement for any side effects that may occur as a result of this program.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate or withdrawal at any time without harming your relationship with the researcher or Rutgers University or in any other way receive a penalty or loss of benefits to which you are otherwise entitled.

You may ask any questions concerning this research at any time by contacting Lauren Poleyeff, Rutgers University, Graduate School of Applied and Professional Psychology at lpoleyeff@stevens.edu or (201) 960-8797.

You may also contact my faculty chair, Dr. Ken Schneider, Rutgers University, Graduate School of Applied and Professional Psychology at schneid@rci.rutgers.edu .

Research at Rutgers University involving human participants must be approved by the Institutional Review Board (IRB). If you have any questions or concerns about your rights as research subject, you may contact the IRB administrator at Rutgers University at:

Rutgers University Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs,
3 Rutgers Plaza
New Brunswick, NJ 088901
(848) 932-0150
Email: humansubjects@orsp.rutgers.edu

Your signature certifies that you have decided to participate and have read and understood the information presented. You will be given a copy of this consent form to keep.

- _____ I am 18 years of age or older.
- _____ I have read and understand the interview procedures described above.
- _____ I agree to participate in the interview.
- _____ I agree to be audio-taped during the interview.

Participant

Date

Principal Investigator

Date

Audio/Videotape Addendum to Consent Form

You have already agreed to participate in a research study entitled: Students with Autism Spectrum Disorders in Higher Education: Managing Challenges and Utilizing Supports conducted by Lauren Poleyeff. We are asking for your permission to allow us to include audiotape as part of that research study. You do not have to agree to be recorded in order to participate in the main part of the study.

The recording(s) will be used for analysis by the research team. The recordings will not include your name or other identifiers. The recordings will be stored in a locked file cabinet and linked with a code to subjects' identity.

Your signature on this form grants the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recordings(s) for any other reason than that stated in the consent form without your permission.

Subject (Print) _____

Subject Signature _____

Principal Investigator _____

Appendix B

Semi- Structured Interview

1. What have been the biggest challenges for you in college?
2. How have you managed these challenges?
3. What do you as a student with an ASD want/need in terms of supports and services?
4. What, if any, supports/services have you used? How have they been helpful /unhelpful?
5. What would improve your college experience and increase your chance for success?

Probes / Sub-questions

Academic and Career Goals

How and why did you decide to go to college?

What is your major/minor? Why did you choose to study this?

What are your career goals?

Accommodations/ Use of Disability Services

What factors influenced whether or not you disclosed your diagnosis of ASD while in college?

What accommodations and supports do disability services provide?

How have professors responded to your need for accommodations in class?

What can professors do to better support your academic needs?

Academic Functioning

Describe how having an ASD impacts your learning

Describe your experience managing your coursework

Describe how peers have been helpful/unhelpful in classes

Social Functioning

Describe your social life as a college student.

Have you ever felt isolated/ lonely while at college? Describe what that has been like for you.

Have you been involved in any romantic relationships while in college? Describe the nature and quality of romantic relationship (s).

What activities or organizations are you involved with in school?

Independent Functioning

Do you live on campus or at home?

What type of support does your family provide while you are in college?

Describe your experiences managing your self-care while in college.

Self-Awareness

In what ways do you think the dx of ASD most impacts you?

What have been your greatest challenges during your time in college so far?

What have been your greatest successes so far in college?

In what ways has having an ASD been a benefit to you as a college student?

Additional Questions for Theoretical Sensitivity

1. What does it mean to you to have challenges?
2. What does it mean to you to manage challenges?
3. What does it mean to you to ask for supports?
4. When do you most typically experience challenges?
5. What do you do to obtain support?
6. Who provides support?
7. What happens if you don't get support?
8. What happens if you do get support?
9. How much stress do you experience before asking for support?
10. How much does your desire for obtaining a college degree influence use of supports?

Table 1

Summary of Participant Demographics

Participant	Age	College, Year	Co-Morbidity	Primary Challenge	Supports Utilized
R1 (male)	22	Public, Senior	OCD	Social	CSP, outside therapy
R2 (female)	21	Public, Sophomore (going on leave)	Mood Disorder, ADHD	Academic, Social	CSP
R3 (male)	21	Public, Sophomore	ADHD	Academic	CSP
R4 (male)	21	Public, Sophomore (currently part-time)	ADHD	Academic	CSP
R5 (male)	21	Public, Senior		Social	CSP, Academic coach
*S1 (male)	30	Private, Post-Graduate	Depression	Social	
S2 (male)	18	Private Freshman	Mood Disorder NOS	Social	Outside therapist
S3 (male)	18	Private, Freshman	Depression, Anxiety	Social	Outside therapist, E.F. coach
S4 (male)	18	Private, Freshman	Anxiety	Social	College counseling, SS group

***Student utilized no support during undergraduate education; he attended outside therapy and support groups during and post graduate school**

Table 2
Categories and Subcategories

Category	Subcategories	# Responses
1. Phenomenon - Challenges	1.1 Social Challenges	9 – 100%
	1.2 Executive Functioning Challenges	9 -100%
2. Stress Context	2.1 Peer Rejection	2 - 22%
	2.2 Academic Problems	6 – 67%
	2.3 Self Isolation	8 – 89%
	2.4 Negative Self Perception	6 – 67%
	2.5 Poor Choices	5 – 56%
3. Intervening Conditions	3.1 Comorbid conditions	8 – 89%
	3.2 Assessing Need for Help	7 – 78%
	3.3 Parental involvement	8 – 89%
	3.4 Motivation to graduate	7 – 78%
4. Controlling Strategies	4.1 Academic Accommodations	8 – 89%
	4.2 CSP Support (s)	5/5 – 100%
	4.3 Join Campus Activities	8/9 – 89%
	4.4 Outside Supports	5/9- 56%
5. Consequences of Support	5.1 Identity Development	2 – 22%
	5.3 Social Success	4 – 44%
	5.3 Improved E.F. Skills	5 – 56%

Figure 1
Grounded Theory Coding Paradigm

