

TRANSITION FROM HIGH SCHOOL TO POSTSECONDARY EDUCATION:  
NARRATIVES OF PARENTS OF COLLEGE STUDENTS WITH  
AUTISM SPECTRUM DISORDERS

by

KATHRYN LUTES EBEL

KAGENDO MUTUA, COMMITTEE CHAIR  
ARLEENE P. BREAUX  
NIRMALA EREVELLES  
KARRI HOLLEY  
DANIELLE MOLINA

A DISSERTATION

Submitted in partial fulfillment of the requirements  
for the degree of Doctor of Education in the  
Department of Educational Leadership,  
Policy, and Technology Studies  
in the Graduate School of  
The University of Alabama

TUSCALOOSA, ALABAMA

2015

Copyright Kathryn Lutes Ebel 2015  
ALL RIGHTS RESERVED

## ABSTRACT

This qualitative study focuses on the experiences of students with Autism Spectrum Disorders (ASD) transitioning from high school to postsecondary education as told from the perspective of their parents. As a group, parents of college-aged youth and young adults with ASD are more deeply involved with the educational process of their children's education compared to other parents. Structured interviews were conducted with parents of a purposively selected sample of students with ASD attending Downtown University, a four-year urban comprehensive university in the Southeastern United States. Parents were asked to describe their experiences with the transition process and, if possible, highlight any information that was not provided to them that would have allowed them to make the transition period a smoother one for their children.

Data collected through these interviews were used to delineate the most common experiences shared by these parents as their children with ASD moved from the K-12 setting to the postsecondary setting. Four particular themes emerged as shared experiences that came to the forefront: being an advocate for the child with autism begins at an early age and continues well into the college years; maintaining a strong line of communication with the young person as he or she transitions to college is critical for the continued growth and development of the student with autism; developing a strong support team along the way provides professional advice to the parent and serves as an outlet that allows the parent to express closely-held emotions and beliefs; and once the transition period is complete, returning to a relatively "normal" life is critical for the health and well-being of the parent. Knowing the importance of these experiences shared by

the parents will allow high schools and college disability services offices to understand the struggles of students with autism as they seek to transition to higher education. In addition, this knowledge will allow school personnel to make recommendations for training, assistance, and information to parents so the transition process takes place in a much smoother manner.

## ACKNOWLEDGEMENTS

First and foremost, to my Creator, with whom, in whom, and by whom all things are possible, I offer thanks and gratitude.

My parents were not highly educated people, but they knew the value of a good education. Although neither of them lived to see me complete this task, I know that they are both watching over me and are proud of my accomplishment.

My husband Marvin Ebel has demonstrated tireless patience with me, especially as I have drawn out this process beyond anything that could be called “reasonable.” His constant cry of “Git ‘er done!” rang in my ears endlessly. Many times I asked him to stop nagging me but now I am glad that he did not do it.

Dr. John Schmitt in the Graduate Office has been most kind in allowing me to continue my work to completion, and for that I am truly grateful. Dr. Kagendo Mutua, my chair, deserves a significant raise for having dealt with my procrastination through this process. The other members of my committee – Dr. Arleene Breaux, Dr. Nirmala Erevelles, Dr. Karri Holley, and Dr. Danielle Molina – are saints as well, and the staff (current and previous) of the Higher Education Administration Executive Program at The University of Alabama are some of the finest people I have had the pleasure to know and learn from.

I offer my undying gratitude to the parents who participated in this study. Their willingness to share intimate recollections of their transition experiences is a gift that I can never repay.

My colleagues at Downtown University were most generous in granting me access to the students in their autism program so that I could reach out to the parents. I am deeply indebted to those professionals that I am also able to call my friends.

Finally, to the members of Cohort 3 – Anne, Andrea, Michele, Stephanie, Jim, Mack, Jeremy, Jeffery, David, Rhett – there are no words to describe the support, laughs, kicks in the rear as needed, and genuine kindnesses that you all have shared with me through the years. 11 In, 11 Out – finally!

## CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iv
LIST OF TABLES .....	x
CHAPTER I: INTRODUCTION.....	1
History of Educational Access for Persons with Disabilities .....	5
Legal Implications for Students with Disabilities in Higher Education .....	8
IDEA Reauthorization of 1990 .....	8
Section 504.....	10
Americans with Disabilities Act Amendments Act (ADAAA).....	11
Autism Spectrum Disorders .....	12
History .....	12
Diagnostic Changes to DSM-5 and Implications for Education.....	14
Prevalence of ASD .....	17
Causes of Autism Spectrum Disorders .....	18
Statement of the Problem .....	18
Purpose of the Study .....	19
Research Questions .....	20
Importance of the Study .....	21
Scope of the Study .....	21

Definition of Terms .....	22
Limitations and Delimitations .....	24
Summary .....	26
CHAPTER II: REVIEW OF LITERATURE .....	28
Transition to Postsecondary Education for Typical Students .....	28
Adjustments to the College Environment .....	28
Development of Coping Strategies .....	29
Developing a Sense of Belonging .....	30
Developing Self-Actualization Skills .....	31
Taking on Adult Roles and Responsibilities .....	33
Chickering and Reisser’s Student Development Theory .....	37
Developing Competence .....	38
Managing Emotions .....	38
Moving Through Autonomy toward Interdependence .....	39
Parent Involvement and Perceptions of College Readiness for Typical Students .....	40
Effect of Parental Involvement .....	41
Relationship Between Parents and Today’s Typical College Student.....	43
Transition to Postsecondary Education for Students with Disabilities .....	45
Reasons for Underrepresentation of Students with Disabilities in Higher Education .....	46
Student Participation in Transition Planning .....	47
Steps to Improve Opportunities for Success in Postsecondary Education .....	48
Parent Involvement and Perceptions of College Readiness for Students with Disabilities .....	52
Parents Learn to Let Go .....	54

Transition to Postsecondary Education for Students on the Autism Spectrum .....	56
Academic Skills .....	57
Communication Skills .....	60
Social/Emotional Skills .....	62
Parent Involvement and Perception of College Readiness for Students with ASD.....	65
Challenges to Transition for Students with ASD.....	66
Expectations of Parents.....	67
Theoretical Framework.....	70
Summary.....	71
CHAPTER III: RESEARCH METHODS .....	72
Introduction.....	72
Qualitative Paradigm .....	73
Researcher’s Role .....	74
Data Source.....	76
Data Collection .....	80
Data Analysis .....	82
Verification .....	82
Ethical Considerations/Researcher Positionality .....	84
Summary.....	86
CHAPTER IV: ANALYSIS OF DATA.....	88
Advocacy Never Ends .....	90
Establishing Lines of Communication is Essential During the Transition Process.....	95
Having Outside Support Provides Information and Resources for Action.....	102

Information-Sharing Leads to a Smooth Transition .....	107
Transition Ends; You Must Take Care of Yourself .....	111
Summary .....	113
CHAPTER V: DISCUSSION.....	115
Introduction.....	115
Discussion.....	117
Implications for Practice .....	123
Conclusion .....	128
REFERENCES .....	131
APPENDICES .....	148

## LIST OF TABLES

1. Comparison between DSM-IV and DSM-5 Diagnostic Criteria for Autism Spectrum Disorders .....16
2. Demographic Information on Parents who Participated in the Study.....79

## CHAPTER I: INTRODUCTION

One of the most exciting periods in the life of a young adult is making the transition from high school to college. This period ushers them into a new environment rife with opportunities to develop new social relationships, meet and work with experts in a specific field of study, create and live by rules that largely are not imposed by parents, and find activities and resources to help relieve stress and anxiety (Hart, Grigal, & Weir, 2010; Pancer, Hunsberger, Pratt, & Alisat, 2000; Pittman & Richmond, 2008). These are challenges that nearly every first-time college student experiences. Despite the uncertainty of this period, most students are excited about the possibility of finding out what they can become on their own, away from parents and teachers who have been the controlling influences in their lives for many years. The choices a student makes as he begins his college years will impact his performance in the classroom, so the importance of making wise choices, or learning quickly from his mistakes, cannot be overstated (Roe Clark, 2005).

If students are skilled at making new friends, the social connections and development of interpersonal relationships that are so critical to the college student's growth and development will come more easily (Chickering & Reisser, 1993). If they have been allowed to make decisions for themselves as they matriculated through high school, they may not have much difficulty setting rules and boundaries for themselves in the new environment that college presents (Pittman & Richmond, 2007). Having a clear career path in mind will allow them to interact knowledgeably with their professors and other experts in their fields (Keup, 2007).

Developing strategies that will help relieve stress and undue pressures will serve them well as the differences between high school and college become apparent to students (Pritchard & Wilson, 2003; Roe Clark, 2005; Wei, Russell, & Zakalik, 2005). Preparation for what to expect at the postsecondary level is perhaps the most important step in making a smooth transition from high school to college (Hicks, 2005).

Given the importance of good self-determination skills for a beginning college student, it is reasonable to presume that students who do not possess these skills may face challenges that might well be qualitatively different from their peers. So the question is - what happens to the student who has difficulty making those social connections, for whom even one-to-one dialogue is a struggle? This is the dilemma that students with Autism Spectrum Disorders (ASD) face when they transition from high school to postsecondary education. Academics may come easily for some of these students, but the majority often lack the skills needed to make new friends or to recognize social cues in settings where many activities are going on at the same time (Yazedjian, Toews, Sevin, & Purswell, 2008).

Student life at the postsecondary level is made up of diverse people from a variety of different backgrounds and experiences, all seeking to relate to others who share common interests, or to expand their boundaries by getting to know people who are very dissimilar to their previous social groups (Wei, Russell, & Zakalik, 2005). If students cannot find ways to move outside their comfort zone and attempt to make appropriate social connections, other areas of the college experience will also suffer (Kuh, Cruce, Shoup, Kinzie, & Gonyea, 2008; Smith, 2007). For example, an intense interest in a particular subject may hold the attention of the student with ASD, but this high level of interest may create problems relating to other students who may not share the same interest or see it as frivolous (Adreon & Durocher, 2007). Sharing

living space with other students also could have an impact on social skill development for students with ASD. Sensory issues such as lighting, noise, and odors that are unfamiliar or unpleasant to the student may create confrontations among roommates (Adreon & Durocher, 2007).

In generating his theory of student development, Astin (1984) proposed that students are more likely to persist in college if they are involved in activities that are available to them on the campus; but if a student has difficulty taking that initial step toward involvement, the likelihood of having a successful college experience diminishes (Adreon & Durocher, 2007; Glennon, 2001). Students with ASD fit this description of social isolation; they do not easily pick up on social cues in group settings, primarily because they are faced with too much information to process at one time, and the task becomes overwhelming (Ghaziuddin, 2007).

Throughout their school years, many students with ASD have had decisions made for them by their parents or their teachers (Ivey, 2004). Adjusting to an environment where the student must make decisions for him/herself and advocate for him/herself in unfamiliar situations makes the transition to college even more difficult (Morningstar, Turnbull, & Turnbull, 1995). Students on the autism spectrum also experience co-morbid conditions, such as Attention Deficit Hyperactivity Disorder (ADHD) and depression, which further impact the student's ability to connect with others in social situations or in the classroom (Lecavalier, Gadow, DeVincent, & Edwards, 2009).

For parents of a child with ASD, the inherent difficulties with their child's ability to make a successful transition to postsecondary education is compounded by a belief that high school instructors are not adequately trained to prepare a student with ASD for the postsecondary arena (Tincani, Cucchiarra, Thurman, Snyder, & McCarthy, 2014). Frequently, parents also feel they

are the only representatives who are focused on the possibility of higher education, constantly challenging school personnel who have low expectations for the child (Hetherington, Durant-Jones, Johnson, Nolan, Smith, Taylor-Brown, & Tuttle, 2010). Parents also disagree with school personnel as to the degree and quality of services provided to students in the high school, often feeling that they have to take the lead in being advocates for their children (Tincani et al., 2014).

This research study investigated the challenges students with ASD experience in making the transition from high school to postsecondary education, based on the narratives of parents who serve as advocates and assistants to their sons and daughters with ASD. Recognizing the importance of the history of inclusion of students with disabilities in higher education is critical to understanding how students with ASD have been a part of the progress toward full college participation for all students with disabilities. This introductory chapter briefly reviews that history. Also of importance is the impact of legislation on educating students with disabilities at all levels, including postsecondary education. Three laws are described as the Individuals with Disabilities Education Act, known as IDEA (2004); Section 504 of the Rehabilitation Act of 1973 (Section 504, 1973); and the Americans with Disabilities Act Amendments Act (ADAAA, 2008). These laws created educational opportunities for all students with disabilities that might not otherwise have been available to them. A description of autism spectrum disorders, including the *Diagnosics and Statistics Manual (DSM)-5* (APA, 2013) criteria for these disorders, is presented to provide background information that relates the difficulties these students experience in college to the characteristics of the disorder. The criteria changes between the *DSM-IV-TR* (APA, 2000) and the *DSM-5* (APA, 2013) are discussed briefly to illustrate the current status of the categorization of people on the autism spectrum.

## **History of Educational Access for Persons with Disabilities**

Three landmark legal cases paved the way for educational opportunities for persons with disabilities. The first was *Wyatt v. Stickney*, filed in 1971 by members of the psychology department staff at The University of Alabama. A cigarette tax, which was meant to provide funding for services to people with intellectual disabilities in the state of Alabama, was cut from the state budget at the last minute. The result of this funding cut was the layoff of many workers, including professional staff, at state mental hospitals. Because of the reduction in staff, the conditions in the hospitals became deplorable. A lawsuit was filed on behalf of Ricky Wyatt, one of the patients at Bryce Mental Hospital in Tuscaloosa, to protest the inhumane treatment of the patients. The lawsuit sought to obtain better educational opportunities, better access to psychological treatment, individualized treatment plans, and fewer restrictions to patient freedom (*Wyatt v. Stickney*, 1971). The case caused Alabama and other states to look at the treatment of mentally ill persons and to develop standards for care, treatment, and education in the community setting that previously had been unavailable (Ricky Wyatt, 2009).

The second landmark legal case that paved the way for inclusion of individuals with disabilities in education was *Pennsylvania Association for Retarded Children (P.A.R.C.) v. Pennsylvania*. Also filed in 1971, parents of children with intellectual disabilities successfully challenged the state of Pennsylvania Department of Education's practice of keeping these students in educational facilities that were separate from their nondisabled peers. The state was ordered to provide free public education to all students with intellectual disabilities living in Pennsylvania (*P.A.R.C. v. Pennsylvania*, 1971). This case served as the foundation on which IDEA was created, providing free, appropriate public education to students with disabilities on a national level (IDEA, 2004).

The third case, *Mills v. Board of Education of Washington, DC*, extended the right to a free public education to all disabled children in the District of Columbia. While all seven children represented in *Mills* were African-American, the court chose not to focus on their race. Since the right to equal access to education for African-Americans had already been established under *Brown v. Board of Education* (1954), their disabilities were viewed as the reason these students were being kept from receiving a public education (*Mills v. Board of Education*, 1972). The standard that ties all three legal cases together is equal access to treatment and educational services, civil rights that long had been denied people with disabilities (Martin, Martin, & Terman, 1996).

With these three legal precedents as the catalyst, the focus on students with disabilities across the country became quite clear; these students were not receiving equal educational opportunities compared to their nondisabled peers. Congress, in reviewing these several cases, determined that action must be taken at the federal level if there was to be a significant change in the way students with disabilities were educated. With the passage of PL 94-142, the Education for All Handicapped Children Act in 1975 (EAHCA, 1975), all school-aged children who had disabilities were given the right to a free, appropriate public education. This legislation established special programs and support services within the already-established primary and secondary educational framework for students who had disabilities.

A byproduct of the inclusion of students with disabilities in public education and their subsequent graduation from high school was a significant increase in the number of these students who began to pursue college and university training. With the initial wave of these students arriving on college campuses in the mid-1980s, colleges were forced to scramble to find appropriate ways to serve them. At that time, there was little legal protection for these students,

since protections under IDEA (2004) ended once the student graduated from or otherwise exited high school. Section 504 was not passed until 1973, and four more years would go by before its implementation (Section 504, 1973). Even though access to higher education had improved, it was not until the passage of the Americans with Disabilities Act (ADA) in 1990 and the more recent amendments to the ADA (ADA, 1990; ADAAA, 2008) that the responsibility for providing equal, accessible postsecondary education fell squarely under the umbrella of these two laws (Schutz, 2002). Section 504 and the ADAAA are described in more detail in Chapter II.

While students with disabilities enrolling at the postsecondary level was not a new phenomenon, the types of disabilities represented with this new generation of students was not the usual disabled student that faculty were accustomed to teaching. After World War II, physically disabled men and women, particularly those returning from combat, were familiar sights on college campuses (Madaus, Miller, & Vance, 2009). These veterans were welcomed home with rousing support from their families, the community, and college administrators as they attempted to regain a sense of self-worth that had been lost (Mull, Sitlington, & Alper, 2001). After 1990 and the passage of the ADA, students with a wide variety of disabilities, especially hidden disabilities such as learning disabilities, psychological disorders, and Attention Deficit/Hyperactivity Disorder (ADHD), began to appear on college campuses in significant numbers. These increases were seen as a direct result of improved educational opportunities for students at the primary and secondary levels due to the enactment of the Education of All Handicapped Children Act in 1975 (EAHCA, 1975) and its subsequent reauthorizations (Eckes & Ochoa, 2005), as well as its interplay with the ADAAA and Section 504.

Students with ASD have been a more recent addition to the ranks of young adults pursuing postsecondary education. For many years these students were thought to be uneducable,

even at the K-12 levels. They were viewed with the same educational regard as children with intellectual disabilities until 1990, when autism was added to IDEA as a stand-alone disability category (IDEA, 1990). With more appropriate educational services being provided in K-12, students with ASD began to demonstrate strong academic skills and were considered to be candidates for postsecondary education (Hart, Grigal, & Weir, 2010). This led educators and counselors at the secondary level to reconsider and begin recommending these students for college preparation courses. Colleges were forced to learn quickly about autism spectrum disorders so campus disability offices could educate faculty and staff about the particular needs of this population (Hurewitz & Berger, 2008; Zager & Alpern, 2010).

### **Legal Implications for Students with Disabilities in Higher Education**

#### **IDEA Reauthorization of 1990**

In the 1990 reauthorization of IDEA, a new element was introduced with the intention of providing for a smoother transition from high school to postsecondary education or job training for students with disabilities. The middle school or high school individualized educational team was now required to create and implement a transition plan for each student by the time the student's 14th birthday was achieved (McAfee & Greenawalt, 2001). The 1990 reauthorization of IDEA defines transition services as

a coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities, including employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities shall be based upon the individual student's needs, taking into account the student's preferences and interests, and shall include instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation. (IDEA, 1990)

This language describing transition planning is somewhat different from the most recent verbiage that addresses how transition planning should be carried out. In the newer version, the word “student” has been replaced with “child.” In addition, the newer language mandates that the transition process be results-oriented rather than “outcome-oriented” and “focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities” (IDEA, 2004). The newer language also adds that the transition plan should be based on the “child’s strengths,” words that were not included in the original language.

The purpose of a transition plan is to create a formal timetable of measurable steps that should be taken by the student that will lead to employment or a college degree (Eckes & Ochoa, 2005). Each year after the initial one, the transition plan must be updated to demonstrate the progress that has been made toward the student’s transition goals (Eckes & Ochoa, 2005; Stodden & Mruzek, 2010). In most cases, this plan is developed by parents, teachers, school administrators, and special education personnel, with only marginal participation from the student. Rarely are any of these participants knowledgeable of the changes the student will encounter once the transition is made to postsecondary education (Schutz, 2002; Wolanin & Steele, 2004). Another weakness in the current transition process is the lack of readiness training provided by the school system to prepare the student for self-determination (Wolanin & Steele, 2004). Because students with disabilities who graduate from high school are not well prepared for the pressures of college life, many of them struggle in their academic pursuits, and they have difficulty maintaining a sufficiently high level of motivation and enthusiasm for learning (Foley, 2006). In their research on the key issues that impact the implementation of federally mandated transition requirements, Johnson, Stodden, Emanuel, Luecking, and Mack (2002) described four

challenges that may impact current and future transition practices. Significant among these challenges is the concern that students with disabilities are not included in the full range of educational opportunities that high schools offer. As a result, these students do not have the same opportunities to participate in college preparatory classes that other students have available to them. In addition, parent participation in transition planning meetings at the high school level may not be viewed as meaningful or valuable by school personnel. Johnson et al. (2002) described the importance of the role that parents play in making transition decisions:

Because of the critical role that parents play in assisting their children in making the transition from school to adult life, additional attention must be given to establishing strategies and methods needed to actively engage them in discussions and decisions concerning school and postschool options. Special attention must be given to funding effective training and outreach strategies for parents from diverse and multicultural backgrounds and those living in poverty. (p. 526-527)

#### **Section 504**

Once a student graduates from high school the requirements of IDEA are replaced by civil rights legislation, specifically Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (1990) and as amended in 2008 (ADAAA, 2008), which will be discussed in the next section. Section 504 of the Rehabilitation Act of 1973 states that

No otherwise qualified person with a disability in the United States...shall, solely by reason of...disability, be excluded from participation in, be denied the benefits or, or be subjected to discrimination under any program or activity receiving federal financial assistance. (Section 504)

Because there are only a few institutions of higher education that receive no federal funding, Section 504 has a significant impact on the majority of colleges and their methods of recruiting, admitting, and educating students who have disabilities. These students may request academic adjustments, including auxiliary aids that will allow them to participate in the programs and activities offered at postsecondary institutions (Department of Education, 2011).

Section 504 is viewed as civil rights legislation for persons with disabilities. If barriers exist that prevent a student's access to programs, activities, or services a college offers because of the student's disability, those barriers must be removed (Scott, 1991). This includes not only architectural barriers, but also barriers to learning, such as printed materials that must be converted to a format that is usable by students with visual impairments, communication access for deaf and hard of hearing students, and modifications to a testing environment for students with distractibility or concentration difficulty (West, Kregel, Getzel, Ming, Ipsen, & Martin, 1993). While these aids and services do not have to be what the student prefers, they do have to be effective. It is, therefore, important that students be knowledgeable of their own needs so they can approach instructors and discuss what barriers the classroom will present and how those barriers can be removed most effectively (Sitlington, 2003).

### **Americans with Disabilities Act Amendments Act (ADAAA)**

Like Section 504, the ADAAA (2008) is a civil rights mandate that guarantees protection from discrimination for persons with disabilities. The ADAAA broadens the responsibility of providing equal access to include all public and private employers, not just those who receive federal funding as provided for in Section 504. In addition, state and local governments must also guarantee transportation access, access to places of public accommodation, accessible government services, and communication access (Wright & Wright, 2008). Both Section 504 and the ADAAA define disability as “a physical or mental impairment that substantially limits a major life activity; a record of such an impairment; or being regarded as having such an impairment” (ADAAA, 2008; Section 504, 1973).

The definition of *disability* is more clearly described in the ADAAA, which states that a “person with a disability is anyone who has a mental or physical impairment that substantially

limits one or more major life activities” (ADAAA, 2008). Included among those major life activities are hearing, speaking, walking, seeing, and learning. In the 2008 amendments to the original act, several changes to the definition of *disability* were made. Among these changes are an expansion of the list of major life activities, a clarification in the definition of “regarded as,” and the removal of mitigating measures as a criterion for determining substantial limitation (Department of Education, 2009).

For most institutions of higher education, Title II of the ADAAA has the most impact. Under this Title, protection is guaranteed for employees and participants in any activity provided by any public institution. Title III covers those same issues for private institutions. As a result, a college or university, whether public or private, must make accommodations that are reasonable to ensure equal access. In addition, there must be a clearly defined grievance procedure in place so employees and students with disabilities have recourse if they feel they have been denied access. The concept of “reasonable accommodation” is used frequently by disability service offices to denote the adjustments that are necessary for students with disabilities so that equal access is available to them (Department of Education, 2008).

## **Autism Spectrum Disorders**

### **History**

There is some evidence that classic autism was present as far back as 250 AD, in descriptions of children, primarily boys, known as “feral children.” These children reportedly were raised by animals or grew up in social isolation. The stories of these children all report difficulties with communication, socialization, and learning appropriate behaviors to live in mainstream society (Koegel, 2008). Whether their symptoms were the result of lack of

socialization or that the symptoms led the children to seek social isolation or to be abandoned by their families, these accounts very closely parallel modern day criteria for diagnosis of ASD.

Contrast these very early accounts with the more official reports of Hans Asperger and Leo Kanner in the 1940s, which described the rather odd behaviors of children who were originally thought to be schizophrenic (Lyons & Fitzgerald, 2007). In 1938, Asperger was the first to use the term “autistic” to describe the behaviors, but Kanner is viewed as the father of autism research. Both men were from Austria originally, but Kanner immigrated to the United States and did his research at Johns Hopkins University, while Asperger remained in Europe and published his work within the psychiatric societies of his region (Cumine, Leach, & Stevenson, 1998; Lyons & Fitzgerald, 2007). In his work, Kanner developed four common characteristics of the disorder: “a preference for aloneness, an insistence on sameness, a liking for elaborate routines, and some abilities that are remarkable compared with those of the average person” (Ratey, 2002, p. 325). Although Asperger was aware of Kanner’s research, he believed that the conditions each was studying were two different disorders (Ghaziuddin, Tsai, & Ghaziuddin, 1992). Asperger’s work was published in German and did not receive widespread notoriety until the early 1980s when Lorna Wing conducted her own research using a translation of Asperger’s work (Wing, 1985). She believed his term “autistic psychopathy” sounded too negative, and suggested that a more pleasant alternative would be “Asperger syndrome.” As a result, one of the disorders at the higher-functioning end of the spectrum bears his name (Cumine, Leach, & Stevenson, 1998). It was Wing who created the term *autism spectrum* to define conditions that fit Kanner’s description of childhood autism. These conditions are more or less pronounced in the essential characteristics of autism: impaired social interaction, impaired communication, and rigid thought processes (O’Connor & Kirk, 2008; Wing, 1988; Wing 1997).

Autism did not become a diagnostic classification until 1980, in the *Diagnostic and Statistics Manual*, Third Edition (*DSM-III*) (APA, 1980; Witwer & LeCavalier, 2008). The term used initially to describe the disorder was *infantile autism*, but the revised edition of the *DSM-III* changed the term to “autistic disorder” (APA, 1987). In 1994, the *DSM-IV* created the category of Pervasive Developmental Disorders (PDD) to describe the variety of conditions along the autism spectrum. This category included autistic disorder, Asperger’s disorder, Rett’s disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) (APA, 1994).

### **Diagnostic Changes to DSM-5 and Implications for Education**

In 2013, the American Psychiatric Association published the *DSM-5* (APA, 2013), the first revision to the *Diagnostics and Statistics Manual* since 2000. The *DSM-5* made significant revisions to the diagnosis of autism, now officially referring to *Autism Spectrum Disorders* as a continuum along which autism and related conditions fall (Vivanti, Hudry, Trembath, Barbaro, Richdale & Dissanayake, 2013). Rett’s disorder, a condition that primarily affects girls and results in severe intellectual disabilities and a regression in fine motor skills, has been removed as a condition under the umbrella of autism spectrum disorders, and Asperger’s syndrome has been included. This change has caused a great deal of controversy among people who have been diagnosed with Asperger’s disorder. They are concerned that the stigma usually attached to autism will now be forced on them, and that they will lose part of their identity by removing this disorder as a unique classifier (Robison, 2012; Schwartz, 2012).

Another significant change to the *DSM-5* is the combining of the social interaction and communication qualifications into one qualifier. In addition, meeting diagnostic criteria has become more specific. The new standards require that three criteria in the social

interaction/communication category are met, and at least two of the four behaviors must be exhibited. The symptoms also must be present in early childhood, although they may not be fully manifested until the child experiences social demands that “exceed the child’s level of social functioning” (Saulnier & Ventola, 2012, p. 7).

These changes in the *DSM-5* have caused concern among researchers and medical professionals. Mattson, Hattier, and Williams (2012) reported on studies comparing the criteria of the *DSM-IV-TR* and the *DSM-5*. The studies show that 30-45% of those who were diagnosed with ASD under the *DSM-IV-TR* criteria will not meet the *DSM-5* criteria. This potentially is a significant number of people who, because of a lack of diagnosis, will not be eligible for educational support services and insurance coverage, resulting in a much heavier burden being placed on the family to provide for these individuals (Mattson, Hattier, & Williams, 2012). In addition, there is the possibility that the next revision of the ICD will not conform to the *DSM-5*’s new criteria, creating a lack of consensus across nations with regard to research initiatives and support (Vivanti, Hudry, Trembath, Barbaro, Richdale, & Dissanayake, 2012).

One positive change coming out of the *DSM-5* allows for the recognition of symptoms that indicate other disorders (such as Attention Deficit Hyperactivity Disorder) may be present, resulting in comorbid diagnoses. This was not possible under the *DSM-IV* (Vivanti, Hudry, Trembath, Barbaro, Richdale, & Dissanayake, 2012). Table 1 provides a comparison between the *DSM-IV* and the *DSM-5* of the diagnosis of autism spectrum disorders.

Table 1

*Comparison between DSM-IV and DSM-5 Diagnostic Criteria for Autism Spectrum Disorders*

	<i>DSM-IV</i>	<i>DSM-5</i>
Category	Pervasive Developmental Disorder	Autism Spectrum Disorder
Category Subtypes	<ol style="list-style-type: none"> <li>1. Autistic Disorder</li> <li>2. Asperger's Disorder</li> <li>3. Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)</li> <li>4. Rett's Disorder</li> <li>5. Childhood Disintegrative Disorder</li> </ol>	None
Symptom Subcategories	<ol style="list-style-type: none"> <li>1. Impairments in Social Interaction</li> <li>2. Impairments in Communication</li> <li>3. Restricted, Repetitive, and Stereotyped Patterns of Behavior, Interests, and Activities</li> </ol>	<ol style="list-style-type: none"> <li>1. Deficits in Social Communication and Social Interaction</li> <li>2. Restricted, Repetitive Patterns of Behavior Interests, or Activities</li> </ol>
Diagnostic Criteria	<ol style="list-style-type: none"> <li>1. <i>Autistic Disorder</i> = at least six total symptoms across all three subcategories, at least two of which are in social interaction</li> <li>2. <i>Asperger's Disorder</i> = symptoms in social interaction and restricted behaviors, with no delays in the development of language, cognition, or adaptive self-help skills in first three years of life; but not to full criteria for <i>Autistic Disorder</i></li> <li>3. <i>PDD-NOS</i> = social impairments <i>and</i> symptoms in either communication and/or restricted behaviors; but not to full criteria for <i>Autistic Disorder</i></li> </ol>	<ol style="list-style-type: none"> <li>1. <i>ASD</i> = three required criteria in social communication and social interaction <i>and</i> at least two out of four restricted and repetitive patterns of behavior</li> <li>2. Symptoms must be present in early childhood (even if not fully manifested until social demands exceed the child's level of social functioning)</li> </ol>

Note. From Saulnier, C.A. & Ventol, P.E. (2012) *Essentials of Autism Spectrum Disorders: Evaluation and Assessment*. Hoboken, NJ: Wiley. Reprinted with permission (see Appendix G).

## **Prevalence of ASD**

According to the Centers for Disease Control and Prevention (2014), 14.7 per 1,000 (one in 68) 8-year olds in the United States fell somewhere on the autism spectrum in 2010. This makes autism disorders the most common developmental disability diagnosed in children (Morrier, Hess, & Heflin, 2008). According to the U. S. Department of Education (2003), autism spectrum disorders are the fastest growing developmental disability. At the 2008 annual conference for the Association for Higher Education and Disability (AHEAD), Jane Thierfeld Brown reported a nationwide increase of 870% in diagnoses of ASD between 1993-2003 (Thierfeld Brown, 2008). Recent debate over the increase in autism spectrum disorder diagnoses centers on two possibilities: an actual increase in the incidence of autism disorders, or an increase in awareness of the disorder by parents and the medical profession (Eaves & Ho, 2008; Kopra, von Wendt, Nieminen-von Wendt, & Paavonen, 2008). Regardless, the increased presence of students on the autism spectrum in institutions of higher education is a concern to the professionals, including faculty, who must guide this group of students in their quest for education and training at the postsecondary level (McKeon, Alpern, & Zager, 2013).

Several studies report that ASD are more prevalent in males than in females (Assouline, Nicpon, & Doobay, 2009; Cumine, Leach, & Stevenson, 1998; Kopra, von Wendt, Nieminen-von Wendt, & Paavonen, 2008). In addition, ASD are found across all cultures, ethnicities, and socioeconomic levels. Children from African-American and Asian/Pacific Island lineage are diagnosed with ASD at a rate approximately two times that of children from American Indian, Native Alaskan, or Latino backgrounds. Prevalence among Caucasian students is highest by far of all racial and ethnic groups (Morrier, Hess, & Heflin, 2008).

## **Causes of Autism Spectrum Disorders**

There are a number of theories as to the causes of disorders along the autism spectrum. In their study attempting to define autism subgroups, Ingram, Takahashi, and Miles (2007) reported that studies of families with twins suggest there is a strong genetic component. Research by McAlonan et al. (2008) focused on abnormal gray matter in the regions of the brain that are thought to be important for socialization and executive functioning skills. No one single cause results in ASD, according to Cumine, Leach, and Stevenson (1998). Instead, a series of triggers occurring at specific points in the development of the child is likely the reason. Differences in social behavior are typically observed prior to the onset of other autistic behaviors (O'Connor & Kirk, 2008). Among the more current popular explanations is a link between autism and early childhood immunizations, although this assertion has been repudiated by the American Medical Association (Price et al., 2010) and was recently refuted in the *British Medical Journal* (Godlee, Smith, & Markovitch, 2011). Other possible causes include a decrease in certain chemicals within the body, and an increase in brain size and head circumference in the first two years of life (Allen, Robins, & Decker, 2008). In keeping with the movement toward the social model of disability current thinking looks at autism as a unique type of neurodiversity rather than as a deficit (Robertson & Ne'eman, 2008).

### **Statement of the Problem**

While a great deal of research has been devoted to the transition of students with disabilities from high school to postsecondary education (Babbitt & White, 2002; Brinckerhoff, 1996; Levinson & Ohler, 1998; Mull, Sitlington, & Alper, 2001; Rothstein, 2003; Williams, 1998), very little research has focused specifically on students with ASD. Even less is known

about the involvement and perceptions of parents of autistic students in assisting with the transition to higher education (L. Klinger, personal communication, October 26, 2010).

Working from the starting point of social and communication deficits that are common to most people with autistic disorders, the existing research does not take the next step to find out what the parents' experiences have been. Instead, the research relies on data that typically comes to the conclusion that, although college is perhaps an appropriate next step for students with ASD, the deficits will prove to be a big hindrance to the success of these students at the postsecondary level (Camarena & Sarigiani, 2009).

Because the deficits in social skills and communication impact these students all through their school years, the solution that should be obvious is to begin preparing students with autism spectrum disorders in middle school and high school for what to expect when they transition to college (Wolf & Thierfeld Brown, 2008). Skills that other students figure out intuitively must be taught explicitly to students on the spectrum, but when and how and by whom these skills are taught seem to be questions that no one wants to assume responsibility for answering, with the possible exception of the parents of these students (Ivey, 2004).

### **Purpose of the Study**

Given the relative lack of instruction provided to students with ASD on how to navigate the qualitative elements of the college experience, this study focused on the role of parents in bridging the gap between high school and postsecondary education. Using a qualitative approach, the narratives of parents of college students with ASD were collected. The purpose of these narratives was to provide in-depth descriptions of the parents' experiences with assisting their sons or daughters in their transition from high school to the postsecondary education environment.

Structured in-depth interviews were conducted with parents, focusing on the skills preparation and supports they provided to the students to help make for a smoother transition from K-12 to higher education, where expectations and roles are qualitatively different in relation to students, instructors, and disability service providers. By putting together these pieces of the puzzle, this study has provided better insight into the transition process from the perspective of the parents.

The results of the study may better inform other parents and higher education personnel who have been, or are currently involved with, students with ASD. Armed with important information about the transition experiences of these students and their families, these support persons may be able to provide more substantial transition training for students with ASD who hope to attend college in the future.

### **Research Questions**

This study included the following research questions:

1. What training or advice was provided to parents of students with ASD to make them aware of postsecondary education options for their child;
2. What information did postsecondary institutions provide to these parents to enable them to prepare those students to have a smoother transition to postsecondary education;
4. To what degree did the parents assist with preparing the student for the transition to postsecondary education; and
5. From the parents' perspective, what issues could have been prevented or lessened if adequate information had been provided by the high school or postsecondary professionals?

### **Importance of the Study**

Previous research on college-bound students with ASD is scarce, particularly when told from the perspective of the parents, who are the primary support system for these students. A study conducted by Morrison, Sansosti, and Hadley (2009), although focused on parent perceptions, only examined support services and accommodations at the college level. It did not address the barriers to transition that occur beginning in the high school setting. This study, therefore, has no other research beside the observations and experiences of the researcher to point to the need for its implementation. Because there is very limited research that addresses the transition process from the perspective of the parents of students with ASD, the proposed study could be an important addition to the small body of research that already exists on students with disabilities and the role their parents play in the process of transition from high school to postsecondary education.

Related to this, the K-12 experiences of the parents and students may impact the level of comfort with the transition process. Whether the child was educated in the public education system, or a private school, or was homeschooled may have direct impact on the transition process and the parents' satisfaction with it. The demographics collected in this study may shed some light on whether the type of educational programming in which the student participates has any relationship to the parents' knowledge of the transition process.

### **Scope of the Study**

The viewpoints of educators within the K-12 system, whether public or private, are not under consideration in this study. In addition, postsecondary disability service providers were not asked to participate. While their personal experiences of the transition process may add another viewpoint to the research, this study focused solely on parents' viewpoints because the parents

are under no legal mandates to provide services or accommodation to their children. Parents, because of their long-standing involvement with their children's education, are natural subjects for a study such as this. Educators, because of legal mandates (IDEA, 1997; Section 504, 1973; ADA, 2008), may present a story that is directed by the language of the law rather than of their own personal experiences.

The importance of viewing disability through a specific lens cannot be overlooked in conducting this research study. In her article *Including All Our Lives: Renewing the Social Model of Disability* (1996), Liz Crow has forced us to look at disability through a social model, whereby disability is viewed as a problem created by a society that has difficulty accepting the "otherness" of a person who is different. As a result, society creates barriers to full inclusion for these persons. Because services for students with disabilities at all levels of education are typically provided after a specific medical or psychological diagnosis has been obtained, educational systems frequently promote the medical model of disability: because a student has received this medical diagnosis, he or she is therefore impaired and is able to receive services that will assist with overcoming the disabling condition (Crow, 1996). Therefore, the medical model is presented as the defining lens through which this study was conducted.

### **Definition of Terms**

Attention Deficit/Hyperactivity Disorder (ADHD): a neurological condition characterized by an inability to focus on tasks for extended periods of time. Characteristics may include daydreaming, hyperactivity, inattentiveness, or a combination of these. The behaviors must be outside the normal range of similar behaviors of children the same age

Autism: a neurological condition characterized by impaired social interaction, communication, repetitive behaviors, delayed motor skills, inflexibility

Autism Spectrum Disorders (ASD): any of the several neurological conditions that are classified under the category of Pervasive Developmental Disorders in the *Diagnostic and Statistics Manual (DSM)*. Conditions along the autism spectrum can range from very severely impaired to mildly impaired

Co-morbid: the existence of two or more potentially disabling conditions at the same time in one person. For example, a person could have a learning disability and a physical disability simultaneously

*Diagnostic and Statistics Manual (DSM)*: published by the American Psychiatric Association, the *DSM* provides a system of classifying various medical and psychological disorders so that a common language and standardized system of criteria is available to practitioners and researchers

Emerging adulthood: a theory, proposed by Arnett, to describe the period of growth and development between the late teens and early twenties. During this period, persons are not quite ready to let go of their childhood and not yet ready to assume the responsibilities associated with full adulthood

Executive functioning: a term used to describe the ability of a person to carry out the necessary cognitive skills for daily living. These skills include problem solving, planning, flexibility, accepting responsibility for one's actions, and paying attention to detail

Persistence: the conscious decision of a student to stay in college to complete a degree or certificate program

Self-determination: the degree to which a person is ready and able to assume responsibility for goal setting, achievement, and failures. Self-determination includes such characteristics as assertiveness, independence, and self-advocacy

Theory of Mind (ToM): proposed by Baron-Cohen, a theory that persons with ASD are not able to assess other people's feelings or emotions because people with ASD do not recognize that other people may feel differently about a situation or event. People with ASD assume that other people share the same feelings they do

Transition: in this study, the process of a student with ASD moving from a high school educational environment to a college or university environment

Transition plan: as required under IDEA, a set of goals and objectives that are determined by parents, professionals, and the high school student. The goals and objectives must be designed to successfully transition the student to whatever post-high school placement is deemed appropriate

Typical student: in this study, the term will be used to describe nondisabled students.

### **Limitations and Delimitations**

The limitations of this study may have had an impact on the number of parents who made themselves available for interviews. The support group for students with autism, from whom the parent participants were invited, has only 31 members at the time the study was conducted. In addition, not all parents live in the local area, so the possibility existed that I might not be able to arrange for a time and place to conduct the interview. Some of the students in the support group did not want to have their parents participate. This also had an impact on the number of available participants.

Although a survey or questionnaire would have afforded a quick turn-around time for the data, I chose to conduct interviews using a structured protocol. This is the primary limitation of the study. I believe the parents were more forthcoming about their experiences when they were

able to share their stories in the interviews and allow me to question deeper, if needed, to draw out more information that was beneficial to the study.

I interviewed the parents of students with ASD who participate in the autism support group at Downtown University, a four-year, comprehensive urban state university in the southeastern United States. This delimitation created a boundary that excluded students at other institutions, including community colleges, private, and for-profit institutions. All of these institution types likely have students with ASD enrolled, but their experiences may be different because of the college or university itself.

While other students with ASD may be enrolled at the institution where the study was conducted, only the parents of those students who have chosen to participate in the ASD support program were asked to provide information for this study. The students' participation in the support program may be parent-motivated, or the students themselves may have chosen to be involved. In either case, students who are participating in the support program may be more motivated to succeed in college, which may be a reflection of the parents' knowledge of the transition process.

Finally, the fee charged by the ASD program at Downtown University may eliminate some students from participation in the program. While financial support is available through the state rehabilitation services program or with federal financial aid assistance to students, the additional cost may be prohibitive to families who are not able to incur that expense. Although the program's website (2014) indicates that financial assistance is available or that fees potentially can be waived in hardship cases, families may view the up-front cost as a barrier to participation for their children with ASD.

## Summary

This introductory chapter has provided information on the history of inclusion of students with disabilities in the existing K-12 educational system. Three landmark legal cases, *Wyatt v. Stickney*, *P.A.R. C. v. Pennsylvania*, and *Mills v. Board of Education of Washington, D. C.*, were described as key turning points for equal access to education for people with disabilities. IDEA (2008) brought changes to elementary and secondary education programs, providing the opportunity for students with disabilities to be educated alongside their nondisabled peers. Federal legislation that expanded the civil rights of people with disabilities was described as broadening the scope of earlier legislation. These new mandates, Section 504 (1973) and the ADA (2008), were far-reaching in that federal, state, and local agencies, both public and private, were now required to provide equal access to persons with disabilities in employment, education beyond the K-12 system, and places of public access.

Autism Spectrum disorders were defined and identified according to criteria in the *DSM*. Prevalence of the condition and possible causes were presented. There is currently no consensus on the definitive cause of autism, but several possibilities continue to be researched.

After setting forth the problem statement and research questions, the purpose of the study, as well as limitations and delimitations were stated. A list of terms used throughout the study was provided as an opportunity to define certain key words. Finally, the scope of the study has been described.

In Chapter II, relevant literature on parent involvement in transition planning will be presented. The literature review is divided into three topics: parents of typical students, parents of students with general disabilities, and parents of students with ASD. In separating the literature in this manner, the reader will better be able to understand the process of growth and

development that each student undergoes as he or she transitions into higher education. In addition, this type of discussion will better delineate some of the similarities and differences in the level and type of involvement that parents have in supporting their children through the transition process.

## CHAPTER II:

### REVIEW OF LITERATURE

#### **Transition to Postsecondary Education for Typical Students**

In years past, a high school diploma was the key to becoming a successful citizen of the world. High school graduates earned more than non-graduates, and their chances for improved self-sufficiency were enhanced as well (Pratt, 2000). Today, these benefits come as a result of a college degree. Earning at least a bachelor's degree increases the graduate's long-term cognitive, social, and economic rewards, but it also allows the graduate to pass these traits down to future generations. A college degree, therefore, can increase the quality of life for the graduate, his family, and the community in which he lives (Kuh, Cruce, Shoup, Kinzie, & Gonyea, 2008).

#### **Adjustments to the College Environment**

In his seminal work on student involvement, Astin (1993) theorized that student persistence in higher education is improved when a student becomes involved and engaged in activities and programs that help connect him to the college. As a follow-up to Astin's work, Braxton, Hirschy, and McClendon (2004) proposed that student psychosocial engagement is directly related to the level of social integration with college life. More than 40 years ago, Stern (1966) coined the phrase *freshman myth* to denote the high expectations that students have prior to beginning their college experience. In his research, Stern (1966) found that these expectations were much more positive than the actual experiences of students who attended college. In fact,

Stern (1966) determined that the idealized image of higher education that students had prior to enrollment showed very little resemblance to any actual college.

The transition from late adolescence to adulthood is an important developmental stage. For many young adults, this transition means that students must deal with multiple adjustments at the same time. These adjustments may include changes in their living arrangements, a change to their academic environment, and the development of social networks while learning how to exercise greater independence and responsibility in their personal and academic lives (Pittman & Richmond, 2008). The most difficult period of adjustment for newly transitioning freshmen is the first two to six weeks. Early encounters with the institution and with others on the campus have significant influences on the student's ability to become involved in the social world of college, such as establishing meaningful friendships, and achieving academic excellence Tinto (1993) first reported that social adjustment is the more critical factor in the early stages of the freshman year. Students who were more likely to complete their degree had established friendships, were adjusting well to college life, and were satisfied with their social lives in the first few weeks of the freshman year (Tinto, 1993).

### **Development of Coping Strategies**

The transition to college comes at a time when young people are struggling to find themselves, to establish their independence, and to move forward with developing their beliefs and values. At the same time, they continue to need support and connection to something or someone that is familiar to them. For these reasons, the first year of college is very important, since students are learning how to integrate these needs into the college environment (Yazedjian, Toews, Sevin, & Purswell, 2008). Transitioning to college includes not only academic, but also social integration, yet students who do well at establishing social connections still have difficulty

making the transition from high school to college. They do not know what will be expected of them once they begin college. Their strategies must be adapted to meet the actual demands of college life, which include making connections to the college itself and to others. Conducting interviews with students, Yazedjian et al. (2008) found students felt stressed about making those connections because they were at a point in their lives when they were developing an entirely new perspective on relationships and social networking. Students participating in the study also indicated their personal development and transitioning into more adult roles was important to their college success (Yazedjian et al., 2008).

The transition from high school to postsecondary education can be very stressful for students who are leaving home for the first time, who are dealing with new social and emotional demands and more strenuous academic challenges (Glennon, 2001). At the same time that college students are dealing with these new circumstances in their lives, they are also in the process of forming a clearer, more stable sense of identity. Students who have established a well-grounded sense of purpose and self-identity are able to cope more effectively with and to adapt to the demands and challenges to daily life (Berzonsky & Kuk, 2000). By investigating the identity types of students, these authors found that students who are more committed and goal-oriented have the adaptive skills necessary to form and maintain solid social relationships.

### **Developing a Sense of Belonging**

While many students make these transitions easily, there are others who experience emotional distress. One-third of all university students leave higher education in their first year because of their inability to adjust to these situations (Pittman & Richmond, 2007). Pittman and Richmond (2008) found that those who do not leave in the first year of college had a stronger sense of belonging to the college and higher quality friendships compared to those students who

left. The sense of belonging encompasses more than just establishing relationships with individuals. It is a more global feeling of being connected to a larger community. The rate of college departures has not changed significantly in the past 100 years, according to Kelly, Kendrick, Newgent, and Lucas (2007). One of the most consistent findings in all of the studies that have been conducted on student departure is that students leave college because they believe they do not fit in, and because college is not a good match for their needs. Research conducted by Kelly, Kendrick, Newgent, and Lucas (2007) demonstrated that socialization and personal adjustment are dominant forces in the decision to drop out, and that peers have a greater impact on that decision than do faculty members. In addition, the research showed that students who are involved in activities tend to have more positive views of themselves and the college they attend. Those who have a strong sense of belonging tend to have lower dropout rates, higher grade point averages, and better social-emotional functioning (Pittman & Richmond, 2008).

### **Developing Self-Actualization Skills**

The primary focus of college is on intellectual development; however, the development of personal and social needs, changes in attitudes, and moral reasoning are also purposes (Pascarella & Terenzini, 2008). Students develop these concepts through their interactions with their environment, particularly with others who are significant to them. Self-esteem develops as the student sees himself as capable and worthy. Over time, these concepts tend to become more positive (Astin, 1993). Pascarella and Terenzini (2008) conducted research on student autonomy and independence, locus of control, and interpersonal relations. For students who persisted to graduation, the long-term effects of college were somewhat positive, particularly with regard to moral reasoning. For students who enter college with a good measure of fear or of uncertainty,

those feelings diminish as the student makes progress toward graduation (Pascarella & Terenzini, 2008).

In her series of interviews with students at various points during their first year in college, Keup (2007) reported two major topics that came forward: academic life and involvement in nonacademic activities. In general, these students felt that the most important objectives prior to the beginning of the year were personal growth and development, initiating new friendships, setting personal and professional goals, and establishing independence. Students also expressed concern about facing new social situations and people who were unlike themselves. As the first year progressed, students began to sever ties with former high school friends or saw those relationships in a different light. Independence translated to assuming responsibility and making decisions that were right for them. In follow-up interviews, Keup (2007) found that students believed having the support of a close network of friends and making progress toward the students' own goals of personal development were the most important facets of well-being during their first year.

In her study of students and their levels of confidence with social situations at college, particularly dating, LeSure-Lester (2001) found that establishing and maintaining interpersonal relationships are stressful events in the early stages of college life, and those students who felt confident about their dating skills were less anxious and more assertive in other social situations. Further, these results were similar across the diverse ethnic and racial backgrounds of the students who participated in the study. Students who are unable to make connections to the college community, or who do not feel a sense of belonging likely will experience increased emotional distress, and the quality of students' relationships with peers appears to be more relevant than college belonging (Johnson et al., 2007).

## **Taking on Adult Roles and Responsibilities**

Students who matriculate to college immediately after high school vary in their perceptions of what is required to be an adult, even though they are legally old enough to be considered adults. Only one-quarter of first-year traditional students consider themselves adults, and many of them are ambivalent toward their adult status (Nelson et al., 2007). Arnett (2000) called this period of the late teens and early twenties as *emerging adulthood*. During this period, students begin to accept responsibility for their own behavior and make independent decisions, yet they are not prepared to take on the full responsibilities that are associated with adulthood (Arnett, 2000). Many of these emerging adults go to college because there was nothing better to do, or because all their friends were going to college, or because attending college was the expected “next step” after completing high school (Arnett, 2004). They develop their own personal identities, experience feelings of instability, focus on themselves, feel somewhere between adolescence and adulthood, and study all the possibilities available to them (Nelson et al., 2007). To make the transition to adulthood, these students need to learn to be self-reliant, to form mature relationships, and to follow societal norms. Research done by Nelson et al. (2007) has indicated that students who are learning to achieve their own identity give a great deal of importance to independence and relationship formation.

Roe Clark (2005) defined success for first-year college students in terms of making the transition from high school to college. Her research focused on how students negotiate that transition – their perceptions, their experiences, and their ability to manage the various influences on them as they move into college. Her research findings indicate four themes that

encompass the students' challenges: "overcoming an obstacle, seizing an opportunity, adapting to change, or pursuing a goal" (p. 302). To overcome obstacles, students must learn how to self-nurture as well as give or receive nurturing from others. Students also must develop strategies for overcoming undesirable emotions and uncomfortable, negative feelings. Roe Clark (2005) found that students worried about their emotional distress and whether it would hinder their success not only in the classroom but also in their personal relationships. The major factor in students' meeting with success was their ability to devise multiple strategies to deal with the changes in their first year of college (Roe Clark, 2005).

Freshman students who have secure attachments to family, friends, and the university should experience higher levels of social competence and less stress during the transition to higher education (Taub, 2008). Most freshmen still experience some degree of loneliness and isolation, and they do not have the necessary social skills to develop close interpersonal relationships. Wei, Russell, and Zakalik (2005) researched two areas of social competence: social self-efficacy and comfort with self-disclosure. In this context, social self-efficacy deals with the individual's belief that he is capable of initiating contact with others and establishing new friendships. Self-disclosure is the ability of the person to talk about socially relevant personal information in order to let others get to know the person better. Research conducted by Wei, Russell, and Zakalik (2005) has shown that students who lack self-efficacy have higher levels of social anxiety, loneliness, and depression. In addition, students who are comfortable with self-disclosure have less anxiety, as well as decreased feelings of loneliness and depression. The interventions these students may need to help with the transition to higher education may be significantly different than those of the average college student.

Although progress has been made on identifying students who will struggle in their college courses, as well as those who will leave college early, there is still much research that needs to be done on the role that perceptions and expectations play in college success and persistence (Hicks, 2005). The challenges that students encounter when making the transition from high school to college are often impacted by the perceptions that students have prior to their enrollment in college programs. Hicks (2005) conducted research with at-risk and low-income minority students and found that their adjustment to college and persistence are enhanced by participation in pre-college summer programs that provide structured academic components, such as advising, tutoring, and study groups. Students who participate in these programs meet with higher levels of academic, personal, and social success than do other first-time freshmen.

Students who are able to succeed at establishing independence and managing their new freedom are generally able to establish new relationships. Women tend to depend on relationship-building to help with the adjustment to college (Enochs & Roland, 2006). Using attachment theory to explain the importance of healthy social and emotional relationships, Enochs and Roland (2006) described students who have an easier time making the transition from high school to postsecondary education. Social adjustment to the college campus is linked to student involvement and is a major factor in the student's overall adjustment. Enochs and Roland (2006) looked at the adjustment to college in female students because their needs are different than those of their male counterparts. Women have more opportunities for involvement available to them than ever before, but many women are still tied to the traditional roles that women play in society and, therefore, do not seek leadership positions. Women are more likely to seek assistance with issues of social and emotional distress, and are also more likely to show outward signs of attempting suicide than males. Depression and difficulty with adjustment are

also greater in female students. Women tend to express their emotions more openly during the transition to college, and their levels of self-esteem and confidence are impacted by their perceptions of acceptance and belonging to the college community.

A college education is no longer presumed to be a rite of passage for wealthy White students. For many students from all cultural, racial, and ethnic backgrounds, it is a requirement to enable them to move into the world of work or to pursue advanced degrees. The idea of campus community has been discussed throughout the literature on student involvement, retention, and persistence. Lloyd-Jones (1989) gave this definition of community: “the condition of community is the binding together of individuals toward a common cause or experience (p. iv).” The student’s sense of community impacts three areas of a student’s college life: students’ feelings that someone cares about them and they are valued as individuals, a sense of loneliness that negatively impacts the students’ sense of community, and a quality of social life that enhances the sense of community (Lloyd-Jones, 1989).

In spite of the challenges that students face when making the transition from high school to college, they expect college life to offer them many opportunities for growth in the personal, social, and academic realms. The realities that often impact them once they are on campus may be far different than their expectations. Not only are they forced to deal with adult responsibilities, but they also must learn to cope with an environment that is considerably different from the one they experienced in high school (Pancer, Hunsberger, Pratt, & Alisat, 2000). As a result, many students have difficulty adjusting to life on a college campus. First-year students report moderate to high levels of loneliness and homesickness, and many of them let their academics slide as they seek ways to alleviate these negative emotions. Turning to alcohol and drugs is not uncommon, while developing health and emotional issues, some of which lead

to students leaving college before completing the first year. Pancer et al. (2000) found that students who strongly prescribe to the “freshman myth” that college will be an ideal growth experience are more likely to have negative experiences during their first year.

### **Chickering and Reisser’s Student Development Theory**

One of the landmark theories of college student development was proposed by Chickering and Reisser (1993). This theory presents seven vectors that influence the development of a student’s individual identity. Chickering called the seven areas *vectors* “because each seems to have direction and magnitude – even though the direction may be expressed more appropriately by a spiral or by steps than by a straight line” (Chickering, 1969, p. 8). One of the prominent psychosocial theories of student development, Chickering and Reisser believe that providing the tools for students to progress along the seven vectors will create “educationally powerful environments” (Chickering & Reisser, 1993, p. 454-55).

Chickering’s model of student development was initially meant to provide guidance to professionals in the student affairs profession who were directly involved with assisting students to find their identity (Taub, 2008). Students, regardless of whether or not a disability is present, go through a process of developing their own identity, and the process may prove to be difficult without trained professionals who can lead the students through each vector to find clarity and understanding on the other side. Taub (2008) feels that parents who are very deeply involved with their children’s lives inhibit the child’s ability to acquire those aspects of development described by Evans, Forney, and Guido-DiBrito (1998). On the other hand, parents who give their children opportunities to solve problems on their own build the child’s confidence and self-worth (Taub, 2008).

In their study of parent perceptions of the needs and support for college-going students with Asperger's Syndrome (AS), Morrison, Sansosti, and Hadley (2009) described Chickering's and Reisser's theory as the major "framework for understanding student development as it relates to successful development of skills and (it) provides a framework for how supports should be aligned for college-bound students with AS" (p. 79). In particular their study references the first three vectors of Chickering's and Reisser's theory as critical for developing "competence, self-advocacy, and autonomy" (Morrison, Sansosti, & Hadley, 2009, p. 79). A brief description of these three vectors is provided for further understanding of the framework that informs this study.

### **Developing Competence**

Competence in three separate areas is necessary if the student is to develop the ability to deal with a variety of situations that may come his way: intellectual competence, physical competence, and interpersonal competence (Chickering, 1969). Intellectual competence is the ability to acquire knowledge and skill in a specific subject area, while physical competence focuses on activities that lead to wellness and an appreciation for artistic activities. A student who has interpersonal competence is able to communicate and work together effectively and can demonstrate leadership (Evans, Forney, & Guido-DiBrito, 1998). For students with ASD, this vector is reflected in the ability to speak appropriately in class and to participate in group activities (Morrison, Sansosti, & Hadley, 2009).

### **Managing Emotions**

Students who are passing through this vector develop the ability to identify and acknowledge their emotions, and to express and control them in an appropriate manner. Chickering's earlier work (1969) focused on aggressive behavior and sexual desires, but his

more recent writing (1993) includes a wider range of both negative and positive emotions that are often experienced by college students, such as depression, anxiety, guilt, optimism, and caring (Evans, Forney, & Guido-DiBrito, 1998). Students with ASD often have difficulty expressing their emotions because they do not know how to verbalize what they are feeling. While they may have an extensive vocabulary, they may not have the ability to put together the words in a way that expresses what they are feeling. Students with ASD also have difficulty responding to emotions in others because they cannot recognize that others may be feeling differently than they do (Graetz & Spampinato, 2008).

### **Moving Through Autonomy toward Interdependence**

This vector provides the foundation for college students to become less and less dependent on others, especially parents, for reassurance and approval (Chickering & Reisser, 1993). As they move through this vector, students develop problem-solving skills and recognize that they are connected with others in a variety of different ways (Evans, Forney, & Guido-DiBrito, 1998). In this vector, students learn to trust in their own abilities to reason and make decisions (Morrison, Sansosti, & Hadley, 2009). Typical students develop these skills by participating in a multitude of extra-curricular activities where they learn to solve problems and work interdependently with co-workers or team members. Students with ASD are more likely to be involved in activities that are focused on the students' individual interests rather than learning how to interact with others (Hurewitz & Berger, 2008).

These three vectors provide the framework for aligning support services for students with ASD who are making the transition from high school to college. "Specifically, Chickering's first three vectors of college student development describe the movement of the entering undergraduate toward greater competence, self-advocacy, and autonomy" (Morrison, Sansosti, &

Hadley, 2009, p. 79). The student with ASD needs assistance working through the challenges and roadblocks that may fall in his path, and positive support, particularly from parents, can provide the foundation for success in college if the parents are aware of what kind of and how much support needs to be provided (Morrison, Sansosti, & Hadley, 2009).

Looking ahead to future research, Pascarella (2006) suggested that colleges expand their ideas of diversity and encourage students to interact with others who are different from their own culture and background to gain new perspectives, values, and ideas. Challenging the assumptions that students bring with them to college enhances the development and growth of students as they progress through college. Pascarella (2006) also suggested that students who have not been studied up to this point likely bring their own development models and challenges to college. Identifying the impact of these unique challenges could be a major contribution to better understanding of the college experience for all students.

### **Parent Involvement and Perceptions of College Readiness for Typical Students**

Although a study conducted by Crosnoe (2001) found that parents were less involved with their children's education the further along in school the children progressed, the research by a number of other authors shows this is not the case (Carney-Hall, 2008; Daniel, Evans, & Scott, 2001; Nelson et al., 2007; Scott & Daniel, 2001; Taub, 2008). Several factors may be influencing this increase in parental involvement, such as changing family structures, changing campus environments, increasing communication through technology use, and marketing higher education (Carney-Hall, 2008). Today's parents have been deeply involved with the lives of their children since birth, and plan to continue that involvement into, and possibly through, the college years (Taub, 2008). Likewise, today's students are "a timid generation of rule followers in an era

that demands bold, new rule makers. They are immature, needy, and tethered to the adults in their lives in a time that requires vision and leadership” (Levine & Dean, 2012, p. 163).

The family support systems of today are very different from those of past generations of college students. Single-parent households have increased over the past twenty years, and the impact of divorce on students can have a detrimental effect on college transition (Daniel, Evans, & Scott, 2001; Levine & Dean, 2012). In some cases, parents of high school and college students have taken in their own parents and are providing care for both older generation parents and younger generation children (Carney-Hall, 2008). Unmarried partners, including same-sex partners; stepparents; grandparents; and adult children living at home create a family environment where decision-making becomes a way for parents to exercise control in the home. This often carries over to the college transition experiences of their teen-aged children. If the parents continue to treat their offspring as children rather than allowing them to develop adult behaviors, the parents enhance their control by being fully involved in the child’s college experience (Daniel, Evans, & Scott, 2001).

### **Effect of Parental Involvement**

Parental involvement in K-12 has been shown to have a positive impact on their children’s education: improved grades, higher self-esteem, more social competence, and aspirations for college (Wartman & Savage, 2008). As the child grows and wants to become more involved with activities outside of the family and the school, often parents are the ones who provide shuttle service and organization to the weekly soccer matches, piano lessons, or school functions. Federal law strongly encourages parental involvement to improve the performance of schools, but these behaviors do not translate well to higher education. What may be seen as supportive actions in K-12 could translate to intrusive behaviors at the postsecondary level

(Taub, 2008). Parents do not relinquish their control to the institution as readily as they once did, and institutions have to pay attention to the parent-student relationship to maintain accuracy and consistency in the messages that are sent (Mullendore, Banahan, & Ramsey, 2005; Scott & Daniel, 2001).

Most colleges encourage parent involvement in the admissions process. By the time the student is ready to make the transition to higher education, the parents have already been on campus tours, participated in orientation sessions, been involved in helping make the decision about which institution to attend, and completing the necessary applications and paperwork necessary for admission (Carney-Hall, 2008). The federal financial aid process actually requires parent involvement: students under the age of 24 must have access to their parents' income information from the previous tax year to complete the application for financial aid. Once the student is admitted, parents pay out a significant amount of money to the school in the form of tuition and other fees, and therefore feel entitled to full access to their child and to the academic and social activities which present themselves (Lange & Stone, 2001; Scott & Daniel, 2001).

One of the primary reasons for parent involvement is to ensure the safety of their children once they have transitioned to higher education. Tragic campus events such as those at Virginia Tech in 2007 and Northern Illinois in 2008 point out the worst possible scenarios that colleges and universities can deal with, but other campus violence, such as date rape, robbery, hate crimes, and bullying have been covered by the media. As a result, parents want assurances from the institution that the campus is safe and that their child will be protected from this kind of brutality (Carney-Hall, 2008; Levine & Dean, 2012; Merriman, 2008; Wartman & Savage, 2008). To help their child make careful decisions, parents should not focus on making decisions

for their child. Instead, parents should teach the skills needed so the child can make mature, informed decisions about their transition to higher education (Nelson et al., 2007).

From the early colonial colleges to the 1960s and 1970s, colleges served in the role of parents. With students' demands for independence and changing federal legislation preventing colleges from sharing information with parents, the role of the institution in overseeing the lives of its students changed significantly (Levine & Dean, 2012; Lowery, 2005; Wartman & Savage, 2008). Because the expectations and understanding of parents may not be in line with those of the institutions, parents must be educated along with their children.

### **Relationship between Parents and Today's Typical College Student**

Parents have high expectations but many of them still see their college-age student as a child who needs their guidance and support (Scott & Daniel, 2001). Student development theories, such as Chickering's seven vectors, point to the need for students to progress from dependency on parents and others to developing skills and competence for making decisions on their own, to developing a sense of self and personal identity (Chickering & Reisser, 1993). Today's college parents, have earned the nicknames *helicopter parents*, *lawn mowers*, and *stealth bombers* because of their tendency to hover over their children, running over anyone who impedes their children's progress, and making decisions for them. These behaviors do not allow their child to pass through the necessary stages of development and therefore hinder the child's growth as an adult (Levine & Dean, 2012; Somers & Settle, 2010; Taub, 2008). Colleges that recognize the need to educate parents about these critical stages of development in their children allow parents to be involved while at the same time helping their children develop a sense of self. In addition, this training provides a common language that parents and school personnel can use to communicate (Taub, 2008).

Today's college-age students and their parents communicate very often, and to the students this is perfectly normal. Their parents have been involved in every aspect of their lives up to this point, so keeping parents informed of events that are impacting their lives is nothing unusual for these students (Wartman & Savage, 2008). The multiple technologies available for communication – E-mail, cell phones, texting, instant messaging, social networks – mean there are more opportunities for chatting or for discussing more serious issues. Students initiate many of the conversations, ranging in topic from personal finances, health issues, career development, health and sexuality, and alcohol use (Carney-Hall, 2008). Institutions must pay attention to these close relationships and develop policies and procedures that send consistent messages to both the parents and the students. By taking a proactive approach to parent involvement, colleges can find areas to collaborate with parents (Mullendore, Banahan, & Ramsey, 2005). This collaboration could include the formation of parent support groups, the creation of parent newsletters, even the establishment of offices devoted solely to activities that reflect parent involvement (Scott & Daniel, 2001).

In the current environment of consumerism in higher education, colleges and universities have developed marketing packages that are enticing to the students and affirming to the parents. In a world where quality customer service is guaranteed and technicians are available to deal with problems 24 hours a day, parents feel entitled to have significant input in their child's education (Daniel, Evans, & Scott, 2001). As parents pay more and more for their child's education, this feeling of entitlement becomes even stronger (Carney-Hall, 2008). Parent programs design material that is disseminated regularly to keep parents informed of campus activities and issues. Parents are invited to participate in parent groups that help plan activities for students or serve as support for those parents who are having difficulty letting go of their

child. Parent weekends are held to encourage parents to return to campus at prescribed times during the year rather than dropping in at points when students should be more focused on academics (Carney-Hall, 2008; Levine & Dean, 2012; Savage, 2008). These activities designed specifically for parents allow them to be involved in their children's lives without intruding on the college experience (Daniel, Evans, & Scott, 2001).

Parental involvement in their child's transition is often painted as a negative thing, but this is not necessarily the case. If the university sends a consistent message to parents about its core values and expectations, parents will be able to understand the collaboration with the university that is expected of them (Daniel, Evans, & Scott, 2001). Colleges must recognize that students welcome and often initiate communication with their parents, seeing their parents as the most influential people in their lives. If students have a positive attachment to their parents, they are more able to develop self-actualization skills that will lead to a successful transition to and passage through higher education. Students who came to college with a secure foundation that was established early in the home are better able to adjust to college life. This solid beginning leads to academic and social success, along with strong identity development (Wartman & Savage, 2008).

### **Transition to Postsecondary Education for Students with Disabilities**

Students with disabilities are participating in higher education in ever-increasing numbers. Schutz (2002) provided data showing that between 1978 and 1998, the percentage of students with disabilities enrolling in higher education increased from 3% of the incoming freshman class in 1978, to 9.4% of the incoming freshmen in 1998. The National Center for Educational Statistics reported 10.8% of students on college campuses for academic year 2007-08 were disabled (NCES, 2011), while the *Annual Disability Statistics Compendium*

(Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2009) reported that 15.5% of U.S. citizens with disabilities aged 18-34 years were enrolled in college in 2007.

### **Reasons for Underrepresentation of Students with Disabilities in Higher Education**

In spite of the increasing numbers of disabled students enrolled in higher education programs, however, students with disabilities are still underrepresented compared to their nondisabled peers. According to Sitlington (2003), 14-19% of students with disabilities who graduate from high school attend college, while the percentage of nondisabled students is 56%. One reason for this gap is the option for students with disabilities to receive a high school diploma that is not the equivalent of a regular diploma. This diploma option is not recognized by colleges and universities as meeting appropriate admission standards (Sitlington, 2003). A second reason for the preparation gap between students with disabilities and their nondisabled peers enrolled in higher education is the lack of understanding of the difference between special education services that are provided in K-12 compared to disability support services available in higher education (Rothstein, 2003). Yet another reason for this gap is the sheltered, team approach to working with students with disabilities in K-12. In this service model, students are rarely involved in their education planning meetings, leaving decisions to their parents, faculty, and school administrators. When students with disabilities make the transition to postsecondary education, they are met with a process that expects them to take on adult responsibilities such as requesting services and becoming active in initiating accommodation requests (Schutz, 2002).

Students with disabilities experience many of the same adjustment difficulties as do their nondisabled peers when making the transition to college life (Williams, 1998), but having a disability adds an additional layer of difficulty. Transition planning is critical to making this process as smooth as possible. Halpern, Yovanoff, Doren, and Benz (1995) conducted a study to predict participation in higher education by students with disabilities. The six predictors that were determined to be significant were 1) high scores on achievement tests; 2) completion of courses in relevant areas; 3) participation in transition planning; 4) parent satisfaction with student's instruction; 5) student satisfaction with instruction; and 6) parent perception that the student no longer needs support in certain critical skills (Halpern, Yovanoff, Doren, & Benz, 1995). Additional research supports two of these predictors: the student's participation in transition planning and the perception of parents that the student has developed the necessary self-help skills to manage the transition to college (Brinckerhoff, 1996; Brinckerhoff, Shaw, & McGuire, 1992; Broatch, nd; Foley, 2006; Harris & Robertson, 2001; Lehmann, Davies, & Laurin, 2000; Levinson & Ohler, 1998; Mellard & Hazel, 1992; Prentice, 2002; Schutz, 2002; Troiano, 2003; Williams, 1998; Sitlington, 2003). The perception of parents that their child is ready to transition successfully to postsecondary education means the parents are ready to shift their role of protector and advocate to one of mentoring their child through the processes of selecting, applying for, and setting goals for college matriculation (Beale & Ericksen-Radtke, 2001; NJCLD, 1996; NCSET, 2002; Smith, English, & Vasek, 2002).

### **Student Participation in Transition Planning**

One of the key elements in the transition to postsecondary education for students with disabilities is the need for the student to understand the disability that is present and how it will impact the student's social and academic achievement in higher education (Schutz, 2002).

Students with disabilities tend to be passive learners who do not participate in outside activities that would increase socialization skills or engage in tasks that would promote higher self-esteem, primarily because they do not understand their disabilities (Levinson & Ohler, 1998). They see themselves through their weaknesses rather than through their strengths, and they have not been provided with the necessary skills instruction that will allow them to generalize their strengths across various academic and extra-curricular settings (Sitlington, 2003).

Postsecondary environments typically require a higher level of individual accountability and social responsibility, far different than the comfortable, routine, supportive setting that secondary education provides (Mellard & Hazel, 1992). Students with disabilities may be overwhelmed by the transition process if they encounter problems that they have not had to deal with previously. While their nondisabled peers may have encountered these problems at a much earlier stage, students with disabilities have not been taught the competencies that would help them fit into the postsecondary environment (Mellard & Hazel, 1992). The safeguards built into IDEA (2004) provide the high school-aged disabled student with a supportive network consisting of parents, teachers, counselors, and other school personnel. Once the student matriculates to college, the legal basis for this support goes away, and the student is left alone to find those personnel at the postsecondary level who will serve as his support network (Scott, 1991).

### **Steps to Improve Opportunities for Success in Postsecondary Education**

Learning to take responsibility for their disability and understanding their individual needs create an easier path for students to transition to postsecondary education. Being able to communicate those needs, taking responsibility, and gaining a sense of control over the activities are skills that may be missing in postsecondary students with disabilities if they do not plan for their transition to college (Troiano, 2003). Harris and Robertson (2001) noted that students with

disabilities do not fail because they lack the academic aptitude, but rather because they are not prepared for the postsecondary environment: "...self-determination and assertiveness are the biggest factors related to success or failure for these students" (p. 126).

Wehmeyer (2002) describes *self-determination* as "a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior; understanding one's strengths and limitations, together with a belief of oneself as capable and effective are essential to self-determination" (Wehmeyer, 2002, p.2). Students who have developed self-determination have the skills and attitude necessary to take responsibility over their lives (Wehmeyer, 2002). Students with disabilities who can demonstrate their ability to take responsibility for planning and decision-making, people around them, including parents and teachers, will change their views of the students and what is expected from them (Wehmeyer, 2002).

Students may not be aware of services that are available to them at the postsecondary level (West, Kregel, Getzel, Ming, Ipsen, & Martin, 1993). They also do not understand the differences between high school and college in terms of the kinds of services, options for class scheduling, adjustments to time spent in and out of class, faculty availability, and subject mastery that is required of them at the postsecondary level (Williams, 1998). Most nondisabled students can make these adjustments rather easily, but students with disabilities may become frustrated or experience a feeling of failure (Babbitt & White, 2002). One of the major reasons that students with disabilities are not prepared for what to expect at the postsecondary level is that teachers and counselors in the high schools are not knowledgeable enough to provide the necessary training or to give solid advice to these students (Williams, 1998). Linking students with disabilities to postsecondary service providers is critical to helping make the transition

smoother, but students are not given this information in a timely manner because they are not involved with the transition planning meetings that the high school teachers or counselors are required to hold (Brinckerhoff, Shaw, & McGuire, 1992).

For the student to be able to contribute successfully to transition planning discussions, Brinckerhoff (1996) suggested that transition planning begin when the student moves from middle school to high school. To support this proposition, Brinckerhoff (1996) presented data that show most students with disabilities who drop out of high school do so at the end of the ninth grade year. This time frame mirrors the mandate in IDEA (2004) that requires a transition plan to be developed for the student no later than age 16, but by as early as age 14 if warranted. Brinckerhoff (1996) further suggested that the junior and senior years in high school be structured similarly to the college environment. This change in structure would involve the student being required to take more difficult classes, to have a heavier work load, and to explore postsecondary options based on the student's interests and aptitudes (Brinckerhoff, 1996). A Position Paper by the National Joint Committee on Learning Disabilities (NJCLD, 1996) further supports skills training focused on developing self-esteem, increasing knowledge of the disability, establishing appropriate postsecondary or career goals, developing and using social skills, and becoming familiar with the rights and responsibilities of a student with a disability at the postsecondary level. At this level, the student is expected to adjust to an adult model of service delivery that requires the student to self-identify and request services, thus becoming an active partner in the transition process (Schutz, 2002).

Mellard and Hazel (1992) suggested the creation of a transition curriculum in the high school, providing the necessary socialization, self-advocacy, and educational outcome skills that will enable the student to participate knowledgably in his own transition meetings. This will

allow the student to make suggestions for the appropriate educational steps to take that will lead to a smoother transition to postsecondary education. Students' lack of readiness for college prevents many of them from being successful. Students who participated in a study conducted by Garrison-Wade and Lehmann (2009) reported that a major weakness of the current high school special education system is the lack of preparation for college. Students must be taught to advocate for themselves, to figure out the academic demands of college or university training, and to perform adequately with the different level of support that is available at the postsecondary level (Durlak, Rose, & Bursuck, 1994; Sitlington, 2003). Another aspect of transition training should be vocational assessment and counseling. Components of this aspect should include exploring career activities that match the student's abilities and interests, administering career inventories, and shadowing people in careers that are of interest to the student (Levinson & Ohler, 1998).

Successful transition planning for students with disabilities who want to participate in postsecondary education must be integrated into the curriculum beginning as early as middle school (Brinckerhoff, 1996). These students must be taught skills that nondisabled students learn on their own (Schutz, 2002). These skills include appropriate socialization skills (Mellard & Hazel, 1992), knowledge of their rights and responsibilities as students with disabilities (Troiano, 2003), the differences in services provided in the high school compared to the college level (Garrison-Wade & Lehmann, 2009; Schutz, 2002; Scott, 1991), knowledge about and advocacy for the disability (Mellard & Hazel, 1992), and thorough assessment of vocational ability and aptitude (Levinson & Ohler, 1998). Students who have these skills are able to be active participants in their transition planning meetings, and are better prepared for the rigors of college life once they have made the transition (Brinckerhoff, 1996; Harris & Robertson, 2001).

When students with disabilities enroll in college, they typically move from an educational environment where they are carefully guided and protected to a setting where they are expected to perform as adults. The U. S. Department of Education (2011) has produced a document that explains a number of the differences between the two educational systems that students with disabilities are likely to encounter. Among those differences is the requirement to self-identify as a student with a disability at the postsecondary institution if academic adjustments and accommodations are needed. At the K-12 level, identification is the responsibility of the school system. In addition, colleges are not required to assess the needs of students with disabilities. In the K-12 setting, the school system is responsible for providing assessment of students who are suspected of having a disability. K-12 school districts are required

to provide a free appropriate public education (FAPE) to each child in the district's jurisdiction. Whatever the disability, a school district must identify an individual's educational needs and provide any regular or special education and related aids and services necessary to meet those needs as well as it is meeting the needs of students without disabilities. (Department of Education, 2011, p. 2)

A postsecondary institution is required to provide "academic adjustments that are necessary to ensure that it does not discriminate on the basis of disability" (Department of Education, 2011, p. 2). The supports that were present in K-12 help the student to gain admission to the college, but when he arrives on campus he expects the same level of support, which is an incorrect expectation (Mott, 2004). At the college level, the need for students to exert more independence runs counter to the decrease in academic support that is available, often leading to frustration and failure for these students (Foley, 2006).

### **Parent Involvement and Perceptions of College Readiness for Students with Disabilities**

For students with disabilities, this disconnect between services provided in high school and those provided in postsecondary education leads to more parental involvement than might

otherwise be necessary. Parent participation in transition planning is one of the most important elements that lead to positive outcomes for students with disabilities (Morningstar, Turnbull, & Turnbull, 1995). Morningstar, Turnbull, and Turnbull (1995) cited three reasons for parent involvement. First, students with disabilities delay making plans for their futures because they feel they are too young to worry about such matters. Parents serve as the catalyst for the process of setting goals and making plans for future education or employment opportunities.

A second reason for parent involvement, cited by Morningstar, Turnbull, and Turnbull (1995), is the need to ensure the student graduates from high school. Students with disabilities often have low self-esteem, and parents can encourage students to continue their education so that the students can realize their dreams.

Finally, parents play a role in the development of self-determination in the student with a disability. When a student reaches the college level, self-determination skills are critical to the student requesting and receiving the adjustments and accommodations that are needed for equal access (Morningstar, Turnbull, & Turnbull, 1995). In addition, Williams (1998) reported that parents can help students with disabilities understand their strengths and limitations so they can communicate their needs to college disability personnel. Parents can also provide opportunities to teach students about time management, organizational skills, activities of daily living, and managing their finances (Williams, 1998).

College admissions literature stresses the importance of a partnership among the college, the student, and the parent. Yet secondary schools tend to ignore the parent piece of this partnership as being critical to the whole transition process (Beale & Ericksen-Radtke, 2001). Most parents are not well-informed about the differences their student is likely to encounter and have not been made aware of the rights and responsibilities of the student and of the college,

leading to clashes with college admissions officers, disability service providers, and instructors (Wolanin & Steele, 2004). Empowering students and their families with knowledge about legal mandates and the obligations of postsecondary institutions under those laws serves to make the transition process much smoother (West, Kregel, Getzel, Ming, Ipsen, & Martin, 1993). Harris and Robertson (2001) called this the *empowerment* model of transition planning as opposed to the *rescuing* environment that is present in most secondary schools.

Parents of students with disabilities have similar expectations with regard to their children's educational goals. High school students with disabilities report that the expectations of their parents have a significant impact on the students' plans for college, as well as on college attendance. In addition, parents who have gone to college themselves are more apt to encourage their children to go (Masino & Hodapp, 1996). Parents serve as role models and key figures in the support system needed for success at the postsecondary level. Unfortunately, the expectations of parents often can derail the transition process. The behaviors they have learned over the years of serving as the advocate and caretaker for their children are difficult to leave behind. When the student reaches high school and is preparing for enrollment in college the parents continue to control the planning and decision-making process instead of the student (Smith, English, & Vasek, 2002). For a number of students, the parents or other family members often have a direct impact on the student's choice of career, even though the student may have never had a conversation with the family member about the chosen career (Morningstar, Turnbull, & Turnbull, 1995).

### **Parents Learn to Let Go**

Parents often find it difficult to let go of the role of advocate for their children. Although parents may trust and respect their child as a person, letting the student make decisions and

learning from the consequences of those decisions is a difficult step for parents to take (NCSET, 2002). The type of support parents give to the student prior to enrollment in higher education can have a significant impact on the ability of the student to understand his disability and to become his own self-advocate (Mott, 2004). Because colleges and university disability service providers are not required to seek out students with disabilities who may be enrolled in their institutions, the student must have the necessary skills to self-identify as a person with a disability and to request appropriate accommodation for that disability (Goldberg, 2001). Parents must remember that the maturity and readiness levels of the student are more important predictors of academic success than are academic grade level scores (Beale & Ericksen-Radtke, 2001).

Parents should be involved in transition planning, but the thrust of that involvement should be to ensure the student stays in school and to help the student develop self-determination skills (Morningstar, Turnbull, & Turnbull, 1995). Parents can achieve this goal by learning to serve as a mentor to their children as they begin to look at life after high school. Clear communication skills are essential between parent and child. This often takes practice, since the student may have very little knowledge about his disability and how it will impact him in the postsecondary environment (NCSET, 2002). Parents can help their children develop critical self-determination skills by rehearsing behaviors like speaking in a clear, understandable voice, and expressing their thoughts honestly but tactfully (Smith, English, & Vasek, 2002).

Parents must be knowledgeable of the differences between special education services provided in K-12 and the postsecondary level. One important step in designing a transition plan for a student with a disability is for parents to review the high school accommodations that have been provided and to insist that the school create an environment that will help prepare the student for college (Madaus, 2005). If attending college is the goal, the student should be taking

college-preparatory classes, being held to the same academic standards as other students, and participating in transition planning meetings. The parents are the catalyst for making this process move forward (Brinckerhoff, Shaw, & McGuire, 1992; NJCLD, 1996; Williams, 1998). Parents can also assist the student in exploring career interests by encouraging volunteerism or part-time work. Parents also have to realize that the path to transition and to a career may not always be as smooth as they would like for it to be (Broatch, nd).

Parents sometimes are unrealistic about their child's potential for success at a four-year institution (Broatch, nd). It may be difficult for parents to accept that attending a community college or a technical school may be the best option, or that the student should take some time away from school and work full-time (Brinckerhoff, 1996). By having these options available, the student and parent can take the additional time needed to mature socially and emotionally, and to acquire the academic skills necessary to be successful at the postsecondary level. Parents need to step back and take an objective look at their child's readiness before making the determination that postsecondary education is a viable option. Academic readiness skills, socialization skills, and self-determination skills must be present at levels equal to that of the student's nondisabled peers (Schutz, 2002). When the student is able to articulate his needs and his goals for the future clearly and directly, and can knowledgeably participate in transition planning, the parents can step back and allow the student to carry out his plan (Lehmann, Davies, & Laurin, 2000).

### **Transition to Postsecondary Education for Students on the Autism Spectrum**

Although ASD are considered low-incidence disabilities, the number of students with these disabilities is rapidly increasing in higher education (Ivey, 2004; Hurewitz & Berger, 2008). The number of children diagnosed with ASD increased 870% from 1993 to 2003

(Department of Education, 2003). The first generation of those who were diagnosed with ASD when the *DSM-III* (1980) recognized autism as a developmental disorder in 1980 have already arrived on college campuses (Walsh, 2010). A great many studies have been conducted on young children with ASD, but there is little literature or research that looks at outcomes for high school or college-aged students (Barnhill, 2007; Camarena & Sarigiani, 2009; Eaves & Ho, 2008; Zager & Alpern, 2010; Smith, 2007). The lack of useful information perhaps is an indicator that there is little interest in increasing an understanding of adolescents and adults with ASD and providing the tools that allow them to explore and develop their interests and talents (Wolf & Thierfeld Brown, 2008).

Leaving high school and moving on to college can be a very exciting yet stressful time for all students and their families (Thierfeld Brown, Wolf, King, & Bork, 2012). This is especially true for students with ASD, because until recently, higher education has not been seen as a viable option for them. As a result, teachers and counselors in high school have done little to prepare students with ASD for the transition (Hart, Grigal & Weir, 2010). The reality is these students typically have average to above average intelligence. Their behaviors related to the non-academic areas, on the other hand, can interfere with their academic performance and their ability to get along in the higher education environment (Dillon, 2007). For students with ASD, transition planning is critical, and this planning has to be more intensive than for other students with disabilities (Freedman, 2010). This planning should include more than just the basic classroom issues. Three particular areas of difficulty will be discussed in more detail: academic life, communication, and social/emotional behaviors.

### **Academic Skills**

Students with ASD are used to a routine and a pattern in their everyday lives.

Unfortunately, college life has little routine to it, and this often proves to be the downfall for someone who might otherwise be a very motivated student (Glennon, 2001). Traditional accommodations provided to other students with disabilities are not effective for students with ASD. Deficits in executive functioning and self-monitoring play a significant role in the success or failure for these students in their academic lives (Wolf & Thierfeld Brown, 2008). Common among the difficulties with executive functioning are planning, time management, and flexibility in shifting tasks. A study conducted by Landa and Goldberg (2005) found that children with high functioning autism had difficulty learning new tasks because of a pattern of returning to previously learned information. The children in the Landa and Goldberg study (2005) also had difficulty with language fluency and abstract language. Sam Goodin, disability services director at Southern Illinois University, reported that he encourages students to use some type of calendar program that will allow the student to take on scheduling responsibilities previously managed by the parents (S. Goodin, personal communication, November 30, 2012).

A number of students with ASD can demonstrate extreme knowledge about specific topics but are unable to generalize that knowledge to other academic areas. Their long-term memory is excellent, particularly for information from the distant past, and they remember material in great detail. Their thinking is very concrete and they are not able to access abstract reasoning (Wolf & King, 2009). Stephen Shore (2003), a noted author, music educator, and activist who has autism, reported that his college experience was very positive. There he was able to focus on his special interest without the bullying he had experienced in public school.

On the other hand, students with ASD typically may be disorganized in their work and study habits and have difficulty with time management, make poor decisions, and are inflexible

in their thinking (Wolf & King, 2009). Tasks that require a high degree of executive functioning require complex thinking and goal setting, both requiring students to think in a more abstract and generalized way (Hart, Grigal, & Weir, 2010; Robertson & Ne'eman, 2008). These students will likely need accommodation for organizational strategies and study skills, planning for long-term assignments, and tutoring for specific subject areas that are not within the student's realm of interests (Adreon & Durocher, 2007). Technology-based solutions may provide structure to an otherwise unstructured environment for students with ASD. The logic behind computers, personal digital assistants, and smart phones appeals to the processing strengths of students who depend on the routine of following the rules (Robertson & Ne'eman, 2008). For these reasons, student with ASD may have more success at large universities. In high school these students may have been viewed as "odd" by other students, but in a large college or university they can find a niche in a particular area of study that is of interest to them and may be able to fit in with a group of peers who share similar interests (VanBergeijk, Klin, & Volkmar, 2008).

Large universities also present challenges to students on the autism spectrum. Class sizes, particularly within the general education curriculum, can be very large, often ranging from 100-400 students. Because of the impersonal nature of these classes, students with ASD have difficulty making a connection with instructors. In addition, large classes are frequently distracting and may be a source of sensory overload for students on the spectrum (Freedman, 2010). In an effort to demonstrate understanding of course material and gain individual attention from the instructor, students with ASD may ask frequent questions in class or make statements that may or may not relate to the discussion topic. While students with ASD may believe they are participating appropriately in the classroom environment, others may see their behavior as annoying and disruptive (Harpur, Lawlor, & Fitzgerald, 2004). Understanding classroom rules

that are understood to exist rather than being explicitly defined is a difficult concept for these students to grasp (Schlabach, 2008).

Regardless of the size of the college or university, students with ASD experience a great deal of difficulty with organizational and time management skills (Wolf, Thierfeld Brown, & Bork, 2009). Hyperfocus on one particular activity or assignment may cause the student to forget about other assignments that are equally as important. Students with ASD may need to work closely with a counselor or disability service provider on their campuses to develop a plan of action for completing homework and assignments (Freedman, 2010). Scheduling also should involve time management because many students with ASD have difficulty keeping track of beginning and ending times for activities, particularly those activities that hold a great deal of interest to the student (Glennon, 2001). Arriving late to class is a common problem for these students, but not only because of time management skills. Students with ASD also have trouble navigating across campus because of the often overwhelming stimuli encountered along the way (Freedman, 2010).

### **Communication Skills**

While students with ASD may have well-developed speech skills, their ability to communicate, especially in social situations, is deficient (Schlabach, 2008). Students with ASD have excellent rote language skills, but their communication tends to be very literal. These students have difficulty understanding sarcasm, jokes, riddles, or idioms (Bauer, 2000), and their patterns and rate of speech, volume, pitch, and intonation are often unusual. For students with high-functioning autism or Asperger's disorder, speech is often very formal, with a vocabulary that may be more advanced than the average college student. Instructors may mistakenly interpret this as the student's comprehension of the course material (Adreon & Durocher, 2007;

Safran, 2002). Students with ASD seem to talk *at* rather than *to* others, and there is little concern about a give and take relationship during the conversation (Adreon & Durocher, 2007; Berney, 2004). Body language, such as facial expressions, may not match what is being said, and there is ample opportunity for misunderstanding (Berney, 2004; Freedman, 2010).

One of the key differences between high school and postsecondary education for this population of students is the need to verbalize strengths and weaknesses at the postsecondary level. Prior to this, parents and teachers have taken care of these issues for the student. In college, if the student is not able to disclose his disability and advocate for himself adequately with campus personnel, the student may not receive the necessary accommodations for his classes and other campus activities (Freedman, 2010; Stodden & Mruzek, 2010). The communication deficits that students with ASD display make disclosure difficult, and college personnel who are not familiar with the characteristics of students with ASD may misinterpret the meaning or intent of the student's message (Adreon & Durocher, 2007).

Students with ASD have difficulty picking up on verbal and non-verbal cues. Because of this, opportunities for teasing and bullying increase (Glennon, 2001; Zager & Alpern, 2010). Recognizing and repairing breakdowns in communication require the student to be aware of the context of the message, the involvement of others in the conversation, and the previous experience of others (Zager & Alpern, 2010). Abstract language skills, applying the appropriate social norms within a conversation, taking turns, and ending the conversation require an advanced level of abstract thinking that the student with ASD does not develop on his own. Their enthusiasm for one topic may lead them to become overly talkative about that subject, to the exclusion of all other topics. Typical students who do not share a common interest in the topic will become bored quickly, try to change the subject without success, or give up on the

conversation completely, thereby losing valuable opportunities for the student with ASD to develop social contacts (Graetz & Spampinato, 2008; Zager & Alpern, 2010).

Verbalizing feelings and emotions are difficult for students with ASD, so if students with ASD are upset about something, they may not say anything. As a result, the students may experience high levels of stress and anxiety, but people around them may not be able to recognize them as students in distress (Glennon, 2001). When student feels as if they are under a great deal of pressure, their judgment about how to respond or react to others may become further impeded, leading the students to say things that are inappropriate, hurtful, or potentially threatening to others. These outbursts lead to ostracism by others and could result in judicial proceedings being carried out against the students if they are severe enough (Harpur, Lawlor, & Fitzgerald, 2004).

### **Social/Emotional Skills**

Students with ASD may have the skills to succeed in college academically, but they are not able to navigate other aspects of college life (Van Pelt, 2008). For a student with ASD to say he is attending college provides a strong connection to typical students and fills a social need that may otherwise be lacking. The young adult with ASD feels less different when he can say he is a college student just like his peers (Hart, Grigal, & Weir, 2010). On the outside, students with ASD may appear to be well adapted and successful, with routine social interactions that appear to be appropriate. Their overall behaviors, however, remain eccentric and formal, making it difficult for them to live and work with others (Freedman, 2010). Poor social skills might prevent the student with ASD from finding success in the academic arena and can result in the student's experiencing rejection and isolation in activities outside the classroom (Dillon, 2007).

For typical students, the unwritten rules for establishing friendships and close social connections are learned by experience, but because of their poor communication and personal interaction skills students with ASD have difficulty figuring out those rules (Glennon, 2001; Williams, 1998). Developing self-awareness skills is critical to the social and emotional growth of students on the spectrum, but because these skills tend to fall in the area of psychological development rather than educational, they are often overlooked as a part of the curriculum that is offered through the course of the student's educational programming (Freedman, 2010). Self-awareness skills are critical for success in the postsecondary environment, where a student has to assume responsibility for disclosing his or her disability to the institution. In addition, the student must also be able to describe the impact of the disability on his ability to learn and to participate in the class activities so that appropriate support services can be arranged (Adreon & Durocher, 2007; Roberts, 2010).

One of the biggest concerns for students with ASD is how to cope socially (Harpur, Lawlor, & Fitzgerald, 2004). College life is full of opportunities for students to meet and interact with others: living in residence halls, joining Greek organizations or other campus clubs, participating in team sports, dating and forming romantic relationships, even working on group projects that are required to complete class assignments (Adreon & Durocher, 2007). As reported previously, Astin (1984) stressed the importance of making connections as a key to student persistence in the first year of college. Kuusikko et al. (2008) reported on their study of social anxiety of students with ASD. Their findings indicate that this group likely experiences anxiety in social situations because of a lack of self-awareness or insight into their own behaviors. Socialization with peers may be the most stressful activity for students with ASD (Attwood,

1998). As students with ASD begin to recognize their faulty skills in social settings, they may withdraw even further from social engagements (Kuusikko et al., 2008).

Although not deliberately so, students with ASD tend to be egocentric in their thinking and behavior, causing significant difficulty in establishing and maintaining long-term relationships (Barnhill, 2007). They are unable to see things from the other person's perspective so they cannot imagine what their actions and words feel like to someone else. This may cause particular problems when students on the spectrum are trying to establish a romantic connection with someone. They can approach someone with inappropriate verbal comments or make physical contact that could be easily misunderstood (Barnhill, 2007; Glennon, 2001; Graetz & Spampinato, 2008). Because college life has its own distinct culture, trying so hard to fit in can have a devastating effect on the student with ASD, and if they cannot resolve the difficulties, either on their own or with support from college personnel, these students may leave college rather than face continued humiliation or defeat (Graetz & Spampinato, 2008).

Much of the difficulty with social interactions results from the concept of Theory of Mind (ToM). First proposed by Baron-Cohen (1997), many adults with ASD can only see their own point of view and assume that everyone shares the same thoughts about life experiences (Dillon, 2007). Typical students use ToM to understand the behavior and the intentions of others while predicting "the effect our own emotions, beliefs, desires, intentions, and perceptions will have on others. There is an intimate interface between ToM and the ability to understand and read nonverbal cues, body language, and facial expressions, and deficits in one or more of these areas usually lead to deficits in all of them" (Freedman, 2010, p. 24). Students with ASD do not realize that others cannot understand what is going on in their minds, nor can they read the minds of

others. This is frequently one of the barriers to effective communication and socialization (Freedman, 2010; Graetz & Spampinato, 2008; Mitchell & O’Keefe, 2007).

The postsecondary environment is replete with stressful situations that confuse students with ASD. These situations may include an increase in the demands of the academic load, dealing with being away from home for the first time, or managing money. Meeting new people, changes to the student’s normal routine, and thinking about life after college, particularly career options or postgraduate school are other possible stressors (Adreon & Durocher, 2007; Wolf & King, 2009). Unfortunately, students with ASD may not demonstrate or be able to communicate their increased levels of stress. As a result, support staff such as counselors or advisors are not able to recognize the need to provide assistance to students with ASD (Glennon, 2001). Co-morbid psychological or psychiatric problems are not uncommon in students with ASD, with anxiety, depression, and schizophrenia being the most common diagnoses (Allen, Evans, Hider, Hawkins, Peckett & Morgan, 2006; VanBergeijk, Klin, & Volkmar, 2008). While depression has been identified as the most common co-morbid condition among adolescents and adults with ASD, establishing a prevalence rate has been difficult because the symptoms of autism tend to mask the characteristics of depression (Barnhill, 2007). Because these students have difficulty identifying and dealing with their emotions, they may express emotions in confusing, unusual, or even threatening ways. These expressions of emotional distress could lead to student code of conduct violations or even intervention by local law enforcement agencies (Allen et al., 2006).

### **Parent Involvement and Perception of College Readiness for Students with ASD**

Parents of students with ASD have been very involved with their child’s education and are used to being in charge. Wolf, Thierfeld Brown, and Bork (2009) called them “commando parents” (p. 62) because of their intrusive nature. While this is not too far removed from the

helicopter parents of typical students, this group of parents takes involvement to a higher level. They have become accustomed to interacting with teachers and school administrators at this level to ensure that appropriate services are provided to their children (Graetz & Spampinato, 2008). Unfortunately, involvement to this degree goes against the goal of making the adult student with ASD more independent. This kind of invasive support also sends the message to students with ASD that they are incapable of resolving issues on their own (Wolf, Thierfeld Brown, & Bork, 2009). Some parents also are hesitant to tell their child that he or she has ASD for fear the child will be permanently labeled by the disorder. Sadly, the parents may not be able to see that this diagnosis of autism likely may be the only way the child will receive special education services in K-12 and accommodations at the postsecondary level (Freedman, 2010).

### **Challenges to Transition for Students with ASD**

One of the biggest challenges for students with ASD and their parents is moving from the familiar environment and hands-on model of special education at the high school level to a system of services at the postsecondary level that is very different (Glennon, 2001; Morrison, Sansosti, & Hadley, 2009). The lack of information provided to parents about transition to college and evaluation of the student's need for services may severely hinder the parents' ability to offer support and advice to their child during this difficult process (Palmer, 2006; Roberts, 2010; VanBergeijk, Klin, & Volkmar, 2008). With the exception of assisting their child with gathering the necessary documentation of the disorder, parents are generally not a part of the accommodation process at the college or university. Without their child's permission they are not allowed to make contact with instructors to get information on how their child is performing academically. This change in parental involvement is surprising to parents who are accustomed

to being very involved with their child's education throughout the earlier years of education (Autism Society of North Carolina, nd).

Transition planning resources are limited for parents of students with ASD, leaving parents to express frustration and anger at not knowing what to do or how to help their child matriculate to the college setting or to post-high school employment (Van Pelt, 2008). Parents may not be aware of services that are available to the student, both at the college and in the community. In a study of decision-making for postsecondary education for students with intellectual disabilities, parents were asked what advice they would give to other families with regard to transition planning. While 56% of the parents said they would warn other families to educate themselves about their rights and plan ahead for whatever postsecondary options might be available to their child, 10% said they would tell parents not to depend on others, but 8% of the parent participants said they could not respond to the question because they needed advice themselves (Griffin, McMillan, & Hodapp, 2010). Without appropriate transition planning, parents worry that their child with ASD may be left sitting at home with nothing to do because no planning for what happens after high school was ever done (Camarena & Sarigiani, 2009).

Typically parents of college students maintain contact with their children to make sure they are safe, happy, and well-adjusted to the college environment. For parents of students with ASD this contact may go through the disability services office on campus (Palmer, 2006; Wolf, Thierfeld Brown, & Bork, 2009). The disability services staff, with the student's permission, can keep the parents informed or seek advice about how to help the student deal with a difficult situation. Because of the close interaction between the parents and the student with ASD, the parents may believe they are in the best position to know the things that trigger inappropriate behaviors and how to help the student learn how to deal with the situation (Ivey, 2004). Ideally,

the student would have been taught these skills in high school, but parents may decide to hire a life coach or personal assistant who accompanies the student as he meets his instructors and explains the need for accommodations (Adreon & Durocher, 2007).

### **Expectations of Parents**

Parents of students with ASD have high expectations for their children. Understanding these expectations is critical to the creation of a support system for college students on the spectrum (Morrison, Sansosti, & Hadley, 2009; Palmer, 2006). At the same time, it is also important to fully understand their child's strengths and weaknesses. To do this, parents should request a complete evaluation of the high school special education department, including educational, vocational, psychological, and social evaluations. These assessments should paint a very clear picture of where the student is and what steps need to be taken to make a successful transition from high school to postsecondary education (Baker, 2005). Some parents are hesitant to talk to their child about having a disability for fear that this knowledge will cause the student to feel inferior and give up on attending college (Freedman, 2010). During an interview with Susan TePaske, director of Disability Resources for Students at the University of Memphis, she shared these observations about the differences encountered at the postsecondary level when dealing with parents of students with disabilities in general and in dealing with parents of students with ASD:

I've found that it's okay to deal more directly in partnership with these parents with or without the student present, depending on where the student is in the transition process. The parents have to learn a different way of behavior, and it's important to get the parents on the same page with the college so the student can meet the same goals as the other students. There are no more "we" projects. It's important to be transparent and intentional when dealing with the student and his parents because this is a difficult step for both of them. (S. TePaske, personal communication, December 21, 2010)

There is very little literature that specifically addresses the role parents play in whether or not a student with ASD has a successful transition to postsecondary education (Morrison, Sansosti, & Hadley, 2009). Parents of typical students gradually decrease their active involvement in the students' education as the student becomes more self-sufficient, but parents of students with ASD continue a high level of involvement through high school and beyond. These parents see themselves as essential members of the educational process for their children. Many times, however, parents are not provided with the support and the information they need to make informed decisions about their child's education and are asked for very little input (Ivey, 2004; Morrison, Sansosti, & Hadley, 2009). They have limited knowledge of the transition process or what constitutes an appropriate transition plan, and about the options for postsecondary education and support services that are available to their children (Griffin, McMillan, & Hodapp, 2010).

Today's college students grew up being shuttled by parents from one structured activity to another in an attempt to build skills in different areas – athletics, music, art, community involvement, or spiritual awareness (Taub, 2008; Wartman & Savage, 2008). These students are often sheltered, protected by parents who fear their children will not be successful and will suffer from feelings of inadequacy (Howe & Strauss, 2003). Today's parents stay in contact with their college-attending children more frequently and use a variety of technologies to maintain lines of communication (Wartman & Savage, 2008). Family involvement includes helping decide which college to attend, providing financial assistance, and checking on their child's academic, social, and emotional growth. Safety is a primary concern for parents of today's college students, as well as assisting the student with making wise decisions about such things as alcohol consumption, exercise, and sexual activity (Carney-Hall, 2008).

The parents of students with ASD want similar outcomes for their children, but because of their substantial involvement in their child's educational programming from the very beginning, these parents feel that their opinions and expectations have more weight than those of college personnel (Ivey, 2004). Students with ASD may have the potential to succeed academically, but other areas of college life, particularly social challenges, may prove to be frustrating to them (Camarena & Sarigiani, 2009). Parents of these students want their children to succeed, but strong self-advocacy skills are necessary for this to happen. For parents, knowing what to expect from the transition process allows them to prepare their college-bound children with ASD for all aspects of the college environment (Camarena & Sarigiani, 2009; Ivey, 2004; Stodden & Mruzek, 2010).

Because of the lack of research that addresses the high school-to-college transition of students with ASD, very little information is available to the parents of these students that will help them guide their child successfully into the postsecondary arena (Griffin, McMillan, & Hodapp, 2010). This current study will add to the small body of research that exists by providing much-needed information from the parents' perspective about the transition process and the information that was provided to them so they could better prepare their child with ASD for college and the potential barriers to successful assimilation that may exist.

### **Theoretical Framework**

The role of parent advocacy in the access and provision of disability services has a well-established history. Using arguments similar to black parents in *Brown v. Board of Education* (1954), parents of children with disabilities in the early 1970s argued for the rights of their children to a free and appropriate public education. Subsequently, litigation that set precedence in how disability services were to be provided in schools and other publically funded programs

firmly established parental advocacy and self-advocacy as compelling means of bringing about social and political change in the disability field. Indeed, in a very similar fashion, parental advocacy has been attributed to the addition of autism as a category in IDEA (1990). Catherine Maurice's (1993) persuasive story titled *Let Me Hear Your Voice: A Family's Triumph Over Autism* spoke of a mother's unrelenting search for help for her two children with autism, and this brought to the fore the need for scientifically substantiated treatments of children with autism. This advocacy role that parents have played all through the history of disability programming undergirds these same roles played by parents of youth and young adults with autism entering college.

The study focused on the role of parents in the implementation of transition programming for youth with ASD from high school to college. Chickering and Reisser (1993) believe that parents are the primary source of values and beliefs that students bring with them to the college campus; therefore, parents who are well-informed about the transition process can provide assistance and advice to their children so they are able to successfully navigate through the transition maze that often overwhelms students with ASD (Morrison, Sansosti, & Hadley, 2009).

### **Summary**

The literature review just presented looked at the transition of students from high school to college from three different perspectives: typical students, that is, students with no disability; students with disabilities, particularly hidden disabilities such as learning disabilities and ADHD; and students with ASD. While each group of students goes through some similar transition experiences, students with ASD have much greater needs in terms of their social awareness and connectivity. Parents of all three groups of students have different challenges. Parents of students with ASD have played a major role in the attainment of educational goals for the students. This

group of parents, more than the other two, must have adequate information about transition services and activities so they can assist the student in making appropriate choices.

Next, the methodology for conducting the research study will be presented. Chapter III will provide information about the study itself, the recruitment of participants, and how the data was gathered and analyzed.

## CHAPTER III: RESEARCH METHODS

### **Introduction**

This study explored the experiences of parents of college students diagnosed with an autism spectrum disorder (ASD) regarding their children's transition from high school to college. The overarching purpose of this research study was to gain insights from the perspective of the parents about the transition process itself and about gaps in transition information provided to them by the high school special education teachers or guidance counselors, as well as by college

disability service providers. Data collected helped to answer the question on possible adverse effects of lack of critical information on the quality of the transition experience of college students with ASD. The data also yielded valuable information on whether or not parents had all the information they needed to better prepare their children to make the transition to postsecondary education.

Parents play a role that is essential to the success or failure of the transition process for students with ASD. Chickering and Reisser (1993) proposed that separation from parents is a critical component in moving through autonomy to interdependence. For students with ASD, their parents may provide a feeling of security that supports and encourages competence and the development of autonomy. As a result, separation may not come as easily for this group of parents and students.

This study answered the following research questions:

1. What training or advice was provided in the high school to parents of students on the autism spectrum to make them aware of postsecondary education options for their child;
2. What information did postsecondary institutions provide to these parents to enable them to prepare those students to have a smoother transition to postsecondary education;
3. To what degree did the parents assist with preparing the student for the transition to postsecondary education; and

4. From the parents' perspective, what issues could have been prevented or lessened if adequate information had been provided by the high school or postsecondary professionals?

### **Qualitative Paradigm**

Qualitative analysis allows the researcher to delve more deeply into the meaning of data beyond just numbers and statistics (Creswell, 2013). Qualitative research emphasizes data that have been gathered on events that occur naturally. This type of research looks closely at people and their relationship to the problem at being studied, and examines the patterns of meaning that are derived from the data (McMillan & Schumacher, 2006). Qualitative methodology was used to in this study, taking a phenomenological approach to the research study design. Because the parent participants in the study have sons and daughters who have experienced the phenomenon of transition to postsecondary education, this design approach allowed the researcher to uncover common ground or shared experiences of the transition process (Creswell, 2013).

Using an interpretivist/constructivist theory of research, I learned how the parents of students with ASD view the transition process for their sons and daughters and what meaning they assigned to it (Rubin & Rubin, 2005). The parents all interpreted the transition process somewhat differently, viewing it from different lenses depending on their individual experiences, and arrived at somewhat different conclusions. Because of this, the parents constructed their own meaning of the transition process (Creswell, 2003). By conducting this study, I discovered and interpreted the shared meanings of the participants, even though each parent experienced the phenomenon of transition in a slightly different manner.

### **Researcher's Role**

In a qualitative study, the researcher must establish an interactive relationship with the participants. The quality of the data depends on a researcher who possesses interpersonal skills that are sufficient to build trust. The researcher also must be nonjudgmental, and must respect the phenomenon being studied (McMillan & Schumacher, 2006). For the researcher, understanding one's own biases and assumptions is critical to the research process, and the determination must be made as to whether these biases and assumptions will become a part of the study (Creswell, 2013).

The researcher becomes the instrument for collecting data in a qualitative study. Guba and Lincoln (1994) describe the role of the researcher as a “‘passionate participant’ as facilitator of multivoice reconstruction” (p. 112). In-depth semi-structured interviews with the parents of students with ASD were conducted. Through their narratives, I came to understand the meaning they assigned to the transition process for their children and found whether there are common areas of concern, weakness, or strength in the process as it was experienced by this collective group of parents. In an educational setting, interviewing has become a primary tool for conducting research over the last one hundred years (Tierney & Dilley, 2001). Interviewing provides a means for gathering information that other methodologies cannot. As humans, we share our experiences through language, and in a research setting, the interviewer is interested “in understanding the lived experience of other people and the meaning they make of that experience” (Seidman, 2006, p. 9).

The purpose of responsive interviewing, according to Rubin and Rubin (2005), is to “generate depth of understanding, rather than breadth” (p. 30). The constructionist approach to research supports the idea that respondents view the world through different lenses and assign meaning to the events based on their individual experiences (Rubin & Rubin, 2005). Data that

are gathered using the constructionist approach are subjective and descriptive, thus providing rich descriptions, using words and pictures rather than numbers (Merriam, 1998) that address the depth of understanding necessary to tell the stories of these parents and to assign meaning to them.

Students with ASD are expected to participate in postsecondary education in much the same manner as their typical peers, yet the inherent difficulties with socialization, organization, and overall executive functioning create barriers for these students that may hinder their progress and success in the postsecondary environment (Hendricks & Wehman, 2009). Parents may be reluctant to talk about these issues when relating them to the experiences of their own child (Thierfeld Brown, Wolf, King, & Bork, 2012). The relationship between the participants and the interviewer is critical to responsive interviewing. In establishing that relationship, the interviewer has the obligation to make the process as pleasant as possible, perhaps helping the respondent understand his or her own experiences (Rubin & Rubin, 2005). The interviewer has an ethical responsibility not only to protect the respondents' confidentiality but also to be loyal to the time and effort put into the interview session by the respondents (Lincoln & Guba, 1985).

This study focused on the relationship between the parents and the educational providers involved with the transition process. The K-12 system has a legal obligation to develop a transition plan for all students with disabilities (IDEA, 1990). This transition plan is designed to provide guidance to the student and to the parents as the student moves on to employment, postsecondary training, or some other form of community-based activity after high school. For students with ASD who are interested in postsecondary education the transition plan should address the weaknesses in executive functioning that will create barriers to the students' success at the postsecondary level (Hendricks & Wehman, 2009). Because the parents have been the

primary advocates for students with ASD all through the school years, the importance of parental involvement and training by the high school and by the postsecondary institution's disability services personnel are critical to the success or failure of the student at the postsecondary level.

### **Data Source**

Nine parents whose sons and daughters participate in the ASD program at Downtown University, a medium-sized comprehensive university in the southeastern United States, were interviewed for this study. This ASD program is one of 19 nationally recognized innovative programs that provide support, counseling, advising, and training for students with ASD.

According to the program's website, the program

... is made up of four primary components. Each of these works in concert with the other to provide a comprehensive program. The components of the (ASD) program include (1) A credit bearing course with a fully established curriculum with a letter grade attached, (2) Coaching, (3) Peer/Faculty Mentoring, and (4) Required supervised study hours. (program website, 2014)

The program is now in its fourth year of operation, with the second-, third-, and fourth-year students building on the skills that were learned in the first year curriculum (program website, 2014). The ASD program at Downtown University is a program that provides wraparound services to students with ASD to enable and empower them to navigate their role as college students successfully. The services that they receive go above and beyond accommodations provided by typical student disability services offices. It is a fee-based program, which means that in addition to regular college tuition, these students pay for the supplementary services that they receive through the Downtown University ASD program.

In accord with the procedures approved by the Institutional Review Board (IRB) and working through the director of the ASD program, I scheduled two meetings with the students who participate in the program to describe the topic and purpose of my study, using a script

approved by the IRB (see Appendix A) and to answer any questions they may have had about my research. Students were encouraged to share this information with their parents and explain the study to them before the students gave permission for parental contact. Because it is required by federal law (Federal Educational Rights and Privacy Act [FERPA], 1974), the students were asked to give permission for me to speak to their parents about the transition experience. Each student who agreed to let me interview his or her parents signed a release form (see Appendix B) to document that permission had been given to proceed with contacting the parents.

As student release forms were received, preferred contact information for the parents was noted (see Appendix B), and parents were contacted by the preferred method to solicit their involvement in the study. Parents who agreed to participate in the study received an explanatory letter by E-mail or postal mail as well as an informed consent document which was signed and dated (see Appendix C). When there was no response to the initial postal mail, E-mail or phone call to the parents after two weeks, a follow-up phone call or E-mail was sent (see Appendix D). Two weeks after the second contact attempt without a response, a third attempt was made to contact the parents (see Appendix E). At that point if there were still no response, the non-responding parents were removed as potential participants in the study.

Initially, 14 students who participated in the ASD program gave me permission to contact their parents. From that group only three parents agreed to be interviewed. Another meeting with the students was scheduled the following semester, so as to capture any new incoming freshmen. From that group of twelve students, nine of them gave me permission to contact their parents. Of that number, six parents agreed to be interviewed, for a total of nine parents. In one case, both father and mother participated in the interview; all other interviews were conducted with the mother only. One parent, Mrs. Jones, has two children who participated

in the program. She responded to the interview questions separately for each child. Table 2 provides demographic information about the parents and the students who were a part of the study.

Table 2

*Demographic Information on Parents who Participated in the Study*

Person Interviewed (Pseudonym)	Occupation	Student Name (Pseudonym)	Student Age	Gender	Race	Student's Living Arrangements	Grade in College	K-12 School Environment
Mrs. Davis	Seasonal employee at a national park	Frank	19	M	Caucasian	Apartment residence hall	Freshman	Public School
Mrs. West	Secretary	Carl	23	M	Caucasian	Apartment residence hall	Freshman	Public school through sophomore year; private school grades 11-12
Mrs. Jones	Special education teacher	David	20	M	Caucasian	Apartment residence hall first semester/ At home with mother second semester	Freshman	Public schools
		Sarah	22	F	Caucasian	Apartment residence hall	Junior	Public schools
Mrs. Smith	Housewife	Michael	18	M	Caucasian	At home with parents	High school senior/dual enrollment freshman	Public schools (kindergarten); private school (first grade); public schools grades 2-4; homeschooled grades 5-12
Mrs. White	Retail clerk	Elizabeth	20	F	Caucasian	At home with parents	Freshman	Public Schools
Mrs. Hunter	Hospital food service worker	Jacob	21	M	African-American	At home with mother	Junior	Public schools
Mrs. Lynch	Housewife	Thomas	20	M	Caucasian	Apartment residence hall	Freshman	Public schools
Mr. and Mrs. Parker	Engineer/Retail clerk	Sheila	20	F	Caucasian	At home with parents	Freshman	Public schools
Mrs. Tucker	Housewife	Jack	19	M	Caucasian	At home with parents	Freshman	Public schools

Students who participate in the ASD program do so voluntarily and are charged an additional fee to participate. As a result, I am not aware of the demographics of the entire ASD support group with regard to race, gender, socioeconomic status, level of parent education, or the type of K-12 school environment (public, private, or homeschooled) in which each student participated. However, for the participants of this study, I collected critical demographic information about the parents as shown in Table 2. Previous studies report that more males than females and more Caucasian students participate in ASD programs (Assouline, Nicpon, & Doobay, 2009; Cumine, Leach, & Stevenson, 1998; Kopra, von Wendt, Nieminen-von Wendt, & Paavonen, 2008; Morrier, Hess, & Heflin, 2008). For this study, the demographics of the parents interviewed mirror those of the studies cited above. Of the nine participants, five were White parents of male students, two were White parents of female students, and one was an African-American parent of a male student. One White parent had both a son and a daughter in the program. Within the design of the research study, I collected additional demographic information to determine whether socioeconomic status and type of school environment had an influence on the parents' experiences with transition.

### **Data Collection**

Before the research study began, Institutional Review Board (IRB) approval from both The University of Alabama and Downtown University were obtained. Obtaining IRB approval is required for any study, but I view the IRB as my commitment to the participants that I will conduct my study in an ethical and truthful manner, representing them as honestly and faithfully as possible (Warren, 2001). Parents were contacted to participate in this study as described in the previous section. Before any interview was conducted, the parents signed a letter of informed consent, giving me permission to move ahead with the interview process (see Appendix C).

Interviews were conducted at a time and location that was convenient for the parents. Allowing the parents to choose the location and time for the interview is one of the characteristics that Rubin and Rubin (2005) ascribed to the responsive interview model. Remembering that the interviewer is trying to establish a relationship with the respondents is critical to the trustworthiness of the data that are gleaned from the interview. Of the interviews conducted, one was held via Skype, six were done by phone, and three were done in person. All of the in-person interviews occurred at my place of work.

An interview protocol was used as the basic structure for each interview so they were relatively similar in format (see Appendix F). This guide helped me keep the interviews on target with regard to answering the research questions, but also allowed me the flexibility to ask follow-up or clarifying questions throughout each interview if there were such a need (Seidman, 2006). The open-ended questions included in the interview guide were informed by the review of literature, the research questions for this study, and my own personal experiences working with students with ASD and their parents who want to attend the college where I am employed. During each interview, I took notes by hand and made an audio recording of the interview. The audio recording was transcribed, then the transcription was returned to the participants for their review. This provided an opportunity for the participants to add any additional information, correct any errors in the transcription, or ask any additional questions. Once transcription was complete, the audio recordings and the printed transcriptions were stored in a locked drawer in my home office. In addition, the transcriptions have been saved on a flash drive that is kept in the locked drawer. I am the only person who has access to this drawer, and the transcriptions, flash drive, and recordings will be destroyed after one year from the date of the interview.

## **Data Analysis**

Once the interviews were transcribed and reviewed by the participants, they were reviewed, compared, and contrasted for the personal truths they contain (Riessman, 2001). Because the interviews have been told as the personal stories of these parents, the stories represent a wide variety of experiences: parents come from different cultures; parents actively may or may not have been involved in the transition process; students attended public or private schools or were home-schooled; the degree of autism may have influenced the students' abilities to understand and learn the skills necessary to transition to postsecondary education. This data was analyzed for common themes, categories, or types of experiences (Merriam, 1998).

The process of data analysis began with taking each transcript and breaking it down into more manageable categories that correlated to the research questions. Text that was relevant to the research questions was separated out from text that had little relationship to the research questions (Auerbach & Silverstein, 2003). Finding relevant text required that I look for statements or phrases that had similar meanings across the transcripts even though different terminology was used. As these meanings began to appear over and over, specific themes began to emerge. These themes, as they relate to the research questions and the theoretical framework of Chickering and Reisser's first three vectors (Chickering & Reisser, 1993), have been developed into a narrative that delineates the shared experiences of all the participants in the study.

## **Verification**

In a qualitative study, determining the validity and reliability are difficult to achieve, yet measuring these two standards by the same criteria used in a quantitative study is not feasible. As respondents tell their stories, the researcher tries to assume a role of objective meaning-maker,

but in this case, because of my close involvement in the transition process for students with disabilities at my own institution, objectivity may not be possible. In a situation such as this, Atkinson (2001) suggested that the researcher follow three basic guidelines: 1) make connections rather than judging; 2) treat the life experiences as if they are the text of a document or story in any other field; 3) use the life experiences of the respondents as teaching tools and take each story as it unfolds. By following these three guidelines, the researcher can begin to uncover the validity and reliability of the study. As a disability services provider at a community college the stories shared by these parents provided me with valuable information that I can put into practice in my program as well as share with others in my profession at the college and high school levels. To make the needed connections with the parents, I am confident I was successful in making them aware of my own need to learn from their experiences so I can better serve the students with ASD on my campus.

In this qualitative study, I was the primary instrument for research, and it was my responsibility to report the truth as seen from the perspective of the parents. By accurately reporting and interpreting the experiences of the parents, I took a position that is “‘closer’ to reality than if an instrument with predefined items had been interjected between the researcher and the phenomenon being studied” (Merriam, 1998, p. 25). With this degree of closeness, my task was to interpret with a faithful voice the parents’ reality of the transition process (Merriam, 1998). Allowing the parents to review the transcripts provided an additional layer to the reality of the stories and therefore added to the validity and reliability of the study being conducted.

Lincoln and Guba (1985) propose four criteria for measuring the trustworthiness of a qualitative research study. First, *credibility* was established by building trust with the participants, investing sufficient time to become familiar with the parents and their positionality

with regard to the transition experience for their sons and daughters with ASD. Credibility was achieved in this study by providing transcriptions of the interviews to the parents for their review and critique, a process that Lincoln and Guba (1985) refer to as *member checks*.

The second criterion that measures the trustworthiness of a qualitative study is *transferability* (Lincoln & Guba, 1985). By providing data and data analysis that is as accurate and complete as possible, I hope to enable other researchers to transfer the knowledge gained through this study to future research of a similar nature.

Lincoln and Guba (1985) presented *dependability* as the third criterion of trustworthiness. In this study, dependability was achieved by providing sufficient detail in reporting the results of the study so that future researchers will be able to duplicate the study or conduct a related study that will be informed by the results of this research.

The final criterion of trustworthiness is *confirmability* (Guba & Lincoln, 1985). In this study, confirmability was achieved by being as objective as possible in my research methods, as well as noting particular biases or predisposition on my part. In addition, clearly describing the reason for the methodology chosen and the steps taken to conduct the research and analyze the results have illustrated the confirmability of the research study.

### **Ethical Considerations/Researcher Positionality**

This study was based on the assumption that parents would respond truthfully to the interview questions. While the individual experiences of the parents may differ, the overall data that were collected reflect the primary areas of concern that parents have, the questions that were not answered by either high school or college personnel, and the problems their children have encountered as a result of the lack of information made available to the parents so they could have made the transition process smoother. The emotional connection of the parents to their

stories is a related assumption which may have impacted the overall truthfulness of their responses. However, this consideration, while an important one, is counterbalanced or somewhat alleviated by the fact that there were several parents interviewed for this study, thereby providing for the repetition of themes that constitute their reliability.

I have a vested interest in the outcome of this study. As a disability service provider at the postsecondary level and a former high school special education teacher, I am very keenly aware of the transition process itself, and of the missed opportunities for educating both parents and students about their rights and responsibilities as students with disabilities at the college level. Armed with proper information, education, and training, parents whose children fall on the autism spectrum can do a better job preparing their children for what lies ahead at the postsecondary level.

My relationship to this topic plays a large role in interpreting the information that was gleaned from the parents who participated in the study. For the past sixteen years, my primary role has been that of directing the office of services to students with disabilities at a medium-sized urban community college in the southeastern United States. Often the disability services office is the point of first contact for students with disabilities and their parents, and disability services personnel want to provide the best, most accurate information we can to these potential students and their parents.

In the later part of the twentieth century, the opportunity to attend postsecondary education was not an option for most students with ASD. Today, the number of these students attending college is rapidly increasing (Thierfeld Brown, Wolf, King, & Bork, 2012). Many college disability services offices are not well-prepared for working with this group of students or their parents, who have been the driving force behind full access for their children throughout

their school lives (Camarena & Sarigiani, 2009). The information that was collected and analyzed in this study will hopefully equip future groups of parents, as well as postsecondary disability service providers, with the tools needed to transition students with ASD to college so they are prepared for the new, unfamiliar experiences they will have (Freedman, 2010).

Finally, I omitted the students' voices from this study. While limited research is available focusing on students with ASD at the postsecondary level, much of what has been written speaks to the parent as the primary information-sharer and educator. However, there is research that shows that listening to the voices of young people with developmental disabilities, including ASD, offers interesting insights about their desired outcomes in areas ranging from education to personal relationships (Erevelles & Mutua, 2005). The students may be able to communicate their thoughts on the transition process, but given the short time in which youth with ASD have been participating in postsecondary education, the centrality of the role of parent as advocate cannot be overstated. It is the parents who seek to fully understand and have influence on the transition planning process at this point in time. When the parents are better informed themselves and can then begin preparing their children for what comes next, the students' voices become stronger because they have been made aware of the steps that need to be taken to avail themselves of all of the services and supports that are available in higher education.

### **Summary**

In this chapter, I re-identified the topic of my study and the research questions that guided me. The study consisted of interviewing the parents of college students with ASD and interpreting their experiences with preparing their sons and daughters for the transition from high school to postsecondary education. I shared my interest in this topic, and outlined the methodology that was used to gather and analyze the data that was obtained through interviews

with the parents. I described particular ethical considerations that impacted the study and addressed the issue of trustworthiness in conducting a qualitative research study. As a professional working as a postsecondary disability services provider, the outcomes of this study are important to me because I can share my findings with college level disability services personnel. The information gleaned from this study will assist them in making transition planning a meaningful and practical part of the experience for students with ASD. In addition, other disability service providers may find the outcomes beneficial to them in making changes or modifications in the approach they currently use to introduce students with ASD to the postsecondary environment.

## CHAPTER IV:

### ANALYSIS OF DATA

As much as my husband and I have been basically hand-holding him through school and kindergarten, I don't think I was fully prepared for what to do as far as getting ready for college in general. I guess I just didn't realize how much work there is in getting someone ready for college. (Mrs. West, parent of Carl, age 23)

The phrase "If you've met one person with autism, you've met one person with autism" is used quite often in the autism community to describe the uniqueness among individuals with autism and their separate experiences in dealing with their environment. The same phrase could be used to describe the lived experiences of the parents who participated in this research study. No two parents related similar experiences as they reflected on the transition of their students from high school to postsecondary education.

In this chapter, I reflect on the common bonds that exist among the parents who participated in this study. While each of the parents experienced the phenomenon of transition in a very different way depending on the nature of the child's autistic characteristics and manifestations, I was able to discern several shared themes throughout their narratives. I have related those themes to the vectors of psychosocial development of college students proposed by Chickering and Reisser (1993) that create the theoretical framework for this study, namely, developing competence, managing emotions, and moving through autonomy toward interdependence. In addition, the four research questions will be addressed:

1. What training or advice was provided to parents of students with ASD to make them aware of postsecondary education options for their child;

2. What information did postsecondary institutions provide to these parents to enable them to prepare those students to have a smoother transition to postsecondary education;
3. To what degree did the parents assist with preparing the student for the transition to postsecondary education; and
4. From the parents' perspective, what issues could have been prevented or lessened if adequate information had been provided by the high school or postsecondary professionals?

The themes that emerged from the narratives reflect not only the parents' frustrations and concerns, but also their visions for the future for their children. Four primary themes were uncovered, and will be discussed in relationship to the research questions. Those themes are: (a) defining the role of parents as advocates for their children throughout the school experience; (b) developing and maintaining lines of communication between the schools, the parents, and their child; (c) developing a strong support team that can provide advice and serve as a resource for information and assistance; and (d) recognizing the need for the parents to take care of themselves after the transition process is complete.

The stories told by the parents and the four themes that emerged from them reflect several important constructs that relate to the psychosocial development of college students progressing through the vectors proposed by Chickering and Reisser (1993) and the involvement of the parents in aiding the student's progression through those vectors. Each of those constructs serves to define more clearly both the positives and the negatives that each parent experienced as the student prepared to go to college.

All of the students whose parents participated in this study are members of an autism support program at Downtown University, an urban comprehensive university in the southeastern United States, one of nineteen such programs nationwide. At the time this study was conducted, a total of 31 students were involved with the ASD program, 27 males, and four females. Twenty-six students gave permission for me to contact their parents, with nine parents agreeing to be interviewed for this study, encompassing the transition experiences of ten different students, ages 18-23. Six of the students were White males, three were White females, and one was African-American male. Three of the families reside out of town; the remaining six reside in the local community near Downtown University. The families all fall into the middle to upper-middle classes socioeconomically, and the majority of the students (8 out of 10) attended public schools exclusively.

### **Advocacy Never Ends**

If you don't make an exception for your child and go all out for your child then you're at fault because you didn't try. You have to try. (Mrs. Hunter, mother of Jacob, age 21)

Relating to the first research question, that is, uncovering the training or advice that was provided to these parents so they would be aware of postsecondary options, the theme of advocacy demonstrates the unending support the parents provided to their children throughout their school careers. While the interviews focused on the degree of advocacy related to the high school to postsecondary education transition, it was evident from the parent narratives that their roles as primary advocates began at a very early point in the educational process. As the students progressed through school and developmental milestones were achieved, the role of parent advocacy changed commensurate with the needs of each developmental period.

An early diagnosis of autism forced several parents to become advocates when their children were still very young. This early diagnosis proved to be the key to educational intervention for Sheila, whose mother had testing done by the school system's early intervention program when Sheila was three. Mrs. Parker, Sheila's mother, told the story in this manner:

When Sheila was three, even before pre-K, we had some neighbors across the street who we were friends with, and the wife was a pediatrician. And we were out in the front of their house – her daughter and my daughter were playing – and she said to me, “You need to have Sheila checked, because at this age I should be able to understand at least 75% of what she's saying and I can't understand 25%.” And she said, “When I talk to her, I can tell she can't understand me, and she's not communicating like she should at her age.” So we set up a time and I took her to get tested at ... the public school system has a preschool testing center, they try to figure out what your child's difficulty is and what to do about it. And her initial testing came back as her being profoundly retarded. And she was attending [a private] preschool at the time, and then the next year she was supposed to go to elementary school. And ... I don't think the elementary school had a program before this, but they kind of put a program together, really, Sheila was the first child that they had a program for. They had people from the preschool assessment office and people from the elementary school go to the preschool and observe her for several days. They actually went there together, they observed her, they had discussions about how best to help her once she gets into the elementary school, and when she got there they actually had a program in place, and I think that's what they're still using now.

For Sheila, advocacy for early intervention by her mother was the key to a mostly successful school experience. For Mrs. Lynch and her son Thomas, age 20 and an aspiring special education teacher, the transition to elementary school was not as positive. Living in a small, mostly rural county meant that the school system had little experience with students on the autism spectrum. According to the superintendent of county schools, only three students with ASD attended schools in the entire system. Mrs. Lynch questioned whether that statement was true but she began pushing the schools to provide services for Thomas. While the family hired tutors to help when Thomas was at home, Mrs. Lynch began urging the school system to attend to his needs while he was in the classroom. She stated, “We demanded things from the school system. I just didn't let the school district decide where he was going to be.”

Finding the right educational placement was important to all of the parents I interviewed, but the story that Mrs. Smith told about finding that right placement for her son Michael was unique among them. Beginning with preschool and kindergarten in the public schools, Michael struggled to meet the goals necessary for progression. Before he began first grade the family moved from New Mexico to Tennessee so he could attend a private school for children with learning disabilities and other special needs. Unfortunately, the school closed shortly after Michael began classes there, so the search began again for an appropriate elementary school placement. The family first tried a well-known kinesthetic, thematic-based learning program, but what worked for other students did not work for Michael. The structure was too rigid and did not allow for the flexibility he needed to prevent boredom in the classroom. Said Mrs. Lynch, “You know, I could just tell, after a while, pretty quickly, what was going to work for him and what was not.” After another brief attempt at placement in the public schools, the family made the difficult decision to home-school Michael, with the mother becoming the teacher. Mrs. Lynch described the family’s struggle:

You know, we made some pretty difficult decisions. When my husband I were both working we had a pretty good income, a nice little house in the suburbs, that kind of thing. When we thought we may well have to homeschool instead, we bought a house that was pretty inexpensive, we did some fix-up work, a little two bedroom, one bath house, and so there have been a lot of compromises we’ve had to make in order to homeschool him and a lot of people just can’t, especially if they have other kids and other obligations.

Mrs. Hunter refused to let the school system put her son Jacob in special education classes after being diagnosed with autism in the first grade. She did not want the *special education* label following Jacob all through school and for the rest of his life: “You automatically give them a subtitle where this is where you’re going to be the rest of your life, and you’re not going to amount to nothing, and I don’t want my son feeling like that.” When he

was old enough she pushed for, and succeeded in, having Jacob placed in a computer technology program, where he thrived.

Addressing the seeming lack of support for and knowledge about ASD that was present in the school system, Mrs. West reported,

And he had, of course, lots of IEPs. That's one thing I will mention – in that the IEPs, the whole deal with that – the people involved with that seemed to be more concerned with actually filling out the IEP form than they were in actually solving any cases or problems kids are having.

Another mother agreed, “You know, something that makes sense to you as a parent isn't necessarily something they can do in the school. We actually had hired an attorney and were looking at suing the schools to implement his IEP.” Mrs. White also considered legal action to force the school system to provide appropriate services for Elizabeth:

I had to fight with all the schools. They got to know me. Some people did things because they knew I was going to call, 'cause I would threaten to say I'll call an IEP meeting every six weeks if you do not do this. I even hired a lawyer one time, I'd warn them ahead of time... I'm calling this meeting...I'm going to go ahead and say this... It's not against you, I'm just giving a heads' up, I'm coming in there.

Mrs. Hunter concurred, “So that was my way of telling them that, look, we're going to do it this way, you're not going to tell me what way you want to do it. This is my child, and if I don't stand up for him, who else will?” Mrs. Lynch gave this admonition to other parents:

I think the biggest thing is not to let the system define them. They shouldn't let the system define them, because the system will take the path of least resistance. They will take... they will let you... pull him out of a class and put him in a room and let him sit there, spend three hours staring at a test overwhelmed as can be, and they will allow that to happen, you know, so I think that would be my biggest thing is that, you know, don't let the system define them.

For all of the parents who participated in this study, this high level of involvement continued throughout school, reaching the high school years. Finding teachers who believed these students could achieve at a level high enough to obtain a college degree was often a hard

task, and more battles had to be fought. Mrs. Jones spoke about her conversation with the teacher who was the sponsor for the technology students group:

In ninth grade I found out about TSA – Technology Students Association – and I wanted (David) in it. And one of the assistant football coaches was the technology teacher, and I went up and asked him and he smiled, kind of like “pat my pretty little head” and said, “He can never handle this, he’s not smart enough.” And I looked at him and I said, “David will be in TSA.” And I said, “He’s probably smarter than cumulatively everyone in your class at that one time,” and he thought I was an arrogant whatever, and that was okay as long as my son got in there... My son was the only one that won first place at the state level and went to nationals with this delightful little technology teacher who said he wasn’t smart enough.

Mrs. Davis addressed accommodating her son in his high school classes and the lack of knowledge about autism on the part of his teachers:

Oh, no, nothing. The high school helped us with... He was allowed to eat lunch in a classroom because of the noise in the cafeteria. His teachers would kind of keep an eye on him, kind of encourage him a little bit more to get his homework turned in, that sort of thing, and he could have a little bit of extended time on tests. Other than that, they didn’t know anything about Asperger’s much at the high school.

Speaking about the role parents should be playing in the educational process for students with autism, Mrs. Lynch stated,

You know, their approach was – don’t get your hopes up, he may not go to school. And I was like, “No, he’s going, he’s going.” They just kind of said, “Well, it doesn’t work out for everybody,” and I was just really shocked that the school didn’t know of more benefits out there for these kids.

Mrs. Davis tried a different approach to dealing with teachers by giving them information that could help them work with her son more effectively:

At the start of each semester in the high school, I would give his teachers a couple of pages that said how best to teach Frank, and it would just talk about how black and white he was. And so there were other things that I would put in there, you know, that would... I’m gonna be more involved with Frank. I understand that this is high school that... that you feel, you know, the transition from high school is to try to make students more independent but with Asperger’s the parent has to be involved. I will be involved. I found an article that I felt gave me permission to do that.

For almost all of the students whose parents participated in this study, not going to college was not an option, and the parents worked very hard with school personnel to ensure that the students were taking the courses necessary for them to move into postsecondary education. For Sheila, her school counselors encouraged her to take honors courses beginning in the tenth grade. Said Mrs. Parker, “But the teachers, her inclusion coordinator, all of them, always encouraged her and told her to take the honors classes, always prepared her for college.” Mrs. Davis supported the idea that her son would attend college, but with some measure of concern:

It was never really a question as to whether he was going or not. He was always going to college. Now...Did we have doubts in our minds that he would be successful in college, especially after we realized his diagnosis? Yeah. And he was always so smart. I mean, 1300 on his SAT – yeah, it was never a question. We thought he would be hugely successful in college. And then the shock was when he was diagnosed with Asperger’s and I started reading and I was like, “Oh, my god! The child could be dependent on us the rest of his life!”

For Mrs. Jones, parental involvement in high school meant that she sat down with her daughter Sarah at the beginning of every semester and put together binders for all of her classes. Mrs. Jones, a special education teacher who focuses on autism disorders in culturally diverse populations, saw this activity as an opportunity to teach Sarah organizational skills that she could use in many situations, “and as the years went on she did more, I did less.”

### **Establishing Lines of Communication is Essential During the Transition Process**

...Probably in the last 2-3 months of last year, and already this year, a lot of communication. He calls me to say, ‘Just wanted to let you know I’m doing this, I’m doing that, and here’s what’s happening here,’ and I wasn’t getting any of that the first year. (Mrs. Lynch, parent of Thomas, age 20)

Research question two addresses information and support the families received from the postsecondary institution that aided in making the transition process smoother. Since the transition to college involves not only high school personnel but also college disability services staff, professionals on both ends of the transition process must be knowledgeable about ASD and

about the services that are available to the students as they make the transition (Camarena & Sarigiani, 2009). Because communication deficits are one of the primary characteristics of autism (*DSM-5*, 2013), the parents who participated in this study experienced barriers in trying to establish discussions with their children about attending college, finding the right college, and maintaining communication with the family once the student had made the transition to college.

This group of parents had varying degrees of satisfaction with the transition process, from Sheila's mother, who felt the process went very smoothly with a great deal of support and encouragement from high school and college personnel, to Mrs. White, who was only marginally involved with the transition process because her daughter was not formally diagnosed with autism until her freshman year in college, to Mrs. Jones, who was a part of the transition every step of the way.

Without exception, it was the parents who made the initial contacts with the autism program directors and once they were satisfied that this was an appropriate option, they encouraged their children to do some investigation of their own. Mrs. West talked about her search for the right college for her son Carl:

Ebel: You said you discovered Downtown University on your own? How did that come about?

Mother: Internet. I mean I just consumed what I could find on the internet, really I did – just hours and hours of research.

The family then visited four colleges across the Southeast, all having specialized autism programs. The initial meeting with the staff of the autism program at Downtown University was the deciding factor for Carl, according to Mrs. West, perhaps because Carl was finally ready to listen to what the staff told him. Carl had previously decided that he needed a “gap year” between high school and college, but that turned into a three-year gap before he made the

decision to go on to college. His friends from home and his sister were all in college and Mrs. West felt that Carl was finally ready to admit that he would need help if he wanted to be successful in college.

Mrs. Davis recalled her search for an autism program in their home state of North Carolina:

I tried to find a program in North Carolina. The answers I got were: we have tutors, we have extended time. I thought, no, you don't get it. He doesn't need tutors. He made a 1300 on the SAT. He doesn't need extended time. No. He has Asperger's. Well... That's what we have to offer. And I mean, these were fabulous colleges. But I just could not find anything for someone with Asperger's. I mean, we researched some of those colleges, but we still did not have a program for undergrad students.

One of the goals that Mrs. Davis had for Frank was to become more socially active once he arrived at the college campus, and the directors of the autism program at Downtown University created a goal as a part of his plan to help him achieve this. Mrs. Davis hoped that "when he went off and, you know, found other Asperger's students that he would have more in common with" that he would establish some emotional connections to other students and his school work that he had not made up to that point. Unfortunately, this goal has yet to be achieved. Mrs. Davis commented on her efforts to promote an emotional connection to people or activities while Frank was still in high school:

He has no friends. And he's fine with that. He would tell you he's fine with that. That's how he likes it. I used to try to get him nervous for his EOG – End of Grade – testing because he would not...he always made fantastic... he was a straight A student for elementary and middle school. He... he would not get nervous... he would not take them... I did not think he was taking the EOGs seriously enough.

For Mrs. Jones, Downtown University's autism program provided support that allowed Sarah to accept that it was all right to ask for assistance. Mrs. Jones told the story in this manner:

[The autism program] was good for her in that there were people for the first time in her life, other than her mother, that had something to say that made sense to her. And that was very important, that was very important. The transition to college for her was not

seamless but it wasn't terrifying once she got accommodations, once she realized that it's not a bad thing to get a little help. That step, and I can't tell you how many people I know – whose kids never take that first step of getting accommodations.

On the other hand, the autism program proved to be detrimental to her son David's progress in college. Mrs. Jones recalled,

[The autism program] was not good for David, and I hate to say that, but David started to see [the program] as another Mom. He wasn't ready for the message, and that's not against [the program], that's saying that he's different, he's not his sister... And we threw everything at it, you know? [The autism program] put together every support possible, but the bottom line is – if you don't want it, it doesn't really matter what you sell.

As a result, David, then an engineering major, stopped attending Downtown University after his second semester in college. He is now living with family members in Florida and is making plans to return to college there in the spring, studying marine biology.

Mrs. White appreciated the autism program for pushing her daughter Elizabeth, particularly in light of Elizabeth's extreme shyness: "The [autism] program pushes you, okay? They know how much to push her. I love [the program director] and Elizabeth likes her, I think [the program director] kind of gets in your face, and Elizabeth needs someone just making her do it." Elizabeth was resistant to participating in the autism program even with encouragement from her parents, perhaps because her diagnosis came so late. Afraid to ask for help, Elizabeth refused to take advantage of the services of the disability office on campus. According to Mrs. White, it was at that point that Elizabeth knew she could not be successful if she did not join the autism program. To provide additional support, "[The program director] told me (parent) I could be at every single meeting, I could go walk her to her classes if she wanted me to, and I offered to sit outside if she needed me to and sometimes we do it."

For students with ASD, a weakness in communication skills often becomes a barrier to determining an appropriate course of action (Hetherington, Durant-Jones, Johnson, Nolan,

Smith, Taylor-Brown, & Tuttle, 2010). Parents who participated in this study were quick to voice their thoughts about the value of maintaining strong lines of communication with their children during the transition process. Mrs. West used communication with her son Carl as a means to instruct and educate him about the autism program itself. When he balked at some of the required components of the program Mrs. West recalled her response:

“Mom, they’re going to make me do this, I’m going to leave!” I said, “Carl, if you work with the program, you’re going to have to do this.” We went back and forth on it, and I said, “Well, you know, you have to talk to [the program director] or [the assistant director],” and I said, “You have to work something out because I...I can’t work this out for you.” I don’t know if he worked it out or not, but after a couple of weeks I didn’t hear any more.

Mrs. Smith encouraged her son Michael to take dual enrollment classes, even though he initially was resistant to the idea. His plan was to completely finish his high school program and then begin college classes, but Mrs. Smith believed that making the transition to college gradually would be a better route for Michael, and they had several discussions about this. Mrs. Smith believes that because she and Michael have a strong line of communication between them, he was able to hear her concerns and think through the process of early enrollment and how it would be to his advantage. Mrs. Smith commented, “We’ve encouraged him to be in situations where he would have to develop his social skills. He’s very comfortable around younger people and can relate to them better, but people his own age and a little older – he struggles with that. That’s why we encouraged him to do the dual enrollment classes first.”

For Mrs. White, trying to build a line of communication with her daughter eventually came at a huge price. Elizabeth had always depended on her family to provide for her. As a very shy young woman, she had never ventured out to seek employment even though she was very capable, relying instead on her parents to finance her personal spending. After Elizabeth was diagnosed as autistic, the parents pulled back from Elizabeth and tried to force her to utilize the

services of the autism program instead of relying on her family to make decisions. Mrs. White recalls, “After a while and her first semester went fine. I think I did the thing that I didn’t realize, that I kind of pushed her away, because I’d always... she’d always be by my side. I did realize that was probably the best thing for her.” As a result Elizabeth shut down and began to resent her parents’ hands-off approach. They continued to encourage her to take advantage of the autism program’s services, but because she had lost her primary means of support Elizabeth found herself on academic probation at the end of her first semester. Mrs. White commented, “There is nothing to tell you as a parent how to...it’s all geared toward kids that have grown up knowing that it’s a different... it’s a different angle to come at than it is the other way.”

Having an open line of communication allowed Mrs. Tucker to work with Jack so he would understand the online component of his classes. She stated, “I think, sometimes, in those online classes...those online pieces that they put out there for the students, the organization of what...the way they put it out there is confusing, it’s confusing to me!” Working with him regularly at the beginning of each semester so he understands the structure and organization of the online components has allowed her to encourage Jack to keep working toward his completion goal. During these work sessions, Mrs. Tucker expressed her confidence in Jack, telling him, “You can do this. This is what you need to do. Jack, I know this is hard for you. But it’s not just you. You have all kinds of college students come in, hit a brick wall, and need help. You’re no different than they are.”

For Sheila, communicating with others is one of her weaknesses, according to Mrs. Parker. Sheila exhibits one of the more typical social skill deficits found in people with autism, that of being very direct and straightforward. The family has had many discussions about the

appropriateness of Sheila's responses to events going on around her, but she has not yet mastered the fine art of subtlety. Mrs. Parker told this story:

Sometimes she's so straightforward to the point that she seems rude. Because so many people are used to so much beating around the bush in their day-to-day communication, and she just does none of that, so she actually seems abrupt and rude sometimes. If she doesn't agree with something she'll come right out and talk about it, she'll call people out. There have been so many times I've had to hold her back in public places because she was going to go tell that man that he shouldn't be hitting on his child, and that that's not right, or she was going to go tell that woman she shouldn't be smoking and I had to say, "Wait a minute! That's not your place!"

Mrs. Parker felt that Sheila may have had opportunities to learn more socially acceptable behaviors if Sheila had had a peer mentor while she was in high school,

... because it would have been nice for her to be with someone who is not on the spectrum, go around with somebody else and have the person say, "Do you see anybody else in here who is doing what you're doing" you know? We just never had the opportunity to mentor her that way.

Sheila shared one moment with her mother that demonstrated her ability to recognize emotions in someone else. As they were walking one evening, Mrs. Parker asked Sheila if she was "okay with not having any friends." Sheila's response demonstrated a great deal of social maturity: "Mom, the only reason I don't have friends and it bothers me is because I know it bothers you."

Thomas Lynch was goaded into keeping in touch with his parents while at college. After four days away from home with no communication, Mrs. Lynch called Thomas and told him, "Listen when you don't live with anybody any more, like your parents, and you talked to them all the time, you need to call sometimes and say how you're doing!" Now the family speaks often, generally just "Things are fine, thanks, I'll talk to you later," but Mrs. Lynch noted that they have

pushed the communication, and every once in a while we do a ... you can tell by the voice that things aren't going quite so well, so we'll just say we're wanting to get out of [our home town] and we're going to come go to lunch in [the college town], you want to meet us for lunch?

### **Having Outside Support Provides Information and Resources for Action**

I guess what I would say is to find a good back-up team. (Mrs. Smith, mother of Michael, age 18)

All of the parents I interviewed admitted that they could not have managed the transition period without the support of a large group of people, including school personnel, family, friends, medical personnel, and other professionals who are familiar with autism. This advice and counsel allowed the parents to pursue the most appropriate courses of action they felt were necessary for their children. To address research question three, this section will look at the effort parents put into the transition process, particularly from the perspective of utilizing outside resources to gather information and provide support for the transition.

Since these parents were so heavily involved with their students' educational process from a very early age, they were able to find a number of resources along the way that aided in making the transition a much smoother process. For Mrs. Tucker, her own experiences as a substitute and then a permanent teacher allowed her to access resources within the school system that she might not otherwise have been aware of. She stated, "When we first went to [elementary school], the teachers just... and I was subbing, so they would be talking about these Pathway (autistic) kids without knowing I had a kid in the program, so I got the dirt, you know?" As a teacher, she was able to participate in an autism partnership program for two years, so even though she did not actually teach children with autism she was able to take advantage of this valuable resource. Mrs. Tucker also pointed to two of Jack's elementary teachers who were instrumental in establishing the first autism program in the local school system, and declared that they were "my strength."

Mrs. Smith felt that establishing a relationship with a good psychologist who was knowledgeable about autism provided Michael with the support he needed to be successful in

school. She feels the relationship that Michael established with the psychologist provided him with someone who could take an outsider's view of the struggles that Michael was going through:

Sometimes, I really want to tell Michael something, that there's something he really needs to understand that this is what he needs to do, but it just doesn't work, it just doesn't get through to him, and he gets mad at me, you know? But he'll talk to [the psychologist] and [the psychologist] explains it and he's like, "Oh, Mom, [the psychologist] says so-and-so." And I'm like, "Oh, did he really? That's exactly what I've been trying to get across for the last 3 weeks!"

A connection from a previous job allowed Mrs. Jones to become good friends with Stephen Shore, a well-known speaker, author, and professor at Adelphi University who was diagnosed with autistic tendencies at an early age. When the opportunity came to invite Dr. Shore to the private college where Mrs. Jones worked, she knew this was something that she had to take advantage of so she could begin to understand more about her children's autism from the perspective of an adult who is autistic and is flourishing. The friendship has continued and Mrs. Jones considers him her personal mentor, flooding him with many questions through the years. Mrs. Jones also called on the director of a local education and training facility for children and adults with intellectual disabilities when she began to recognize the possibility that autism was present in all of her children. She tells the story this way:

But I remember calling [the director] at the time, I was home, and I called and I said, "I need some help." He said, "Well, do you want me to give my official, my personal, my head of [facility] opinion, what do you want?" I said, "All of the above." He goes, "All right. You ready for it?" I said yes. And he says, "If it looks like a duck, and it quacks like a duck, and it waddles like a duck, it's really, probably a duck."

On another occasion, Mrs. Jones was able to connect her son David with a mentor at her place of worship, an engineer. She hoped that the interaction between the two of them would encourage David in his studies. David would spend time with the mentor, go to work with him,

work on school projects together, and learn what was involved with being an engineer. After a few weeks, Mrs. Jones spoke to David,

“Did you notice anything about [the mentor]?” He had spent a lot of time with him alone, and spent a week with him, and David goes, “Mom, does [the mentor] have Asperger’s?” I said, “Very good. Don’t you ever ask him that!”

Mrs. West related the story about a special education teacher at Carl’s private Christian high school who was instrumental in facilitating Carl’s acceptance to the autism program at Downtown University. Carl’s grades were not stellar, but the letter that this particular teacher wrote is what Mrs. West feels tipped the hand of the university in admitting him to the program. Ironically, it was this same teacher who provided the family with a list of colleges that she felt would be “disabled-friendly,” and Downtown University was not on the list. The family visited with the disability services offices at the other colleges on the list, all state universities in Tennessee and Kentucky, but none of them gave any encouragement to the family about support services for students with ASD. It was only after Mrs. West did a great deal of research on her own that she discovered the autism program at Downtown University. When the family visited the autism program and met the staff, Mrs. West declared, “This is what we’re looking for!”

Jacob’s interest in martial arts led Mrs. Hunter to enroll him in karate classes, but she had an ulterior motive:

My son was making Ds and Fs in school. I put him in karate and he started making As and Bs. That was the structure, foundation with him to do better, because it had rules and regulations he had to follow in order to stay with it, and if he couldn’t follow the rules and regulations then he couldn’t be in the program.

The karate instructor proved to be a strong influence in Jacob’s life, especially after the death of Jacob’s father. The instructor required Jacob to bring his progress reports and report cards to karate class to provide proof that he was maintaining good grades in school. The instructor also visited the home to make sure Jacob was maintaining the same structure there.

Mrs. Hunter believes the “drill sergeant, no excuses” personality of the karate instructor influenced Jacob to become more organized, to develop coping skills for when he experienced a difficult situation, and to mature into a young man who is respectful and trustworthy, traits that are necessary for a student to have a successful college transition. Mrs. Hunter remains concerned that Jacob, as a young African-American man, will fall prey to the lifestyle that so many other young men his age and race have taken up. Encouraging him to participate in self-defense classes is one way she hopes will allow Jacob to resist gang activity:

So that’s one of the reasons I let him take self-defense, is to be able to defend himself if something happens to where I’m not around to make him aware of his surroundings, you know, while he’s out. You can sense when something is not right, and I’ve told him to go with that sense, that’s your intuition, you go with that because usually 9 times out of 10 that’ll keep you from getting in a predicament that you can’t get out of.

Mrs. Parker relied on the school system to provide her with information regarding the transition process. Having taken the initiative to plan appropriate programming for Sheila even before she started kindergarten, the professionals in the school system crafted a program to fit Sheila’s needs early on, and Mrs. Parker was very satisfied with the resources that the schools provided her. However, taking honors classes in high school took a toll on Sheila, leading her to act out inappropriately. When this occurred, the family reacted calmly, asked that Sheila receive whatever punishment was necessary for a situation of this magnitude, and then took one further step to involve someone outside the family to help Sheila resolve the issues that she was dealing with: “Last year, after Sheila had her little meltdown over the AP English class situation we started going to [a counseling center] for her to get some help with therapy, and that’s really the only outside resource we have.”

For the Lynches, it was early advice from the doctor who first diagnosed Thomas as autistic that provided them with the tools to encourage Thomas to keep moving forward:

You know, [the doctor], who worked with us a long time ago when he diagnosed Thomas, the first words out of our mouths were, “Okay, now what do we do?” He said, “Well, you start pushing him. You expect everything of him. You don’t slack off for one minute, not one day.” And we didn’t. I don’t know if Thomas says some days that’s a good thing and other days he says no, that’s not.

The support provided by the autism program at Downtown University reinforced the doctor’s advice when Thomas has to have answers to questions right away. By discovering the right amount of impetus to put behind Thomas, the staff of the autism program were able to help him begin to understand that sometimes he must wait for things to happen, that answers do not come so quickly for some people, but that the answers will come.

Mrs. Davis spoke about sending Frank away to a two-week summer bridge program between his junior and senior years in high school. For Frank, it was the first time he had ever been around other people with autism. Nine other students participated in the summer program with Frank, with the focus being on developing life skills such as washing clothes, behaving appropriately in public places such as restaurants, managing money – the kinds of activities that would serve him well once he matriculated to college away from home. Because Frank was a loner growing up, the family felt that this kind of experience would serve him well, and while he learned the skills taught by the bridge program, he was not able to form any connections between himself and the other students in the program. The one regret Mrs. Davis expressed is that she wished they had made the decision to send Frank to the summer bridge program at the end of his senior year. She felt too much time had passed since he had attended the summer program and the benefit it could have provided to Frank as he made the transition to college was mostly lost. Mrs. Davis reported that even at Downtown University he remains a loner, perhaps the most isolated of any student who has participated in the autism program, according to the program staff.

## **Information-Sharing Leads to a Smooth Transition**

Facilitate independence, not dependence. (Mrs. Jones, parent of Sarah, age 22, and David, age 20)

The parents who responded to this study were very open with their thoughts and concerns about the transition process, particularly with regard to information they would have liked to have known in advance of making the transition. This section will address research question four by looking at whether the information provided to the parents could have prevented or lessened any issues the student may have encountered during the transition from high school to postsecondary education.

Only Mr. and Mrs. Parker were complimentary of the school system for the way they and their daughter Sheila had been prepared to transition from high school to postsecondary education. This was due, in no small way, to the early preparation that the school system engaged in to that the necessary educational tools would be in place once Sheila began kindergarten. Mrs. Parker recalled the experience. She stated,

And I hate to hear the stories from most of the people I hear from where they say, “The school my child went to was a great school as long as you were fitting a round object into a round hole. But in our child’s case you were trying to fit a square peg through a hole. And it just wasn’t working. Nothing ever worked.” And our experience just was not that at all. When people tell me throughout these years... the last several years I’ve had people come up to me and say – my friend, my sister, my so-and-so just found out their child is on the autism spectrum what do you think they should do? And I always say, “Tell them to put their house on the market right now and move to where they’re zoned for [our elementary school, middle school, and high school]!”

For most of the parents, however, the lack of information provided to them proved to be the biggest hurdle in preparing for the postsecondary experience for their sons and/or daughters. Even though the parents sought information from the schools their child attended, the school personnel were not knowledgeable about autism itself and were not aware of programs or services that might be available to the children as they approached high school graduation and

were looking forward to college attendance. Mrs. Jones, who is a special education teacher and has been passionate about autism since she was in high school herself, was the exception in the group, because her training and experience as a full-time advocate in the school system provided her with the tools and information she needed to guide both Sarah and David through the transition process. Her involvement with each of them, however, was different because of the particular needs of each child. For Sarah, she made the rules that had to be followed and as time went on and Sarah was able to take on more and more responsibility, Mrs. Jones was able to take a few steps back. In the case of David, however, her involvement was more direct and firm, even after he transitioned to college. She stated,

So, first semester, being the sergeant that I am, as my son calls me, gets on campus and I had times...I ask the questions and I get the answers that I want to hear, so he believes: "Doing great, Mom, doing great, great, great!" "How are your grades? I need to see your grades, and I trust you until you give me reason not to." Anyway, I went in and he was imploding. I had to drop something off with Sarah and I said, "You know, I'm going to turn around and go back and pop in." And that day was "intense, intense, intense studying," he was sitting in front of the TV. He came home and he didn't go back. I brought him home. He actually eked out a 1.9.

A number of the parents expressed frustration at not having the necessary support from the school system that would allow the family to prepare for postsecondary education. The reasons for this lack of support were varied, from the school personnel only being concerned with completing the necessary paperwork, to a lack of awareness of the capabilities of someone with autism, to an unwillingness to accept that college might be a realistic option for a student with autism.

For Mrs. Smith, the lack of information manifested itself in the attitude of the teachers at an early learning center, who were so rigid in their adherence to the curriculum that when Mrs. Smith suggested to a teacher that there might be other ways children could play with blocks besides stacking "them neatly, you know, in a step pattern, and I said, 'Well, what if they want to

build a house with the blocks?’ And she said, ‘That would be misuse of the appliances.’” The decision to homeschool Michael was made easier for Mrs. Smith after she and her husband realized that the public school system was not going to be able to address the particular needs that Michael had. Like many other children with autism, Michael had a hyperfocused interest in one particular topic, in his case, German U-boats. Because the school system’s curriculum is driven by state-mandated standards, the teachers would not have been able to use this interest to create an appropriate educational program for Michael. But in the homeschool environment, she said

I mean he knew everything about U-boats. He could tell you all the details about U-9 and U-7, and all the... what their displacement was and how far they could dive and their crash depth, and how fast. And that’s not something they can use in the public school but we could do that at home. We counted U-boats, we made stories about U-boats, we implemented that into his curricula and he really did well with that.

Bullying by his fellow ROTC cadets and the public high school’s response to the situation led Mrs. West to move Carl to a private school to complete his junior and senior years of high school. Ironically, Carl plans to join the Air Force after he graduates from college, so Mrs. West was concerned that this behavior, particularly from this group of students, would impact the career decision Carl had made. Whether the school was ignoring the possibility that bullying was actually taking place or was choosing to overlook it because Carl was autistic and it would have no real impact on him, Mrs. West knew that the environment would no longer be a healthy one for Carl if they did not act. Although she felt that Carl does not immediately display behaviors that are generally observed in a person with autism, his classmates apparently sensed the difference in him, and when Mrs. West reported it to the school administrators, the response was

Oh, that can't be happening, it's just the normal, you know, teenage angst and the kids are just playing with each other. Well it was quite more than that but at that point we thought, "You know what? Let's get him out of here."

Mrs. Lynch recalled an incident when Thomas first began elementary school. Thomas had difficulty speaking clearly, and school personnel, who had little knowledge about autism, according to the superintendent, were concerned that they would not understand him if he needed something. Mrs. Lynch was not willing to accept that as an excuse to keep Thomas out of school. She stated,

He had a tremendous amount of difficulty speaking, that was one of his biggest challenges, so when he started school they didn't want him to be in the classroom because they couldn't understand him. And so I said, "Well, good news. His brother's just right down the hall so if you get really stuck just run down the hall." I mean, I just didn't let the school district decide where he was going to be.

Although she was comfortable with the school system's eventual programming for Jacob, Mrs. Hunter nevertheless felt that problems could have been avoided if the teachers at Jacob's zoned elementary school had been willing to work with him to keep him actively involved in the curriculum. A self-confessed computer geek, Jacob was bored in the regular classroom setting and began acting out. Mrs. Hunter intervened when she realized that Jacob would not be successful if he remained in his zoned schools. She recounted the story as follows:

The only problem is – y'all don't know how to deal with it because you don't know how to keep his mind going. I can handle that, so all I'm asking you to do is do your part and I can do mine at home, and if you can't do your part here, then I can come here and help him with doing the part by saying, "This is boring." That's why he's going into the outbursts that he does because he's bored. He needs a challenge. You have to keep him challenged, you have to keep him going.

Her intervention at this stage of Jacob's education led the school system to allow him to attend a vocational high school where he could receive training and further hone his self-taught computer skills. Jacob now works part-time in the college's information technology office and is hopeful that he will be hired into a full-time position after he graduates.

According to Mrs. Tucker, Jack's initial delays in receiving services in school could have been avoided if the family had initially sought an evaluation from the school system. Instead, they looked to a local private agency that conducted evaluations on children with suspected learning differences, but this alternative did not provide any answers for the family. The evaluation report was slow to come, and Mrs. Tucker eventually had to quit working so she could oversee Jack's educational placement. Mrs. Tucker remembered,

I wish I would have gotten the school system right off... and got to the school system. As a matter of fact the lady at [the school system assessment center] I worked with a lot, but ... actually she became my lead teacher years later, but she... you know, we got in.

A fight to keep her son out of special education programming led Mrs. Davis to push the school system to evaluate her son, because the school personnel did not recognize that, even though he was intelligent, Frank was still in need of support services to help overcome the barriers that had been created by his autism. Mrs. Davis viewed the incident as a call to arms against administrators who were not informed. She stated,

When I was trying to get an IEP and they said he's too smart, he's three grade levels ahead, um...and this is a school counselor telling me this...He's three grade levels ahead and until he's behind can he get an IEP. And I knew he was not performing at the level he could perform, and part of it was dysgraphia and part of it was the ADHD, and I tried for a year talking to the school counselor, and finally I called the head of the county, and they finally tested him... They had him tested within three weeks. So don't be afraid of going over somebody's head!

### **Transition Ends; You Must Take Care of Yourself**

Although not directly related to any of the research questions, a fourth theme did emerge through the parent narratives. When asked what advice they would share with other parents who were going through similar circumstances, several of the respondents cautioned other parents to remember that, once the transition process is complete and the student with autism is moving more and more toward independence, life does go on. Mrs. Jones said it best. She said,

I didn't think about me for 21 years, and it was time to start putting the oxygen mask on myself. I gave up, and I would give up all over again, but at this point in my life, I'm 52, it was time to think about me. I was divorced in 2001 and I really only started dating this year. And I would do it all over again, but you have to start thinking back about you. And I don't even mean just dating, forget that. Like – no hobbies, no... it's just about the kids, the kids... No social life, forget it, no, no, the kids need money, the kids need whatever. You gotta start to put the oxygen mask back on yourself, and here's the deal: we forget how to do it. And here's another thing: I started not wanting to socialize. You don't want to socialize a lot of times with neurotypical families because Tommy, Janie, Bobby and Susie – that they grew up with – are all going to college, and have boyfriends and girlfriends, or getting jobs, or driving a car, or taking a trip to Bermuda, or going here or ...It's not that you wish anyone ill. It's just – leave me my own little world and my level of normalcy is totally normal, albeit skewed, but it is normal, because I don't see anyone else, you know?

Both Mrs. Parker and Mrs. Hunter urged parents to seek outside advice in the form of coaching or networking with other parents. Mrs. Parker encouraged parents to seek out coaching if they are not aware of the resources that may be available to them, both in the school system and in the community. In her words, "They have to get involved, they have to not be afraid of staring people down, they have to just go advocate for their child." Mrs. Hunter admonished parents to talk to others who have children with autism, either through a local support group or in an online chat group. In her words, "You can tell them what your child's going through, and they can tell you what their child's going through and you can compare notes."

Mrs. Smith's story was the most telling with regard to the sacrifices these parents have made to ensure educational success. She gave up her career to homeschool Michael, and now she is re-entering the workforce after a nine-year hiatus. She related her concerns by saying

I never expected to be a housewife. I gave up my work and I have basically devoted myself to his education. I never expected to be a teacher, that just wasn't in my plan, so it's been... I've read this essay, I'm sure you've heard about it, they talk about when your child is born you're going to Holland, and you expect to go on a vacation to the Caribbean, but you're going to Holland because the child is born and that's just what the child needs, you know, so it was really a repositioning of who I was and what I was going to do with my life. You know, I'm going back into the workforce, hopefully next year when Michael is in college full time, and people are going to say, "What did you do for the last 9 years," you know?

## Summary

Parents who participated in this research study were very vocal in their thoughts about the transition process. Although four research questions were proposed, most of the responses to the interview questions could be categorized under the first theme that was uncovered, that of being life-long advocates for their children. Throughout school, parents are the first line of offense and defense for their children, but when parents are faced with the challenges that accompany a child that is born with autism, there is a burning need to become educated about the disorder itself and what the implications are for the child's educational future. Finding a college with an autism program was critical to this group of parents, because they knew the program has professionals in place who understand autism and who could help them guide the students through the maze that is college. This had not been true in the K-12 environments, where most parents encountered uncertain and uninformed teachers and administrators, school systems that were not prepared to address the needs of students with autism, and lack of instruction to the parents themselves as to what resources were available to them to assist their children to make satisfactory progress toward graduation and the transition to postsecondary education.

Along the way, some parents were able to connect with professionals both in and out of the school system who were able to provide insights about autism and about support services that were available to move the students forward in their educational quests. This group of support personnel included family members, psychologists, teachers, and college disability service providers, and each support person provided a unique viewpoint to the struggles of the parents. With the advice and counsel of this group, the parents were able to make choices that fit the needs of the students. The "support team," as one parent called it, allowed her to take a step back and look at the daily struggles with fresh eyes.

Finally, after the transition to postsecondary education has been accomplished, parents were quick to caution others who were going through similar experiences not to let the transition experience define who they are. As parents, they are responsible for raising their children to be productive citizens of the world, but once that has happened, parents should remember to put their own lives back together. The parent respondents who had reached that milestone along the journey were still learning how to find their way back to themselves, a difficult task to undertake after so many years of focusing solely on the needs of their children.

## CHAPTER V:

### DISCUSSION

He's growing up, we're not growing down. (Mrs. Davis, mother of Frank, age 19)

#### **Introduction**

The findings of the study will be discussed in this chapter. As stated previously, transition programming for students with ASD, in general, seldom includes the skills necessary to navigate the qualitative elements of the college experience. This study focuses on the role of parents in bridging that gap in preparation between high school and postsecondary education, as told through their narratives. The purpose of these narratives was to provide in-depth descriptions of the parents' experiences with assisting their sons and/or daughters in their transition from high school to the postsecondary education environment. Structured in-depth interviews were conducted with parents, focusing on the skills, preparation, and supports they provided to the students to help make for a smoother transition from K-12 to higher education, where expectations and roles are significantly different with relation to other students, instructors, and arranging for services because of the disability. This chapter synthesizes the research findings in light of the four research questions:

1. What training or advice was provided to parents of students with ASD to make them aware of postsecondary education options for their child;

2. What information did postsecondary institutions provide to these parents to enable them to prepare those students to have a smoother transition to postsecondary education;
4. To what degree did the parents assist with preparing the student for the transition to postsecondary education; and
5. From the parents' perspective, what issues could have been prevented or lessened if adequate information had been provided by the high school or postsecondary professionals?

The results of the study may better inform other parents and higher education personnel who have been, or are currently involved with, students with ASD. Armed with important information about the transition experiences of these students and their families, these support professionals may be able to provide more substantial transition training for students with ASD who hope to attend college in the future. The discussion suggests that there is need to recognize the expertise that parents bring to the transition process, as well as look at measures that can be taken to allow for more functional transition planning for students with ASD. Using the four research questions as the guidelines for discussion, I highlight areas where school systems and universities can create a more supportive and encouraging environment for these students and their parents, particularly since research has shown that the students with ASD are attending college in larger numbers than any other time in history (Camarena & Sarigiani, 2009; Peña & Kocur, 2013; VanBergeijk, Klin, & Volkmar, 2008; Thierfeld Brown, 2008).

The incidence of individuals being diagnosed with ASD continues to rise. Most recently, the Centers for Disease Control (2014) reported that 1 in 68 individuals now falls somewhere on the spectrum. As more and more children are diagnosed with ASD, schools are being forced to

design appropriate curricular interventions to meet the needs of this population (Peña & Kocur, 2013). With appropriate intervention and support while they are in grades K-12, students with ASD can develop the necessary skills, both academically and socially, that will allow for successful progress toward graduation from high school and the transition to postsecondary education.

The narratives of the parents who participated in this study reflect the struggles and successes they and their children have experienced, and the information gleaned from these narratives can inform future practices of not only high school personnel when preparing students with ASD to enter postsecondary education, but also college disability services providers who receive these students after graduation from high school

### **Discussion**

The educational goals of high school students with ASD are essentially the same as the goals of any other student: to have the opportunity to “acquire skills that increase personal independence and social responsibility” (Hendricks & Wehman, 2009, p. 78.). For most typical students, attending college is a goal that is not only desirable but also attainable, but for students with ASD, looking ahead to college enrollment requires appropriate intervention by the school system as well as significant parental involvement, both beginning at an early age. As the parent narratives in this study have shown, parents of children with ASD assume the role of primary advocates for their children early on, and that role continues even after the student arrives on the college campus.

Because students with ASD have such diverse needs, the challenges to appropriate transition planning for this group are many (Griffin, Taylor, Urbano, & Hodapp, 2013). Deficits in communication and social skills create barriers to their participation in planning for the

transition from high school to postsecondary education. As a result, parents become their voices at required transition planning meetings in the high school. These parents, who have guided the educational programming for their children for many years, have dedicated a good portion of their lives to finding and fighting for educational training that has a positive impact on the development of their children into college-ready students, often without any support for themselves (Tincani, Cucciarra, Thurman, Snyder, & McCarthy, 2014).

In this research study, no two parents related the same experiences as they reflected on the transition of their students from high school to postsecondary education. While there is some research that addresses the needs of students with ASD as they matriculate to college (Camarena & Sarigiani, 2009; Griffin, Taylor, Urbano, & Hodapp, 2013; Morrison, Sansosti, & Hadley, 2009; Palmer, 2006; Roberts, 2010; Tincani, Cucchiarra, Thurman, Snyder, & McCarthy, 2014; VanBergeijk, Klin, & Volkmar, 2008; Van Pelt, 2008), a much smaller body of work speaks to the role and experiences of the parents as they go through the process with their child (Camarena & Sarigiani, 2009; Griffin, McMillan, & Hodapp, 2010; Hendricks & Wehman, 2009; Hetherington, Durant-Jones, Johnson, Nolan, Smith, Taylor-Brown, & Tuttle, 2010; Peña & Kocur, 2013). By sharing the rich narratives of the parents who participated in this study, valuable information was gleaned that could be beneficial to both high school and postsecondary education personnel, as well as to other parents who are experiencing similar struggles with the transition of their own children with ASD.

The stories told by the parents reflect several important constructs that relate to the psychosocial development of college students, and particularly students with ASD, as they progress through the vectors proposed by Chickering and Reisser (1993). The narratives reflect the involvement of the parents in aiding the student's progression through those vectors. Each of

those constructs serves to define more clearly both the positives and the negatives that each parent experienced as the student prepared to go to college. This group of parents expressed the hope that their now-grown children have developed maturity by learning and demonstrating appropriate behaviors in their interactions with others, and by showing growth in their ability to solve problems through sound reasoning and decision-making. Most of the parents felt these skills were not addressed at the high school level, thereby leaving their children unprepared for what to expect in the college environment.

The transition to college involves not only high school personnel but also college disability services staff. Professionals on both ends of the transition process must be knowledgeable about ASD and about the services that are available to the students as they make the transition. The majority of the research done on educational programming for students with ASD has focused on children in the lower grades (Camarena & Sarigiani, 2009). As this population has grown older and the students and their parents have begun to look at post-high school options, information is lacking that could guide them and school personnel through the transition process.

From the stories told by these parents, it appears that much work still needs to be done to address the issues of training and advice provided to parents of students with ASD who are considering the option of college, as suggested by research question one. Either high school personnel are not well-informed about the capabilities of students with ASD beyond simple vocational training or community-based living arrangements, or they are not able to structure the high school programming to meet the needs of these students beyond the scope of the traditional high school curriculum. The parents who participated in the current study had varying degrees of satisfaction with the transition process, from Mrs. Parker, who felt the process went very

smoothly with a great deal of support and encouragement from the high school, to Mrs. White, who was only marginally involved with the transition process because her daughter was not formally diagnosed with autism until her freshman year in college, to Mrs. Jones, who was an assertive member of the transition planning team every step of the way for both of her children.

Research question two addresses the information provided by postsecondary institutions that would enable parents to prepare their students for college and university life. According to the parents that were interviewed, the autism program at Downtown University played a key role in the decision to attend college. In almost all cases, the parents were the primary catalyst in encouraging their children to attend Downtown University, but for a few of the students, a campus visit and interaction with the directors of, and other students who were participating in, the program helped sway their opinions. While most of the parents agreed that the program itself has proven to be beneficial to their child, they also agreed that their child had to be ready to accept the structure and procedures that the program requires. In the case of two of the students, David Jones and Elizabeth White, their levels of readiness proved to be inadequate and they were not able to remain at the university. These two examples support the idea that K-12 personnel are not adequately prepared to meet the needs of students with ASD. While these students possess the intellectual capability to meet the academic rigors of college, they experience serious shortfalls in the qualitative elements of a successful college experience.

Colleges and universities appear to be leading the way with regard to transition efforts for students with ASD. Certainly, schools with specialized autism programs such as Downtown University are on the cutting edge in providing the necessary support and programming that can lead to successful college placement for students with ASD, but even colleges that do not have specialized ASD programs recognize the need to prepare themselves for the increasing number

of students with ASD that are college-bound. Typical college disability service programs offer accommodations to all students who self-identify as having a disability, but disability services professionals are recognizing the need to provide more in-depth services for students with autism, such as tutoring, informal support groups, workshops on time management and organizational skills, and frequent check-in meetings with a disability services staff member. Colleges also recognize that significant parental involvement in planning for accommodations and support will be the norm rather than the exception.

The Association on Higher Education and Disability (AHEAD), the professional organization for disability service providers at colleges and universities across the country, holds an annual conference where attendees can participate in workshops, seminars, and information sessions to learn about current trends and best practices in disability services. At the 2013 AHEAD conference six concurrent sessions addressed the issue of students with ASD in higher education (AHEAD website, 2013). In 2014, the number of concurrent sessions dropped to three, but there were two poster sessions, along with a full day pre-conference institute focusing on working with college students with ASD (AHEAD website, 2014).

Because of their heavy involvement with educational planning all through the school years, parents of students with ASD become familiar with the role of communication facilitator between their children and school personnel (Peña & Kocur, 2013). Research question three required that I look at the degree of parental involvement in the transition planning process. In their study of postsecondary educational aspirations for student with ASD, Camarena and Sarigiani (2009) considered other postsecondary options that might be available to this group of students, such as vocational training or planning for independent living. While the students and parents involved in that study felt that college might be one of the available options, it was not

the primary consideration. For the parents in my research study, attending college was the only option considered for their children. All of their efforts, from the earliest stages, were focused on helping their children be better prepared so they would meet with success at the college level.

Even though parental participation in educational planning for students with disabilities is mandated by federal law, a study conducted by Defur, Todd-Allen and Getzel (2001) speaks to the notion that parents of exceptional students feel school personnel treat them as if they are not knowledgeable about their own child or his educational needs, when in reality the parent is most often the first and longest-term teacher of the child. Ivey (2004) spoke about the role parents should be playing in the educational process for students with ASD, and yet the parents who participated in her study felt they received little support and were expected to have virtually no input in developing an appropriate educational plan. The study reports that the parents felt “because they were the primary contact in their children’s lives, their opinions and expectations should have more importance than the judgments or opinions of school personnel” (Ivey, 2004, p. 27). The parents who participated in this research study would agree with these two conclusions. A number of them spoke of a lack of information provided to them by school personnel, as well as the lack of cooperative planning and encouragement for seeking out postsecondary education as a viable option even though the parents strongly believed that college was a possibility for their child. A “one size fits all” approach to educational programming for students with ASD is not an appropriate option, given the diverse needs of this group.

Findings that address research question four discovered it is imperative that information about postsecondary options for students with ASD be made available to parents as early as possible as they assist their students in working through the transition process. Proper transition planning is a collaborative effort that includes parents, teachers, other professional service

providers, and the student. It is important, therefore, that both parents and school personnel have adequate information about ASD and about appropriate postsecondary options for the student. For the parents in this study, information from the various school systems was generally lacking. Some felt school personnel did not have adequate information and training about ASD themselves, while others believed that the school system professionals did not take seriously the possibility that a student with ASD could be successful at the college level. In both instances, the parents understood it was their right to “knock heads,” as Sheila Parker’s mother so clearly stated, in order to make it clear to school personnel that college was indeed an option, and one that their children would be pursuing. This attitude by K-12 teachers, resulting in low expectations of students with ASD and their potential to attend college, might be explained in part by examining the lack of services for this group of students since, up until the 1990 amendment of IDEA, autism did not exist as a category of disability. Indeed, many students with ASD were viewed as having intellectual disabilities, thereby precluding all expectations of college attendance. More than two decades have now passed since IDEA provided specific guidelines for service and educational programming for children with ASD, and yet many of these students still are not viewed as potentially successful college students (VanBergeijk, Klin, & Volkmar, 2008).

### **Implications for Practice**

The federal government mandates that transition planning must begin at the age of 16 when a student is involved in special education programming (IDEIA, 2004), and that the student must participate in this planning. For students with ASD, transition planning must begin earlier in the school career, perhaps while they are still in middle school. The communication and social skills deficits that are common among this group of students prevent them from interacting

appropriately in group settings, particularly when thoughtful decisions are being made that have an impact on the student's educational future. For a student with ASD, being able to articulate goals and ambitions clearly generally requires mastery that does not take place over a short period of time. The more exposure students with ASD have to the decision-making process, the more likely they are to understand the role they play in transition planning, and the more likely they are to give careful input into the decisions that are made in these meetings.

Contrary to the findings of Griffin, Taylor, Urbano, and Hodapp (2014), the current study found no evidence that students with ASD are “the least likely to participate in postsecondary employment or education” (p. 263). Attending college was the only option considered by this group of parents. While the transition planning process was labored, the parents indicated they had fought battles over appropriate programming and placement with K-12 school personnel throughout their child's educational lives, keeping in mind the long-term goal of college attendance. This resulted in the parents' becoming advocates for their children at all levels. Their role in locating the autism program at Downtown University speaks to the degree of involvement of these parents in the educational planning of their children.

For students with ASD to be well-prepared to assume leadership roles in the transition process, parents must be considered equal partners with school personnel. It is the parents who have been at the forefront of educational planning for this group of students for many years and as such, the parents likely are more knowledgeable about the strengths and weaknesses of their children than are school personnel. Parents are also more aware of the developmental milestones, such as social maturity and communication skills that set students with ASD apart from typical students. Parents who are well-informed and feel they are a part of a collaborative transition

effort can better prepare their children for what to expect during transition planning meetings and work with them to develop appropriate interactions during the meetings.

Parental involvement in the transition process is critical to the success of this group of students (Peña & Kocur, 2013), but school personnel do not appear to take into consideration the level of importance of parental involvement. As many of the parents in this study reported, often teachers gave no encouragement to the parents that their child was capable of being successful in college. Teachers and other school personnel must be receptive to the knowledge set that parents bring to transition planning meetings and take advantage of the valuable information that parents have to share with regard to the development of their children. Transition planning should not be an adversarial process; it should be a process where all parties involved respect each other and respond appropriately to meet the needs of the child, within the scope of the guidelines for transition planning that have been set out by federal, state, and local governments.

School personnel must be knowledgeable about ASD so they can prepare these students for the transition to postsecondary education. Although students with ASD likely have been a part of the school population for many years, it was not until 1990 that autism was recognized as one of the categories of disability that was eligible for services under federal legislation (IDEA, 1990). A cursory look at the special education teacher education curriculum requirements of the three largest universities in a southeastern state reveals that autism is included as a part of the curriculum in survey courses only. As the number of students with ASD continues to increase, teachers must have more in-depth instruction. Teacher preparation programs, particularly special education teacher programs, must undergo a shift in pedagogy that primarily advocates education for the masses and turn to intensive training for groups of students, such as students with ASD, who are often marginalized during their school years.

School administrators also must shoulder part of the responsibility for the gaps in knowledge about ASD, since they are ultimately responsible to the school system for the decisions that are made within their respective buildings. Yet administrators lack even a basic foundation in education of students with special needs (Horrocks, White, & Roberts, 2008; Neumann, Meyer, & Buchanan, 2011). A review of the catalogs for the same three universities revealed that one has no program in educational leadership, while the other two colleges do have master's level school leadership programs, each curriculum having a single course that focuses strictly on special education law and policies. School system administrators and state education leaders must make appropriate training in ASD a required component of any professional development activities that school personnel are required to complete.

Because colleges and universities appear to be taking the lead in planning appropriate educational interventions for students with ASD, K-12 school systems would be wise to take advantage of the expertise that is available through special postsecondary programs for students with ASD, such as the one at Downtown University. General disability services offices at colleges and universities also have trained professional staff who are knowledgeable about ASD and who can provide assistance to schools in the K-12 system. A question was posed to disability service providers at community colleges and universities in a large state college system in the southeastern United States, inquiring as to whether they offer any additional support to students with ASD beyond basic accommodations. Over half the institutions (11 out of 19) reported some type of support group, coaching, social skills training, or other programming that has been created to address the needs of students with ASD. The knowledge base at these and other postsecondary institutions around the country could provide valuable information to educational

personnel in the K-12 system and better equip teachers and administrators at that level to prepare students with ASD and their parents for the transition to postsecondary education.

In a related vein, college and university officials must acknowledge that parents will continue to be heavily involved with students who have ASD even after they have transitioned to higher education. Colleges are accustomed to reminding typical students that they now shoulder the legal responsibility for decision-making rather than their parents, who may have provided assistance to the students over the years. Parental involvement is an ongoing and critical component of growth and development for students with ASD; therefore, including the parent in training the student to become more autonomous, as well as contributing to the child's social, emotional, and academic adjustment is imperative for college success (Carney-Hall, 2008). College disability services offices must work with parents of students with ASD differently than they might the parents of other students with disabilities, knowing that these parents have been deeply involved with their child's education from the beginning. The parents know their child; the disability services provider knows how to navigate the roads of college. If both parties approach the transition process with mutual respect and understanding, a strong partnership can be created that will lead to a successful transition experience for the student with ASD.

Several weaknesses exist in both the K-12 and higher education systems with regard to the full involvement of students with disabilities. Using the medical model of disability to define the student and make a determination of the services and support that should be provided does an injustice to the student and his/her family. By viewing the student as something that needs to be "fixed," no room exists for communication and dialogue between school personnel at both levels and the parents who are the most knowledgeable experts on the needs of the student. Therefore,

it is important that education as a whole begin to view disability through another lens, one that adds value to the person as a full partner in the transition process.

Finally, both high schools and colleges must create a supportive environment for parents during the transition process. Research has shown that raising a child with ASD “can increase parents’ stress, depression, anxiety, and financial burdens, and decrease overall quality of life” (Tincani, Cucchiarra, Thurman, Snyder, & McCarthy, 2014, p. 331). Parents must feel they are valued as knowledgeable experts on their children, and their opinions must be respected and strongly considered. Support groups for parents or other parent organizations at both the high school and college levels would allow parents of students with ASD to share successes and challenges, providing learning opportunities for all involved. In the words of Susan TePaske, director of Disability Resources for Students at the University of Memphis, “I agree that the parents need help. They often feel alone if they have not hooked up with other parents of kids on the spectrum” (S. TePaske, personal communication, October 23, 2014).

### **Conclusion**

The purpose of this study was to learn about the experiences of transition from high school to postsecondary education from the narratives of parents whose children have ASD. With the exception of one student who was dually enrolled in both high school and college classes, these students had successfully completed high school and had entered college as a member of a special program for students with ASD at Downtown University, an urban comprehensive university in the Southeast. I attempted to ascertain whether parents of students with ASD felt they had the necessary tools to assist with the transition of their children from high school to postsecondary education. In addition, the role the college played in providing

information to the student and parents was critical, since the students were participating in a special program designed to provide emotional, social, and educational support for them.

The parents' stories most often told of frustrations and challenges experienced at the high school level, primarily grounded in the high school personnel demonstrating a lack of knowledge about ASD and the options that are available to students with ASD after high school. In addition, the parents believed they are not taken seriously during transition planning, as witnessed by the numerous recollections of struggling with school personnel to ensure their child received appropriate placement and services in the high school. As life-long advocates for their children, the parents had valuable information that could have made the transition process smoother, but school personnel either did not view the parents as experts on their own children, or did not recognize the parents as equal partners in the transition planning conversation.

Successes did occur, particularly in situations where parents, school personnel, and outside support people worked together to plan and execute transition activities for the student with ASD. These positive transition experiences should serve as examples to high school and college personnel if they are to begin to collaborate on making transition to postsecondary education a successful part of the child's growth and development. Opportunities to teach the child self-advocacy, knowledge of his particular strengths and weaknesses, and options that are available after high school should be available to the student from middle school onward, and the only way this can occur is in finding a mutual respect between parents and school personnel, and a recognition that parents are a valuable, knowledgeable, and critical members of the transition planning team.

Colleges and universities appear to have moved to the forefront of training and support for students with ASD, and the valuable knowledge that is present at postsecondary institutions

could be shared with K-12 personnel in a number of ways so educators and administrators at that level can make better choices for transition planning. Postsecondary institutions like Downtown University, that have taken the next step to provide a special college-level support program for students with ASD, should take the lead in providing education and support to high schools that struggle with how to work successfully and appropriately with students who have ASD. If the student with ASD has the support of empowered parents and knowledgeable school personnel at both the high school and college levels, the likelihood of a successful transition experience can become a reality.

## REFERENCES

- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-function autism spectrum disorders. *Intervention in School and Clinic, 42*, 271-279. doi: 10.1177/10534512070420050201
- Allen, D., Evans, C., Hider, A., Hawkins, S., Peckett, H., & Morgan, H. (2008). Offending behavior in adults with Asperger Syndrome. *Journal of Autism and Developmental Disorders, 38*, 748-758. doi: 10.1007/s10803-007-0442-9
- Allen, R. A., Robins, D. L., & Decker, S. L. (2008). Autism spectrum disorders: Neurobiology and current assessment practices. *Psychology in the Schools, 45*, 905-917. doi: 10.1002/pits.20341
- American Psychiatric Association (APA). (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: Author.
- American Psychiatric Association (APA). (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed. Rev.). Washington, DC: Author.
- American Psychiatric Association (APA). (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- American Psychiatric Association (APA). (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author
- Americans with Disabilities Act (ADA)*, 42 U.S.C. §§ 12101 et seq (1990).
- Americans with Disabilities Act Amendment Act (ADAAA)*, 42 USCA § 12101 et seq (2008).
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469-480. doi: 10.1037/0003-66x.55.5.469
- Arnett, J. J. (2004). *Emerging adulthood: The winding road from the late teens through the twenties*. New York, NY: Oxford.

- Association on Higher Education and Disability (AHEAD) (2013). *2013 AHEAD Conference*. Retrieved from <http://ahead.org/conferences/2013>
- Association on Higher Education and Disability (AHEAD) (2014). *2013 AHEAD Conference*. Retrieved from <http://ahead.org/conferences/2014>
- Assouline, S. G., Nicpon, M. F., & Doobay, A. (2009). Profoundly gifted girls and autism spectrum disorder: A psychometric case study comparison. *Gifted Child Quarterly, 53*, 89-105. doi: 10.1177/0016986208330565
- Astin, A. W. (1984). Student involvement: A developmental theory for higher education. *Journal of College Student Personnel, 25*, 297-308.
- Astin, A. W. (1993). *What matters in college? Four critical years revisited*. San Francisco, CA: Jossey-Bass.
- Atkinson, R. (2001). The life story interview. In J. Gubrium & J. A. Holstein (Eds.). *Handbook of interview research: Context and method* (pp. 121-140). Thousand Oaks, CA: Sage.
- Attwood, T. (1998). *Asperger's syndrome: A guide for parents and professionals*. London, England: Jessica Kingsley.
- Autism Society of North Carolina. (nd). *Preparing for the transition to college for a student with ASD*. Retrieved from [http://www.autismsociety-nc.org/transition\\_to\\_college.pdf](http://www.autismsociety-nc.org/transition_to_college.pdf)
- Babbitt, B. C., & White, C. M. (2002). "R U READY?" Helping students assess their readiness for postsecondary education. *Teaching Exceptional Children, 35*(2), 62-66. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=102&sid=a5ae2652-b8fb-4c5b-a4d7-9da2eb2eaf46%40sessionmgr115>
- Baker, J. (2005). *Preparing for life: The complete guide for transitioning to adulthood for those with autism and Asperger's syndrome*. Arlington, TX: Future Horizons.
- Barnhill, G. P. (2007). Outcomes in adults with Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities, 22*(2), 116-126. doi: 10.1177/10883576070220020301
- Baron-Cohen, S. (1997). *Mindblindness: An essay on autism and theory of mind*. Cambridge, MA: The MIT Press.
- Bauer, S. (2008). *Asperger Syndrome*. OASIS @ MAAP. Retrieved from <http://aspergersyndrome.org/Articles/kelley.aspx>
- Beale, A. V., & Ericksen-Radtke, M. M. (2001). Preparing students with learning disabilities for college: Pointers for parents, part 2. *Exceptional Parent, 31*(10), 56-58. Retrieved from <http://go.galegroup.com.libdata.lib.ua.edu/ps/retrieve.do?sgHitCountType=None&sort=DA-SORT&inPS=true&prodId=ITOF&userGroupName=tusc49521&tabID=T003&>

searchId=R3&resultListType=RESULT\_LIST&contentSegment=&searchType=AdvancedSearchForm&currentPosition=25&contentSet=GALE|A103378842&&docId=GALE|A103378842&docType=GALE&role=&docLevel=FULLTEXT

- Berney, T. (2004). Asperger syndrome from childhood into adulthood. *Advances in Psychiatric Treatment, 10*, 341-351. doi: 10.1192/apt.10.5.341
- Berzonsky, M. D., & Kuk, L. S. (2000). Identity status, identity processing style, and the transition to university. *Journal of Adolescent Research, 15*, 81-98. doi: 10.1177/0743558400151005
- Braxton, J. M., Hirschy, A. S., & McClendon, S. A. (2004). Understanding and reducing college student departure. *ASHE-ERIC Higher Education Report, 30*(3), XI-97. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=8&hid=20&sid=0ada0852-5f14-45d0-93d5-373e93655bdd%40sessionmgr15>
- Brinckerhoff, L. C. (1996). Making the transition to higher education: Opportunities for student empowerment. *Journal of Learning Disabilities, 29*, 118-136. doi: 10.1177/002221949602900202
- Brinckerhoff, L. C., Shaw, S. F., & McGuire, J. M. (1992). Promoting access, accommodations, and independence for college students with learning disabilities. *Journal of Learning Disabilities, 25*, 418-429. doi: 10.1177/002221949202500702
- Broatch, L. (nd). *Is there life after high school? A Primer for teens with learning disorders*. Great Schools. Retrieved from <http://www.greatschools.org/special-education/health/909-life-after-high-school.gs?page=all>
- Brown v. Board of Education*, 347 U.S. 483 (1954) (USSC+).
- Camarena, P. M., & 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. doi: 10.1177/1088357609332675
- Carney-Hall, K. C. (2008). Understanding current trends in family involvement. *New Directions for Student Services, 122*, 3-14. doi: 10.1002/ss.271
- Centers for Disease Control and Prevention (28 March, 2014). Prevalence of autism spectrum disorder among children aged 8 years — Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report (MMWR)*. Retrieved from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s\\_cid=ss6302a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w)
- Chickering, A. W. (1969). *Education and identity*. San Francisco, CA: Jossey-Bass.

- Chickering, A. W. & Reisser, L. (1993). *Education and identity* (second edition). San Francisco, CA: Jossey-Bass.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles, CA: Sage
- Crosnoe, R. (2001). Academic orientation and parental involvement in education during high school. *Sociology of Education*, 74, 210-230. doi: 10.2307/2673275
- Crow, L. (1996). Including all our lives: Renewing the social model of disability. In J. Morris (Ed.), *Encounters with strangers: Feminism and disability*. Retrieved from <http://www.roaring-girl.com/wp-content/uploads/2013/07/Including-All-of-Our-Lives.pdf>
- Cumine, V., Leach, J., & Stevenson, G. (1998). *Asperger syndrome: A practical guide for teachers*. London: Routledge.
- Daniel, B. V., Evans, S. G., & Scott, B. R. (2001). Understanding family involvement in the college experience today. *New Directions for Student Services*, 94, 3-13. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=102&sid=abc880a9-b97b-4272-8a99-c7baecff7b6c%40sessionmgr111>
- Defur, S. H., Todd-Allen, M., & Getzel, E. E. (2001). Parent participation in the transition planning process. *Career Development for Exceptional Individuals*, 24, 19-36.
- Department of Education. (2003). *25th annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Office of Special Education and Rehabilitative Services. Retrieved from <http://www2.ed.gov/about/reports/annual/osep/2003/25th-vol-2-front.pdf>
- Department of Education. (2008). *Frequently asked questions about Section 504 and the education of children with disabilities*. Washington, DC: Author. Retrieved from <http://www2.ed.gov/about/offices/list/ocr/504faq.html>
- Department of Education. (2009). *Questions and answers on the ADA Amendments Act of 2008 for students with disabilities attending public elementary and secondary schools*. Washington, DC: Author. Retrieved from <http://www2.ed.gov/about/offices/list/ocr/docs/dcl-504faq-201109.html>
- Department of Education. (2011). *Students with disabilities preparing for postsecondary education: Know your rights and responsibilities*. Washington, DC: Author. Retrieved from <http://www2.ed.gov/print/about/offices/list/ocr/transition/html>

- Dillon, M. (2007). Creating supports for college students with Asperger Syndrome through collaboration. *College Student Journal*, 41, 499-504. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=5&hid=1&sid=9668a158-2311-4e7a-b4a3-d7eba4f1e0a2%40sessionmgr12>
- Durlak, C. M., Rose, E., & Bursuck, W. D. (1994). Preparing high school students with learning disabilities for the transition to postsecondary education: Teaching the skills of self-determination. *Journal of Learning Disabilities*, 27, 51-59. doi: 10.1177/002221949402700108
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 739-747. doi: 10.1007/s10803-007-0441-x
- Eckes, S. E., & Ochoa, T. A. (2005). Students with disabilities: transitioning from high school to higher education. *American Secondary Education*, 33, 6-20. doi: 10.2307/41064551
- Education for All Handicapped Children Act (EAHC), 20 U.S.C. § 1400, et. Seq (1975).
- Enochs, W. K., & Roland, C.B. (2006). Social adjustment of college freshmen: The importance of gender and living environment. *College Student Journal*, 40, 63-73. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=5&hid=4&sid=59406668-6748-4d4c-b080-b36442635073%40sessionmgr11>
- Erevelles, N., & Mutua, K. (2005). "I am a woman now!": Rewriting cartographies of girl-hood from the critical standpoint of disability. In P. J. Bettis & N. G. Adams (Eds.), *Geographies of girlhood: Identities in-between* (pp. 253–269). Mahwah, NJ: Erlbaum.
- Evans, N. J., Forney, D. S., & Guido-Di Brito, F. (1998). *Student development in college: Theory, research, and practice*. San Francisco, CA: Jossey-Bass.
- Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. 1232g (1974).
- Foley, N. E. (2006). Preparing for college: Improving the odds for students with learning disabilities. *College Student Journal*, 40, 641-645. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?sid=0be950ce-bc98-4b22-bf19-dd46f5f0a1b8%40sessionmgr11&vid=28&hid=101>
- Freedman, S. (2010). *Developing college skills in students with autism and Asperger's Syndrome*. Philadelphia, PA: Jessica Kingsley.
- Garrison-Wade, D. F., & Lehmann, J. P. (2009). A conceptual framework for understanding students' with disabilities transition to community college. *Community College Journal of Research and Practice*, 33, 415-443. doi: 10.1080/10668920802640079
- Ghaziuddin, M. (2007). Defining the behavioral phenotype of Asperger syndrome. *Journal of Autism and Developmental Disorders*, 38, 138-142. doi: 10.1007/s10803-007-0371-7

- Ghaziuddin, M., Tsai, L. Y., & Ghaziuddin, N. (1992). Brief report: A comparison of the diagnostic criteria for Asperger syndrome. *Journal of Autism and Developmental Disorders*, 22, 643-649. doi: 10.1007/BF01046332
- Gillberg, C. (1989). *Diagnosis and treatment of autism*. New York, NY: Plenum Press.
- Glennon, T. J. (2001). The stress of the university experience for students with Asperger syndrome. *Work*, 1, 183-190. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=13&hid=101&sid=59406668-6748-4d4c-b080-b36442635073%40sessionmgr11>
- Godlee, F., Smith, J., & Marcovitch, H. (Eds.). (2011). Wakefield's article linking MMR vaccine and autism was fraudulent. *British Medical Journal*, 342, 342. doi: <http://dx.doi.org/10.1136/bmj.c5347>
- Goldberg, L. S. (2001). What is a parent to do? The parents' roles in college planning for children with learning disabilities. In T. A. Citro (Ed.), *Transitional skills for postsecondary success: Reflections for students with learning disabilities* (pp. 74-90). Lanham, MD: Rowan & Littlefield Education.
- Graetz, J. E., & Spampinato, K. (2008). Asperger's Syndrome and the voyage through high school: Not the final frontier. *Journal of College Admission*, 198, 19-24. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=1&sid=60baad0d-1c43-402f-b08c-b1d7a03d4fd4%40sessionmgr13>
- Griffin, M. M., McMillan, E. D., & Hodapp, R. M. (2010). Family perspectives on post-secondary education for students with intellectual disabilities. *Education and Training in Autism and Developmental Disabilities*, 45, 339-346. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=1&sid=fcabae29-7155-4cbc-926c-f49466dd6ee2%40sessionmgr14>
- Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Halpern, A. S., Yovanoff, P., Doren, B., & Benz, M. R. (1995). Predicting participation in postsecondary education for school leavers with disabilities. *Exceptional Children*, 62, 161-164. Retrieved from <http://go.galegroup.com.libdata.lib.ua.edu/ps/i.do?id=GALE%7CA17411780&v=2.1&u=tusc49521&it=r&p=ITOF&sw=w>
- Harpur, J., Lawlor, M., & Fitzgerald, M. (2004). *Succeeding in college with Asperger Syndrome: A student guide*. Philadelphia, PA: Jessica Kingsley.
- Harris, R., & Robertson, J. (2001). Successful strategies for college-bound students with learning disabilities. *Preventing School Failure*, 43, 125-131. doi: 10.1080/10459880109603327

- Harrocks, J. L., White, G., & Roberts, L. (2008). Principals' attitudes regarding inclusion of children with autism in Pennsylvania public schools. *Journal of Autism and Developmental Disorders*, 38, 1462-1473. doi: 10.1007/s10803-007-0522-x
- Hart, D., Grigal, M., & 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. doi: 10.1177/1088357610373759
- Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24, 77-88. doi: 10.1177/1088357608329827
- Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities*, 25, 163-172. doi: 10.1177/1088357610373760
- Hicks, T. (2005). Assessing the academic, personal and social experiences of pre-college students. *Journal of College Admission*, 186, 18-24. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=20&hid=102&sid=06adccad-ea26-42d2-906c-0f6bfa637cd0%40sessionmgr111>
- Howe, W., & Strauss, N. (2008). *Millennials go to college: Strategies for a new generation on campus*. Washington, DC: AACRAO.
- Hurewitz, F., & Berger, P. E. (2008). Preparing students with autism for college, and preparing colleges for students with autism. *Speakers Journal: The Pennsylvania House of Representatives*, 8, 109-117. Retrieved from [http://www.autismspeaks.org/docs/family\\_services\\_docs/College2.pdf](http://www.autismspeaks.org/docs/family_services_docs/College2.pdf)
- Individuals with Disabilities Education Act*, 20 U.S.C. § 1401, et. Seq (1990).
- Individuals with Disabilities Education Improvement Act*, 20 U.S.C. § 1401, et. Seq (2004).
- Ingram, D. G., Takahashi, T. N., & Miles, J. H. (2007). Defining autism subgroups: A taxometric solution. *Journal of Autism and Developmental Disorders*, 38, 960-960. doi: 10.1007/s10803-007-0469-y
- Ivey, J. K. (2004). What do parents expect? A study of likelihood and importance issues for children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 19, 27-33. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=9&hid=1&sid=fb29e235-9f7a-4bb3-9073-c936d8c038c6%40sessionmgr12>

- Johnson, D. R., Stodden, R. A., Emanuel, E. J., Luecking, R. & Mack, M. (2002). Current challenges facing secondary education and transition services: What research Tells Us. *Exceptional Children*, 68, 519-531. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?sid=795bfccf-e98c-4097-977b-15914c736e1f%40sessionmgr115&vid=6&hid=6>
- Kelly, J. T., Kendrick, M. M., Newgent, R. A., & Lucas, C. J. (2007). Strategies for student transition to college: A proactive approach. *College Student Journal*, 41, 1021-1035. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=26&hid=2&sid=dd0352cd-d6b6-4705-aaa2-a09f26e02999%40sessionmgr10>
- Keup, J. R. (2007). Great expectations and the ultimate reality check: Voices of students during the transition from high school to college. *Journal of Student Affairs Research and Practice*, 44, 3-31. doi: 10.2202/1949-6605.1752
- Koegel, A. K. (2008). Evidence suggesting the existence of Asperger syndrome in the mid-1800s. *Journal of Positive Behavior Intervention*, 10, 279-272. doi: 10.1177/1098300708320238
- Kopra, K., von Wendt, L., Niemi-von Wendt, T., & Paavonen, E. J. (2008). Comparison of diagnostic methods for Asperger syndrome. *Journal of Autism and Developmental Disorders*, 38, 1567-1573. doi: 10.1007/s10803-008-0537-y
- Kuh, G. D., Cruce, T. M., Shoup, R., Kinzie, J., & Gonyea, R. M. (2008). Unmasking the effects of student engagement on first-year college grades and persistence. *The Journal of Higher Education*, 79, 540-563. doi: 10.2307/25144692
- Kuusikko, S, Pollock-Wurman, R., Jussila, K., Carter, A., Mattila, M., Ebeling, H., Pauls, D. L., & Moilanen, I. (2008). Social anxiety in high-functioning children and adolescents with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 38, 169701709. doi: 10.1007/s10803-008-0555-9
- Landa, R. J., & Goldberg, M. C. (2005). Language, social, and executive functions in high functioning autism: A continuum of performance. *Journal of Autism and Developmental Disorders*, 35, 557-573. doi: 10.1007/s10803-005-0001-1
- Lange, D. K., & Stone, M. E. (2001). Parental involvement in admissions and financial aid. *New Directions for Student Services*, 94, 15-26. doi: 10.1002/ss.8
- LeCavalier, L., Gadow, K. D., DeVincent, C. J., & Edwards, M. C. (2009). Validation of DSM-IV model of psychiatric syndromes in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39, 278-289. doi: 10.1007/s10803-008-0622-2

- LeSure-Lester, G. E. (2001). Dating competence, social assertion and social anxiety among college students. *College Student Journal*, 35, 317-320. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=22&hid=2&sid=dd0352cd-d6b6-4705-aaa2-a09f26e02999%40sessionmgr10>
- Levine, A., & Dean, D. R. (2012). *Generation on a tightrope: A portrait of today's college student*. San Francisco, CA: Jossey-Bass.
- Levinson, E. M., & Ohler, D. L. (1998). Transition from high school to college for students with learning disabilities: Needs, assessment, and services. *The High School Journal*, 82, 62-69. doi: 10.2307/40364711
- Lehmann, J. P., Davies, T. G., & Laurin, K. M. (2000). Listening to student voices about postsecondary education. *Teaching Exceptional Children*, 32(5), 60-65. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/detail?vid=3&hid=1&sid=be42fe39-e591-48ae-950d-628a4fd7588e%40sessionmgr10&bdata=JnNpdGU9ZWhvc3QtG12ZQ%3d%3d#db=eft&AN=507694044>
- Lincoln, Y. S., & Guba, E. G. (1985) *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lloyd-Jones, E. M. (1989). Forward. In D. C. Roberts (Ed.), *Designing campus activities to foster a sense of community* (New Directions for Student Services, No. 48, i-iv). doi: 10.1002/ss.37119894802
- Lowery, J. W. (2005). Legal issues regarding partnering with parents: Misunderstood federal laws and potential sources of institutional liability. In K. Keppler, R. H. Mullendore, & A. Carey (Eds.), *Partnering with the parents of today's college students* (pp. 43-51). Washington, DC: NASPA.
- Lyons, V., & Fitzgerald, M. (2007). Asperger (1906-1980) and Kanner (1894-1981), the two pioneers of autism. *Journal of Autism and Developmental Disorders*, 37, 2022-2023. doi: 10.1007/s10803-007-0383-3
- Madaus, J. W. (2005). Navigating the college transition maze: A guide for students with learning disabilities. *Teaching Exceptional Children*, 37(3), 32-37. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=102&sid=be42fe39-e591-48ae-950d-628a4fd7588e%40sessionmgr10>
- Madaus, J. W., Miller II, W. K., Vance, M. L. (2009). Veterans with disabilities in postsecondary education. *Journal of Postsecondary Education and Disability*, 22, 10-17. Retrieved from ERIC database (EJ844247).
- Martin, E. W., Martin, R., & Terman, D. L. (1996). The legislative and litigation history of special education. *Special Education for Students with Disabilities*, 6, 25-39. Retrieved from [http://www.princeton.edu/futureofchildren/publications/docs/06\\_01\\_01.pdf](http://www.princeton.edu/futureofchildren/publications/docs/06_01_01.pdf)

- Masino, L. L., & Hodapp, R. M. (1996). Parental educational expectations for adolescents with disabilities. *Exceptional Children*, 62, 515-523. Retrieved from [http://go.galegroup.com.libdata.lib.ua.edu/ps/retrieve.do?sgHitCountType=None&sort=DASORT&inPS=true&prodId=ITOF&userGroupName=tusc49521&tabID=T002&searchId=R6&resultListType=RESULT\\_LIST&contentSegment=&searchType=AdvancedSearchForm&currentPosition=3&contentSet=GALE|A18273848&&docId=GALE|A18273848&docType=GALE&role=](http://go.galegroup.com.libdata.lib.ua.edu/ps/retrieve.do?sgHitCountType=None&sort=DASORT&inPS=true&prodId=ITOF&userGroupName=tusc49521&tabID=T002&searchId=R6&resultListType=RESULT_LIST&contentSegment=&searchType=AdvancedSearchForm&currentPosition=3&contentSet=GALE|A18273848&&docId=GALE|A18273848&docType=GALE&role=)
- Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. New York, NY: Ballantine
- McAfee, J. K., & Greenawalt, C. (2001). IDEA, the courts, and the law of transition. *Preventing School Failure: Alternative Education for Children and Youth*, 45, 102-107. doi: 10.1080/10459880109603323
- McAlonan, G. M., Suckling, J., Wong, N., Cheung, V., Lienenkaemper, N., Cheung, C., & Chua, S. E. (2008). Distinct patterns of grey matter abnormality in high-functioning autism and Asperger's syndrome. *Journal of Child Psychology and Psychiatry*, 49, 1287-1295. doi: 10.1111/j.1469-7610.2008.01933.x
- McKeon, B., Alpern, C. S., & Zager, D. (2013). Promoting academic engagement for college students with autism spectrum disorder. *Journal of Postsecondary Education and Disability*, 22, 353-366. Retrieved from ERIC database (EJ1026894).
- McMillan, J. H., & Schumacher, S. (2006). *Research in education: Evidence-based inquiry*. New York, NY: Pearson.
- Mellard, D. F., & Hazel, T. S. (1992). Social competencies as a pathway to successful life transitions. *Learning Disability Quarterly*, 15, 251-271. Retrieved from <http://www.jstor.org/stable/1511317>
- Merriam, S. B. (1998). *Qualitative research in practice: Examples for discussion and practice*. San Francisco, CA: Jossey-Bass.
- Merriman, L. S. (2008). Managing parent involvement during crisis. *New Directions for Student Services*, 122, 57-66. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=102&sid=17af8810-2254-4caa-8a9b-4104507449ee%40sessionmgr112>
- Mills v. Board of Education of the District of Columbia*, 348 F. Supp. 866 (D. DC 1972).
- Mitchell, P., & O'Keefe, K. (2008). Brief report: Do individuals with autism spectrum disorders think they know their own minds? *Journal of Autism and Developmental Disorders*, 38, 1591-1597. doi: 10.1007/s10803-007-0530-x
- Morrier, M. J., Hess, K. L., & Heflin, L. J. (2008). Ethnic disproportionality in students with autism spectrum disorders. *Multicultural Education*, 16, 31-38. Retrieved from

<http://go.galegroup.com.libdata.lib.ua.edu/ps/i.do?id=GALE%7CA193510680&v=2.1&u=tusc49521&it=r&p=ITOF&sw=w>

- Morningstar, M. E., Turnbull, A. P., & Turnbull III, N. R. (1995). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children*, 62, 249-260. Retrieved from <http://go.galegroup.com.libdata.lib.ua.edu/ps/i.do?id=GALE%7CA17819218&v=2.1&u=tusc49521&it=r&p=ITOF&sw=w>
- Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's Syndrome. *Journal of Postsecondary Education and Disability*, 22, 78-86. Retrieved from <http://www.eric.ed.gov/contentdelivery/servlet/ERICServlet?accno=EJ868133>
- Mott, N. (2004). A preliminary investigation of the factors influencing successful transition to higher education for students with learning disabilities [Online forum article]. Retrieved from <http://www.newfoundations.com/OrgTheory/MottStudy.htm>
- Mull, C., Sitlington, P. L., & Alper, S. (2001). Postsecondary education for students with learning disabilities: A synthesis of the literature. *Exceptional Children*, 68(1), 97-118. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=57&hid=27&sid=33db642f-ffca-4aca-8e04-e2e634ba3c01%40sessionmgr114>
- Mullendore, R. H., Banaham, L. A., & Ramsey, J. L. (2005). Developing a partnership with today's college parents. In K. Keppler, R. H. Mullendore, & A. Carey (Eds.), *Partnering with the parents of today's college students* (pp. 1-10). Washington, DC: NASPA.
- National Center for Educational Statistics (NCES). (2011). *Students with disabilities at degree-granting postsecondary institutions*. Washington, DC: Department of Education.
- National Center on Secondary Education and Transition (NCSET). (2002). *Parenting post-secondary students with disabilities: Becoming the mentor, advocate, and guide your young adult needs*. Retrieved from <http://www.ncset.org/publications/viewdesc.asp?id=208>
- National Joint Committee on Learning Disabilities (NJCLD). (1996). Secondary to postsecondary education transition planning for students with learning disabilities. *Learning Disability Quarterly*, 19, 62-64. doi: 10.2307/1511054
- Nelson, L. J., Padilla-Walker, L. M., Carroll, J. S., Barry, C. M., Madsen, S. D., & Badger, S. (2007). "If you want me to treat you like an adult, start acting like one!" Comparing the criteria that emerging adults and their parents have for adulthood. *Journal of Family Psychology*, 21, 665-674. doi: 10.1192/apt.10.5.341
- Neumann, E. V., Meyer, L. S., & Buchanan, S. M. (2011). *Autism for public school administrators: What you need to know*. Robbinsville, NJ: Autism New Jersey.

- O'Connor, K., & Kirk, I. (2008). Brief report: Atypical social cognition and social behaviours in autism spectrum disorder: A different way of processing rather than an impairment. *Journal of Autism and Developmental Disorders*, *38*, 1989-1977. doi: 10.1007/s10803-008-0559-5
- Palmer, A. (2006). *Realizing the college dream with autism or Asperger syndrome: A parent's guide to student success*. Philadelphia, PA: Jessica Kingsley.
- Pancer, S. M., Pratt, M., Hunsberger, B., & Alisat, S. (2000). Cognitive complexity of expectations and adjustments to university in the first year. *Journal of Adolescent Research*, *15*, 38-57. doi: 10.1177/0743558400151003
- P.A.R.C. v. Commonwealth of Pennsylvania*, 334 F. Supp. 1257 (E.D. Pa. 1971).
- Pascarella, E. T. (2006). How college affects students: Ten directions for future research. *Journal of College Student Development*, *47*, 508-520. doi: 10.1353/csd.2006.0060
- Pascarella, E. T., & Terenzini, P. T. (2008). *How college affects students, volume 2: A third decade of research*. San Francisco, CA: Wiley and Sons.
- Peña, E. V., & Kocur, J. (2013). Parents' experiences in the transition of students with autism spectrum disorders to community college. *Journal of Applied Research in the Community College*, *20*(2), 5-12. Retrieved from <http://eds.a.ebscohost.com.libdata.lib.ua.edu/eds/detail/detail?vid=3&sid=6a218d53-0cbe-41da-8958-417793a2b6b1%40sessionmgr4001&hid=4105&bdata=JnNpdGU9ZWRzLWxpdmUmc2NvcGU9c2l0ZQ%3d%3d#db=eft&AN=97405822>
- Pittman, L. D., & Richmond, A. (2007). Academic and psychological functioning in late adolescence: The importance of school belonging. *The Journal of Experimental Education*, *75*, 270-290. doi: 10.1353/csd.2005.0022
- Pittman, L. D., & Richmond, A. (2008). University belonging, friendship quality, and psychological adjustment during the transition to college. *Journal of Experimental Education*, *76*, 343-361. doi: 10.3200/JEXE.76.4.343-362
- Prentice, M. (2002). Serving students with disabilities in community colleges. *ERIC Clearinghouse for Community Colleges*. ERIC: Los Angeles, CA.
- Price, C. S., Thompson, W. W., Goodson, B., Weintraub, E. S., Croen, L. A., Hinrichsen, V. L., Marcy, M., Robertson, A., Eriksen, E., Lewis, E., Bernal, P., Shay, D., Davis, R. L., & DeStafano, F. (2010). Prenatal and infant exposure to thimerosal from vaccines and immunoglobulins and risk of autism. *Pediatrics*, *126*, 656-664. doi: 10.1542/peds.2010-0309

- Pritchard, M. E., & Wilson, G. S. (2008). Using emotional and social factors to predict student success. *Journal of College Student Development*, 44, 18-28. doi: 10.1353/csd.2003.0008
- Ratey, J. J. (2002). *A user's guide to the brain: Perception, attention, and the four theaters of the brain*. New York, NY: Vintage.
- Rehabilitation Research and Training Center on Disability Statistics and Demographics. (2009). *Annual Disability Statistics Compendium: 2009*. New York, NY: Author. Retrieved from <http://disabilitycompendium.org>
- Ricky Wyatt. (2009, Winter). *Listen*. Retrieved from <http://www.mh.alabama.gov/brycehospitalproject/History/RickyWyatt.pdf>
- Riessman, C. K. (2001). Analysis of personal narratives. In J. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 695-710). Thousand Oaks, CA: Sage.
- 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. doi: 10.1177/1088357610371476
- Robertson, S. M., & Ne'eman, A. D. (2008). Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly*, 28. Retrieved from <http://dsq-sds.org/article/view/146/146>
- Robison, J. E. (2012, January 23). How will the DSM V changes in autism affect people? Changes coming in the autism definition – what will they mean? [Web log post]. Retrieved from <http://www.psychologytoday.com/blog/my-lfe-aspergers/201201/how-will-the-dsm-v-changes-in-autism-affect-people>
- Roe Clark, M. R. (2005). Negotiating the freshman year: Challenges and strategies among first-year college students. *Journal of College Student Development*, 46, 296-316. doi: 10.1353/csd.2005.0022
- Rothstein, L. (2003). Disabilities and higher education: A crystal ball? *Change*, 35(3), 39-40. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?sid=fb29e235-9f7a-4bb3-9073-c936d8c038c6%40sessionmgr12&vid=18&hid=5>
- Rubin, H. J. & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Safran, J. S. (2002). A practitioner's guide to resources on Asperger syndrome. *Intervention in School and Clinic*, 37, 283-291. doi: 10.1177/105345120203700504

- Schlabach, T. L. (2008). *The college experience of students with Asperger's disorder: Perceptions of the students themselves and of college disability service providers who work with these students*. Retrieved from ProQuest. (Document No. 304606618)
- Schutz, P. F. (2002). Transition from secondary to postsecondary education for students with disabilities: An exploration of the phenomenon. *Journal of College Reading and Learning*, 33, 46-61. Retrieved from <http://go.galegroup.com.libdata.lib.ua.edu/ps/i.do?id=GALE%7CA95913538&v=2.1&u=tusc49521&it=r&p=ITOF&sw=w>
- Schwartz, C. (2012, January 20). A new definition of autism could exclude many now diagnosed, expert says [electronic news list]. Retrieved from <http://thedailybeast.com/articles/2012/01/20/a-new-definition-of-autism-could-exclude-many-now-diagnosed-expert-says.html>
- Scott, S. S. (1991). A change in legal status: An overlooked dimension in the transition to higher education. *Journal of Learning Disabilities*, 24, 459-466. Retrieved from <http://web.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?sid=1943238c-67e6-458a-92a5-c259eb8e30a7%40sessionmgr4&vid=4&hid=28>
- Scott, B. R., & Daniel, B. V. (2001). Why parents of undergraduates matter to higher education. *New Directions for Student Services*, 94, 83-89. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/pdfviewer?vid=3&hid=101&sid=52bfec6e-4356-4d74-9a0a-98701c5ef46e%40sessionmgr112>
- Section 504 of the Rehabilitation Act*, 29 U.S.C. §794 et seq (1973).
- Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3<sup>rd</sup> edition). New York, NY: Teachers College Press.
- Shore, S. (2003). Life on and slightly to the right of the autism spectrum: A personal account. *Exceptional Parent*, 33, 85-90. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?sid=9cd449d2-5262-42bc-857f-4cbacc5deb37%40sessionmgr113&vid=4&hid=4>
- Sitlington, P. L. (2003). Postsecondary education: The other transition. *Exceptionality*, 11(2), 103-113. doi: 10.1207/S15327035EX1102-05
- Smith, C. P. (2007). Support services for students with Asperger's syndrome in higher education. *College Student Journal*, 41, 515-531. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?sid=0be950ce-bc98-4b22-bf19-dd46f5f0a1b8%40sessionmgr11&vid=28&hid=101>
- Smith, S. G., English, R., & Vasek, D. (2002). Student and parent involvement in the transition process for college freshmen with learning disabilities. *College Student Journal*, 36, 491-503. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/ehost/pdfviewer/>

pdfviewer?vid=3&hid=5&sid=c1059159-e676-490b-b5f3-a522308f3435%  
40sessionmgr13

- Stern, G. S. (1966). *Studies of college environments*. Syracuse University. Retrieved from <http://www.eric.ed.gov/contentdelivery/servlet/ERICServlet?accno=ED010647>
- Stodden, R. A., & Mruzek, D. W. (2010). An introduction to postsecondary education and employment of persons with autism and developmental disabilities. *Focus on Autism and Other Developmental Disabilities, 25*, 131-133. doi: 10.1177/1088357610371637
- Szatmari, P. (2000). The classification of autism, Asperger's syndrome, and pervasive developmental disorder. *Canadian Journal of Psychiatry, 45*, 731-739. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/detail?vid=4&hid=27&sid=0be950ce-bc98-4b22-bf19-dd46f5f0a1b8%40sessionmgr11&bdata=JnNpd GU9ZWRzLW xpdmUmc2NvcGU9c2l0ZQ%3d%3d#db=edsbl&AN=RN087648850>
- Szatmari, P., Bremner, R., & Nagy, J. (1989). Aspergers syndrome – a review of clinical features. *Canadian Journal of Psychiatry, 34*, 554-560.
- Taub, D. J. (2008). Exploring the impact of parental involvement on student development. *New Directions for Student Services, 122*, 15-28. doi: 10.1002/ss.272
- Thierfeld Brown, J. (2008, July). *Transitions of students with autism spectrum disorders*. Presentation at the meeting of Association on Higher Education and Disability, Reno, NV.
- Thierfeld Brown, J., Wolf, L. E., King, L., & Bork, G. R. K. (2012). *The parent's guide to college for students on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing.
- Tidmarsh, L., & Volkmar, F. R. (2003). Diagnosis and epidemiology of autism spectrum disorders. *Canadian Journal of Psychiatry, 48*, 517-525. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/pdfviewer/pdfviewer?vid=6&hid=27&sid=0be950ce-bc98-4b22-bf19-dd46f5f0a1b8%40sessionmgr11>
- Tierney, W. G., & Dilley, P. (2001). Interviewing in education. In J. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 453-471). Thousand Oaks, CA: Sage.
- Tincani, M., Cucchiarra, M. B., Thurman, S. K., Snyder, M. R., & McCarthy, C. M. (2014) Evaluating NRC's recommendations for educating children with autism a decade later. *Child Youth Care Forum, 43*, 315-337. Doi: 10.1007/s10566-013-9240z
- Tinto, V. (1993). *Leaving college: Rethinking the causes and cures of student attrition* (2<sup>nd</sup> ed.). Chicago, IL: University of Chicago Press.

- Troiano, P. F. (2003). College students and learning disability: Elements of self-style. *Journal of College Student Development, 44*, 404-419. doi: 10.1353/csd.2003.0033
- Van Pelt, J. (2008). Autism into adulthood – Making the transition. *Social Work Today, 8*(5), 12. Retrieved from [ww.socialworktoday.com/archive/090208p12.shtml](http://ww.socialworktoday.com/archive/090208p12.shtml)
- VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders, 38*, 1359-1370. doi: 10.1007/s10803-007-0524-8
- Vivanti, G., Hudry, K., Trembath, D., Barbaro, J., Richdale, A., & Dissanayake, C. (2013). Towards the DSM-5 criteria for autism: Clinical, cultural, and research implications. *Australian Psychologist, 1-4*. doi: 10.1111/ap.12008
- Volkmar, F. R., State, M., & Klin, A. (2009). Autism and autism spectrum disorders: Diagnostic issues for the coming decade. *The Journal of Child Psychology and Psychiatry, 50*, 108-115. doi: 10.1111/j.1469-7610.2008.02010x
- Walsh, B. (2010, October 24). Making up the rules about Asperger's. *Metro*. Retrieved from <http://www.metro.us/newyork/life/article/671648--making-up-the-rules-about-asperger-s>
- Warren, C. A. B. (2008). Qualitative interviewing. In J. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 83-101). Thousand Oaks, CA: Sage.
- Wartman, K. L., & Savage, M. (2008). *Parental involvement in higher education: Understanding the relationship among students, parents, and the institution*. ASHE Higher Education Report: 33. San Francisco, CA: Wiley.
- Wehmeyer, M. L. (2002). *Self-determination and the education of students with disabilities*. Reston, VA: ERIC Clearinghouse on Disabilities and Gifted Education. Retrieved from <http://permanent.access.gpo.gov/lps44738/ED470036.pdf>
- Wei, M., Russell, D. W., & Zakalik, R. A. (2005). Adult attachment, social self-efficacy, self-disclosure, loneliness, and subsequent depression for freshman college students: A longitudinal study. *Journal of Counseling Psychology, 52*, 602-614. doi: 10.1037/0022-0167.52.4.602
- West, M., Kregel, J., Getzel, E. E., Ming, Z., Ipsen, S. M., & Martin, E. D. (1993). Beyond Section 504: Satisfaction and empowerment of students with disabilities in higher education. *Exceptional Children, 59*, 456-468. Retrieved from <http://go.galegroup.com.libdata.lib.ua.edu/ps/i.do?id=GALE%7CA13671931&v=2.1&u=tusc49521&it=r&p=ITOF&sw=w>
- Williams, T. M. (1998). *Life after high school: Transitional issues for learning disabled students* (Unpublished master's thesis). Chicago State University, Chicago, IL.

- Wing, L. (1985). *Autistic children: A guide for parents and professionals*. London, England: Routledge.
- Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler & G. Mesibov (Eds.), *Diagnosis and assessment in autism* (pp. 91-110). New York, NY: Plenum.
- Wing, L. (1997). The autistic spectrum. *Lancet*, *350*, 1761-1766. Retrieved from <http://ehis.ebscohost.com.libdata.lib.ua.edu/eds/detail?vid=15&hid=109&sid=33db642f-ffca-4aca-8e04-e2e634ba3c01%40sessionmgr114&bdata=JnNpdGU9ZWRzLWxpdmUmc2NvcGU9c2l0ZQ%3d%3d#db=rzh&AN=1998035674>
- Witwer, A. N., & LeCavalier, L. (2008). Examining the validity of autism spectrum disorder subtypes. *Journal of Autism and Developmental Disorders*, *38*, 1611-1624. doi: 10.1007/s10803-008-0541-2
- Wolanin, T. R., & Steele, P. E. (2004). *Higher education opportunities for students with disabilities: A primer for policymakers*. Washington, DC: Institute for Higher Education Policy.
- Wolf, L. E., & King, L. (2009). Students with Asperger Syndrome: Challenges for counseling and student affairs. Presentation at AHEAD Conference, 23 July, 2009, Louisville, KY.
- Wolf, L. E., & Thierfeld Brown, J. (2008). *Supporting students with autism spectrum disorders in college: Strategic education*. Retrieved from <http://www.collegeautismspectrum.com/>
- Wolf, L. E., Thierfeld Brown, J., & Bork, G. R. K. (2009). *Students with Asperger Syndrome: A guide for college personnel*. Shawnee Mission, KS: Autism Asperger Publishing.
- World Health Organization. (2008). *ICD-10: International statistical classification of diseases and related health problems* (10th Rev. ed.). New York, NY: Author.
- Wright, P., & Wright, P. (2008). Key Differences Between Section 504, the ADA, and the IDEA. *Wrightslaw*. Retrieved from <http://www.wrightslaw.com/info/sec504.summ.rights.htm>
- Wyatt v. Stickney*, 325 F. Supp. 781(M.D. Ala.1971).
- Yazedjian, A., Toews, M. L., Savin, T., & Purswell, K. E. (2008). "It's a whole new world": A qualitative exploration of college students' definitions of and strategies for college success. *Journal of College Student Development*, *49*, 141-154. doi: 10.1353/csd.2008.0009
- Zager, D., & Alpern, C. S. (2010). College-based inclusion programming for transition-age students with autism. *Focus on Autism and Other Developmental Disabilities*, *25*, 151-157. doi: 10.1177/1088357610371331

## APPENDIX A

### Script for Introducing Research Study to Students

First, let me say thank you for letting me come into your class for a few minutes. Let me introduce myself: I am Kathy Lutes Ebel, and I am an assistant vice president for Student Affairs at Chattanooga State, just down the road from you here at [REDACTED]. I supervise several offices on campus at Chattanooga State, but my main responsibility is overseeing the office that serves students with disabilities, similar to what [REDACTED] does here at [REDACTED]. I've been in my position for 15 years, and I have learned a lot about myself and about students with disabilities in all of that time.

I am also a student at the University of Alabama, in a doctoral program for higher education administration. I have finished all of my classes and now I'm down to doing my final research study so I can write my dissertation. This is where I am asking for your assistance. In my dissertation, I have proposed that I will conduct interviews with the parents of students who have autism spectrum disorders (ASD). The topic of the interviews will be finding out what the transition from high school to college was like from your parents' perspective. My research so far indicates that the parents of students with ASD are far more involved with their children's educational programming than the usual parent is, even parents who have children with other kinds of disabilities. Your parents probably have been partners with you all the way, and sometimes they were the only ones fighting for you, so I want to know about their experiences, both good and bad, because I think what they have learned in the transition process can help other parents of students who will be coming to college in the future.

As you probably know, I need your permission to talk to your parents, and that is the reason I am here today. I am asking you to sign a permission form that will allow me to get in touch with your parents, and to give me contact information so I can call or e-mail them and get started with the interviews. Just to put your minds at ease, I will not be asking for personal information, and will not use any real names in my study. I will not even mention that I am using the [REDACTED] at [REDACTED] as my “base of operations.” What I am looking for are common themes in the stories your parents tell, similar experiences that several of them may have shared to see if there are things that are being done well all across the board, or if there are certain things that are not being done well, and what might have helped make the transition experience a smoother one for them and for you.

You are under absolutely no obligation to have your parents be a part of my study. Obviously, I hope you will say yes so I can hear the stories your parents have to tell, but if you would rather not have them involved, or if you are just not interested, or for whatever reason you don’t want to be involved with the study, I will certainly understand and respect your decision. I will not call you or e-mail you or keep bugging you about it. Your decision is final, as far as I am concerned.

Do you have any questions for me? (Answer questions that may come from the group)

If there are no other questions, I’m going to leave the Permission to Contact Parents forms with [REDACTED]. (Show form to students) If you are willing to have your parents be a part of my study you can pick up a form from [REDACTED], fill it out and sign it, and then if you will write down a phone number or e-mail address or street address, whichever would be the best way to contact your parents, I will be sending them a message explaining the study I will be doing and asking them to participate. When you’ve completed the form, you can give it back to [REDACTED]

and she can fax it to me. As soon as I get the form from her, I will be in touch with your parents to set up a time and place to meet for the interview.

If you have any questions that come to mind after I've left, please get in touch with me or Dr. Mutua, my dissertation chair at the University of Alabama. Our contact information is on the bottom of the form. I want you to feel that I've explained everything to you and answered all the questions you may have before you make your decision.

Thank you again, and I look forward to working with your parents. I think this is going to be a very valuable study that will help parents and future college students have a much easier transition.

APPENDIX B

Student Permission to Contact Parents Form

I, \_\_\_\_\_ give permission for Kathy Lutes Ebel to contact my parents. I understand that she will ask them to participate in a research study that focuses on looking at the transition from high school to college from their perspective. I understand that she wants to gather information that will assist future parents by having better information available to them. This information could make the transition process a smoother experience for future students with autism spectrum disorders who might otherwise have difficulty making that transition.

I understand that the information my parents provide will be kept confidential and that no personally identifying information will be used in the study.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

If you have questions about the study, please contact

Kathy Lutes Ebel, doctoral candidate  
Phone: [REDACTED]  
E-mail: [REDACTED]

Dr. Kagendo Mutua, dissertation chair  
University of Alabama  
Phone: [REDACTED]  
E-mail: [REDACTED]

Best method for contacting my parents:

Phone: \_\_\_\_\_

E-mail: \_\_\_\_\_

Physical address: \_\_\_\_\_

## APPENDIX C

### Introductory Parent Letter and Informed Consent Form

Dear Parents:

My name is Kathy Lutes Ebel, and I am a doctoral candidate at the University of Alabama, majoring in higher education administration. I work at Chattanooga State Community College, and serve as assistant vice president for counseling and educational support. One of my responsibilities at Chattanooga State is serving as director of the office for services to students with disabilities. Because my professional career has always centered on working with people who have disabilities, I have chosen to focus my doctoral study in this area.

My study will consist of interviewing parents of college students who have autism spectrum disorders. I want to learn about the experience of transitioning from high school to college for these students, but told from the perspective of the parents. Because parents have most likely been the strongest supporters and advocates of their children throughout school, I want to know whether you received enough information about the transition to postsecondary education that you were able to prepare your child adequately for the experience, or if you experienced any bumps in the road where you felt un- or under-prepared to assist your child with transition. Because parents of students on the autism spectrum spend a great deal of time working with their children away from school, you are the best resources on how to make the transition process as smooth as possible for this group of students.

I will not delve into your personal life; I am only interested in finding out what information you as parents received about the transition process, and whether that information was useful in helping prepare your students for college. If the information was not useful, I want to know what you would have liked to know that would have made the transition process smoother. It is my hope that the knowledge you have gained through the process can be used to better prepare other parents whose children are preparing to transition to postsecondary education.

Your participation is completely voluntary, and your responses to my interview questions will remain confidential. You can withdraw from participation at any time. My study has been approved by the Institutional Review Boards at the University of Alabama and the [REDACTED], and has been authorized by my dissertation committee.

Please complete the attached Consent Form and return it to me by May 15, 2013. If you have any questions, please feel free to contact me. My e-mail address is [REDACTED], and my phone number is [REDACTED]. My committee chair is Dr. Kagendo Mutua, associate

professor in the department of special education and multiple abilities at the University of Alabama, [REDACTED]. Her E-mail address is [REDACTED]. I look forward to hearing from you and working with you to complete this useful research that could allow other parents to make the transition process smoother for their children.

Sincerely,

Kathy Lutes Ebel

**AAHRPP DOCUMENT #192**

**UNIVERSITY OF ALABAMA  
HUMAN RESEARCH PROTECTION PROGRAM**

**Informed Consent for a Non-Medical Study**

**Study title: *Transition from High School to Postsecondary Education: Narratives of Parents of college Students with Autism Spectrum Disorders***

**Investigator's Name, Position, Faculty or Student Status: *Kathryn Lutes Ebel, Doctoral Student in Higher Education Administration***

**Institution if other than or collaborating with UA [REDACTED]**

You are being asked to take part in a research study.

This study is called "Transition from High School to Postsecondary Education: Narratives of Parents of college Students with Autism Spectrum Disorders." The study is being done by Kathy Lutes Ebel, who is a graduate student at the University of Alabama. Ms. Ebel is being supervised by Professor Kagendo Mutua, who is a professor of Special Education and Multiple Abilities at the University of Alabama.

**What is this study about? What is the investigator trying to learn?**

This study is being done to find out about the roles parents play in bridging the gap between high school and postsecondary education for students with autism spectrum disorders. Interviewing parents will provide in-depth descriptions of their experiences with assisting their sons or daughters in their transition from high school to the postsecondary education environment. There is very little research that talks about the transition process for students on the autism spectrum, and particularly when told from the perspective of the parents, who are often the primary support system for these students. The goals of the study are to find out what advice or training parents received

about postsecondary options from both the high school and the college, the amount of support and advocacy provided by the parents during the transition process, and what issues could have been avoided if adequate information had been provided by high school or college disability services professionals.

**Why is this study important or useful?**

This knowledge is important because there is only a small amount of research that has been done on students with autism spectrum disorders at the college level. This is especially true about the transition from high school to college and the role that parents play in this process. This study could be an important addition to the limited research that has been done on this group of students and the involvement of their parents in the transition process.

**Why have I been asked to be in this study?**

You have been asked to be in this study because your son or daughter participates in the [REDACTED] at the [REDACTED]. [REDACTED], director of the [REDACTED] program, has given her support to this study, and I believe the parents of this group of students will have valuable information to share about their experiences in the transition to college for their child.

**How many people will be in this study?**

Up to twenty (20) parents will be included in this study.

**What will I be asked to do in this study?**

If you agree to be in this study, you will be asked to be interviewed by Ms. Ebel. The interview will be recorded and then transcribed. Once the transcription has been done, Ms. Ebel will contact you so you can review the transcript and reflect on your responses, make any additions or corrections, or ask any further questions. Ms. Ebel will work with you on where and when the interview will take place so that you are inconvenienced as little as possible.

**How much time will I spend being this study?**

The interview itself will take approximately one hour, with the follow-up to review the transcript taking an additional hour.

**Will being in this study cost me anything?**

The only cost to you from this study is your time and travel to the interview location.

**Will I be compensated for being in this study?**

You will not be compensated for being in this study.

**What are the risks (dangers or harms) to me if I am in this study?**

There should be very little risk to you. Some of your transition experiences may not be particularly pleasant, but this should not rise to the degree of being a risk. If you become more anxious or upset than might be expected, Ms. Ebel will provide you with contact

information for the counseling office at [REDACTED], where you can speak with a qualified professional who can assist you in dealing with your anger or anxiety.

**What are the benefits (good things) that may happen if I am in this study?**

Although you will not benefit personally from being in the study, you may feel good about knowing that you have helped other parents who might go through similar experiences in the transition of their child with autism who plans to attend college.

**What are the benefits to science or society?**

This study will provide information that may be useful for high school and college level disability service providers. The results could provide them with more appropriate tools for educating both students with autism spectrum disorders and their parents in the steps that need to be taken to make transition a smoother, more manageable process.

**How will my privacy be protected?**

Interviews will be conducted at a location of your choosing so that others cannot see the interview taking place, or hear the questions and answers. You do not have to answer any questions that make you uncomfortable, and Ms. Ebel will not discuss your interview with other parents. Please note that Ms. Ebel is responsible for reporting any signs of abuse or other malicious behavior if she observes them.

**How will my confidentiality be protected?**

The recorded interview, the transcript, and the memory device where the information is stored will be kept in a locked drawer in Ms. Ebel's home. She is the only person who has access to this drawer, and will keep it locked at all times when she is not involved with documenting the research study. All information that documents your participation will be destroyed one year after the interview has taken place. Your name will not be used in the report of the study; rather letter names (Mrs. A, Mr. B) or common last names (Mrs. Jones, Mr. Smith) will be used (unless one of those common names is the family's name).

**What are the alternatives to being in this study? Do I have other choices?**

The alternative to being in this study is not to participate.

**What are my rights as a participant in this study?**

Taking part in this study is voluntary. It is your free choice. You can refuse to be in it at all. If you start the study, you can stop at any time.

The University of Alabama Institutional Review Board ("the IRB") is the committee that protects the rights of people in research studies. The IRB may review study records from time to time to be sure that people in research studies are being treated fairly and that the study is being carried out as planned.

**Who do I call if I have questions or problems?**

If you have questions about the study right now, please ask them. If you have questions about the study later on, please call the investigator Kathy Ebel at [REDACTED], or the faculty advisor Dr. Kagendo Mutua at [REDACTED].

If you have questions, concerns, or complaints about your rights as a person in a research study, call [REDACTED], the Research Compliance Officer of the University of Alabama, at [REDACTED] or toll-free at [REDACTED].

You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach website at [http://osp.ua.edu/site/PRCO\\_Welcome.html](http://osp.ua.edu/site/PRCO_Welcome.html) or email the Research Compliance Office at [participantoutreach@bama.ua.edu](mailto:participantoutreach@bama.ua.edu).

After you participate, you are encouraged to complete the survey for research participants that is online at the outreach website or you may ask the investigator for a copy of it and mail it to the University Office for Research Compliance, Box 870127, 358 Rose Administration Building, Tuscaloosa, AL 35487-0127.

I have read this consent form. I have had a chance to ask questions. I agree to take part in it. I will receive a copy of this consent form to keep.

You may audio record my interview.  
 I prefer to be interviewed without audio recording.

---

Signature of Research Participant

---

Date

---

Signature of Investigator

---

Date

If you have any questions or comments related to the study at [REDACTED]

[REDACTED]

## APPENDIX D

### First Follow-Up Letter

Dear parents:

You received a letter from me approximately two weeks ago, asking for your involvement in a research study I will be conducting. As you may recall, I am a doctoral candidate at the University of Alabama, and my major is higher education administration.

As a part of the requirements for my degree, I will be conducting a research study on transitioning students with autism spectrum disorders from high school to postsecondary education. The reason I am asking for your participation is that I want to tell the story about transition from the perspective of the parents.

I know that you have been very supportive of your student, but I believe that you were not provided with some important information when your student graduated from high school. This information would have been very helpful in making the transition process much smoother for your student, and because you have been so involved with your student's education, I would like for you to tell the story of what you know now that you wish you had known at the time your student was going through the transition experience. I think this is important information that will help other parents and students with autism spectrum disorders make a much more successful transition.

I have enclosed another consent form for you to sign, as well as a self-addressed, stamped envelope for you to return it to me. Please consider participating in this research study. I believe that this is an important story that needs to be told.

On the other hand, if you do not wish to participate, please write "Not Interested" across the consent form, along with your name, and return the form to me. At that point I will not contact you again.

If you have any questions about the research study, please do not hesitate to contact me at [REDACTED], or by phone at [REDACTED]. The chair of my dissertation committee is Dr. Kagendo Mutua of the University of Alabama. She can be contacted at [REDACTED] or [REDACTED].

Thank you for your consideration,

Kathy Lutes Ebel

## APPENDIX E

### Second Follow-Up Letter

Dear parents:

You should have received an introductory letter and a follow-up letter from me about two weeks ago, asking for your participation in a research study I will be conducting. As you may recall, I am a doctoral candidate at the University of Alabama, and my major is higher education administration.

As a part of the requirements for my degree, I will be conducting a research study on transitioning students with autism spectrum disorders from high school to postsecondary education. The reason I am asking for your participation is that I want to tell the story about transition from the perspective of the parents.

I know that you have been very supportive of your student, but I believe that you were not provided with some important information when your student graduated from high school. This information would have been very helpful in making the transition process much smoother for your student, and because you have been so involved with your student's education, I would like for you to tell the story of what you know now that you wish you had known at the time your student was going through the transition experience. I think this is important information that will help other parents and students with autism spectrum disorders make a much more successful transition.

I have enclosed another consent form for you to sign, as well as a self-addressed, stamped envelope for you to return it to me. Please consider participating in this research study. I believe that this is an important story that needs to be told.

If you have any questions about the research study, please do not hesitate to contact me at [REDACTED], or by phone at [REDACTED]. The chair of my dissertation committee is Dr. Kagendo Mutua of the University of Alabama. She can be contacted at [REDACTED] or [REDACTED].

Thank you for your consideration,

Kathy Lutes Ebel

## APPENDIX F

### Interview Protocol

Name:

Date:

Race:

Gender of student:

Socioeconomic status (upper, middle, lower):

K-12 school environment (public, private, home-school):

College living arrangements (at home, college housing, private apartment complex, family member, other):

Questions:

What role did you play in your son/daughter attending this college?

How would you describe your role in the transition process for your son/daughter?

How did you help your child develop problem-solving skills? When did you begin to work on this skill? How well-developed was this skill when your child reached the college level?

How do you communicate your confidence in your child's ability to cope with problems? Is your child able to take risks (i.e., move outside his/her comfort zone)?

Describe your child's competence in the academic arena? Social arena?

How would you describe your child's attachment to you as his parents throughout the transition process? Did that attachment change as the process moved forward?

Tell me about the level of independence that your child has achieved (need continual support and reassurance, initiate and carry out activities independently, begin to rely on peers and other significant adults, etc.).

What opportunities did your son/daughter have to make choices before college?

How well does your child access necessary resources (tutoring, counseling, peer support, academic services, etc.)? Who/what are his primary supports on the campus?

Describe your child's comfort level with his/her own body and appearance. What about his/her sexuality (approaching someone he/she is attracted to)? Identity in a social setting?

What role did you play in your child's development of his/her sense of self? Who are the other members of his/her reference group?

Anything else you would like to add?

## APPENDIX G

### Publisher's Permission to Reprint Table 1

#### JOHN WILEY AND SONS LICENSE TERMS AND CONDITIONS

Oct 06, 2014

This is a License Agreement between Kathryn L Ebel ("You") and John Wiley and Sons ("John Wiley and Sons") provided by Copyright Clearance Center ("CCC"). The license consists of your order details, the terms and conditions provided by John Wiley and Sons, and the payment terms and conditions.

**All payments must be made in full to CCC. For payment instructions, please see information listed at the bottom of this form.**

License Number	3483281272239
License date	Oct 06, 2014
Licensed content publisher	John Wiley and Sons
Licensed content publication	Wiley Books
Licensed content title	Essentials of Autism Spectrum Disorders Evaluation and Assessment
Book title	Essentials of Autism Spectrum Disorders Evaluation and Assessment
Licensed copyright line	Copyright © 2012, John Wiley and Sons
Licensed content author	Celine A. Saulnier, Pamela E. Ventola
Licensed content date	Apr 1, 2012
Type of use	Dissertation/Thesis
Requestor type	University/Academic
Format	Print and electronic
Portion	Figure/table
Number of figures/tables	1
Original Wiley figure/table number(s)	Table 1.1 Comparison Between DSM-IV and Proposed DSM-5 Diagnostic Criteria for Autism Spectrum Disorders
Will you be translating?	No
Title of your thesis / dissertation	Transition from High School to Postsecondary Education: Narratives of Parents of College Students with Autism Spectrum Disorders
Expected completion date	Dec 2014
Expected size (number of pages)	150

APPENDIX H

IRB Approval

April 3, 2014

Office for Research  
Institutional Review Board for the  
Protection of Human Subjects

THE UNIVERSITY OF  
**ALABAMA**  
R E S E A R C H

Kathy Ebel  
ELPTS  
College of Education  
The University of Alabama

Re: IRB # 13-OR-144-ME-R1 "Transition from High School to  
Postsecondary Education: Narratives of Parents of College Students with  
Autism Spectrum Disorders"

Dear Ms. Ebel:

The University of Alabama Institutional Review Board has granted  
approval for your renewal application.

Your renewal application has been given expedited approval according to  
45 CFR part 46. Approval has been given under expedited review  
category 7 as outlined below:

*(7) Research on individual or group characteristics or behavior  
(including, but not limited to, research on perception, cognition,  
motivation, identity, language, communication, cultural beliefs or  
practices, and social behavior) or research employing survey, interview,  
oral history, focus group, program evaluation, human factors evaluation,  
or quality assurance methodologies.*

Your application will expire on April 2, 2015. If your research will  
continue beyond this date, complete the relevant portions of Continuing  
Review and Closure Form. If you wish to modify the application,  
complete the Modification of an Approved Protocol Form. When the  
study closes, complete the appropriate portions of FORM: Continuing  
Review and Closure.

Please use reproductions of the IRB approved informed consent form to  
obtain consent from your participants.

Should you need to submit any further correspondence regarding this  
proposal, please include the above application number.

Good luck with your research.

Sincerely,



Stuart Usdan, PhD.  
Chair, Non- Medical Institutional Review Board  
The University of Alabama



358 Rose Administration Building  
Box 870127  
Tuscaloosa, Alabama 35487-0127  
(205) 348-8461  
FAX (205) 348-7189  
TOLL FREE (877) 820-3066

Institutional Review Board

TO: Kathryn Lutes Ebel  
Dr. Kagendo Mutua

IRB # 13-032

FROM: [REDACTED], Director of Research Integrity  
[REDACTED], IRB Committee Chair

DATE: May 7, 2014

SUBJECT: IRB # 13-032: Transition from High School to Postsecondary Education: Narratives of Parents of College Students with Autism Spectrum Disorder

The Institutional Review Board has reviewed and approved your application for Annual Renewal for the IRB project listed above.

You must include the following approval statement on research materials seen by participants and used in research reports:

***The Institutional Review Board of the [REDACTED] (FWA00004149) has approved this research project # 13-032.***

Please remember that you must complete a form for completion when the project is completed or provide an annual report if the project takes over one year to complete. The IRB Committee will make every effort to remind you prior to your anniversary date; however, it is your responsibility to ensure that this additional step is satisfied.

Please remember to contact the IRB Committee immediately and submit a new project proposal for review if significant changes occur in your research design or in any instruments used in conducting the study. You should also contact the IRB Committee immediately if you encounter any adverse effects during your project that pose a risk to your subjects.

For any additional information, please consult our web page [REDACTED] or email [REDACTED].

Best wishes for a successful research project.