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SELF-DETERMINATION AMONG COMMUNITY COLLEGE STUDENTS
DIAGNOSED WITH ASPERGER'S SYNDROME: A QUALITATIVE STUDY

by

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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Education
in the Department of Educational Research, Technology and Leadership
in the College of Education
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2009

Major Professor: Rosa Cintrón

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ABSTRACT

This qualitative research study investigated the self-determination of community college students diagnosed with Asperger's syndrome (AS). Varying levels of self-determination were displayed within each of the five participants. However, despite the unique characteristics and experiences of the participants, five major and two minor themes related to the collegial experiences of these students were revealed. The major themes highlighted were that community college students with AS (a) enjoyed academic success, (b) found disability services and accommodations important, (c) chose majors based on personal interests, (d) relied on family members for support, and (e) had difficulty developing social connections on campus. The minor themes related to the particular importance of faculty and attendance at a community college to some of the students.

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CASE STUDY

Jonathon is a first time in college student, who began attending the local community college two weeks ago. Like other students, this morning he navigates his way through the maze of cars in the parking lot to find a good spot. He luckily finds one not too far away and quickly grabs his backpack and hurries to his first class which starts at 10:00 a.m. He arrives early, at 9:20 a.m., and quietly waits in the hallway for the previous class to finish. He is alone for a little while, but eventually other students begin to meander in the hallways and he recognizes some from his class. Jonathon thinks one or two recognize him, too, because one of the girls glances at him and even smiles a little, but he isn't sure because they walk past him and stand further down the hall. A few other classmates congregate by the doorway a little closer to him and he overhears them talking about a particular scene in a popular action movie that came out last weekend. Jonathon knows the movie they are talking about; he has seen it twice already. He listens intently to their conversation and wants to tell them about a program he saw on t.v. about how the special effects were done, but he doesn't join in their conversation and continues to stare at the floor avoiding eye contact. He appears uncomfortable and a little aloof.

As soon as the current class lets out, Jonathon rushes into the classroom to make sure he gets his regular seat. He sits down quickly and begins to set out his course materials neatly on his desk. The noise level in the room escalates as more students filter in and begin to talk to, and over, each other. Jonathon finds the amount of conversations going on at once overwhelming and focuses on the cover of his textbook. Just as the competing sounds almost become unbearable, the professor enters and prompts the class to settle down. Jonathon starts to relax a little but then he hears his professor announce that today they will be assigned into groups so they can begin work on their class projects. He can feel his body temperature rise and his heart begins to pound loudly in his chest. Jonathon knew from a review of the syllabus that a group project was required, but he didn't know that they would start this early in the semester. His palms are now wet and he is wondering if he still has time to drop this class.

CHAPTER 1 INTRODUCTION

Background

Historically, students with disabilities have counted for a very small minority population on college and university campuses (Russo Jameson, 2007); however, with the advent of federal legislation aimed at providing non-discrimination and equal access for people with disabilities, young adults with disabilities have been exploring postsecondary education as a realistic goal when planning for their futures (Hawke, 2004; Russo Jameson). According to national data from the 2003-2004 academic year collected by the National Center for Education Statistics, students with disabilities made up over 11% of the overall undergraduate population, accounting for about 2.09 million students nationwide (Horn & Neville, 2006).

Over time, this population has expanded to include individuals diagnosed with Asperger's syndrome (AS). Asperger's syndrome, also referred to as Asperger syndrome, Asperger's disorder, or just Asperger's, is a neurological developmental disorder characterized by difficulties with social interaction, restricted interests, and stereotyped and repetitive behavior in the absence of significant cognitive and language delay (American Psychiatric Association [APA], 1994). The exact cause of AS has not been identified, but researchers have associated brain abnormalities with the disorder (National Institute of Neurology and Stroke, 2005).

AS is one of five disorders, collectively known as Pervasive Developmental Disorders (PDD). PDD “are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities” (APA, 1994, p. 65). Other PDD include: Autism disorder, Rhettt’s disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder--Not Otherwise Specified (APA). These neurological disorders, along with AS, have often been referred to as Autism Spectrum Disorders (ASD) or those on the autism spectrum.

Considered by some to be a milder form of autism (Attwood, 2007; Tryon, Mayes, Rhodes, & Waldo, 2006), AS individuals are known to socially isolate themselves, to lack empathy and intuition, and have a tendency to be clumsy (Fitzgerald & Corvin, 2001; Gillberg, 2002; Szatmari, Bremner & Nagy, 1989; Welkowitz & Baker, 2004). These individuals find it difficult to read facial expressions and body language and themselves have difficulty expressing their emotions through these means (Johnson, 2005).

Individuals with AS also tend to interpret things very literally and struggle when there is a change in routine. Their overall inability “to effectively discern the thoughts and feelings of others, so failing to respond to or meet other people’s emotional needs” (Johnson, 2005, p.10) can earn them a reputation of being remote and uninterested. In addition to social interaction impairments and speech and communication problems, individuals with AS typically have

academic difficulties, sensitivity to sensory stimuli, and physical and motor-skill abnormalities (Myles & Simpson, 1998).

Asperger's syndrome was named after researcher and pediatrician, Hans Asperger. Asperger observed a group of young boys and their unique social and communication characteristics and wrote about them in 1944. His work, written in German, remained relatively unknown until it was rediscovered by English researcher, Lorna Wing. Wing introduced Asperger's original research to the English-speaking world in an article she published in 1981. In this article, she referred to his work and renamed the condition he was describing as Asperger's syndrome. Wing never listed specific diagnostic criteria, but based on her research and Asperger's original descriptions, Fitzgerald and Corvin (2001) listed the following as markers of AS as

(a) a lack of normal interest and pleasure in people around them, (b) a reduction in the quality and quantity of babbling, (c) a significant reduction in shared interests, (d) a significant reduction in the wish to communicate verbally or non-verbally, (e) a delay in speech acquisition and impoverishment of content, (f) no imaginative play or imaginative play confined to one or two rigid patterns. (p. 310)

Since Wing first presented her account and discussion of AS, different criteria have been presented as a means of diagnosis stirring some controversy over what criteria was most appropriate. Ultimately, the American Psychiatric Association settled on its criteria of choice. The diagnosis entered the mainstream and was subsequently widely applied beginning in 1994 when it was

entered into the *Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV)*.

Although the *DSM-IV* is the rubric most commonly used for diagnosis there has been much debate between clinicians and researchers about the absence of any “clinically significant language delay or delay in cognitive development or other skills” (American Psychiatric Association, 1994, p. 77) as a requirement of diagnosis, or even if in fact AS is a separate disorder from autism (Attwood, n.d.; Fitzgerald & Corvin, 2001). The *DSM-IV* criteria were more narrowly defined than were the criteria defined by Wing and other subsequent researchers, thus, limiting those who might otherwise be served by an AS diagnosis (Fitzgerald & Corvin). Debate aside, AS has been widely recognized as a disability that affects individuals on a day-to-day basis and there has been ongoing research on what type of programs and services would best serve individuals with AS.

In the mid-1990s, children began being officially diagnosed with AS according to the *DSM-IV* criteria. Since then, there have been marked increases in the diagnosis of AS and other ASD (Graetz & Spampinato, 2008). According to the Centers for Disease Control and Prevention (2007), as many as one in 152 births may be affected by ASD. Many of the children originally diagnosed, having become young adults, have chosen to pursue higher education. This has created an influx in the number of students diagnosed with AS on campuses in the early 21st century (Attwood, 2007). Although there have been no statistics reported as

to the numbers of AS students enrolled at colleges and universities (Welkowitz & Baker, 2004), anecdotal stories have been used to account for the growing number of AS students on college campuses today (Dutton, 2008; Farrell, 2004; Moore, 2006; Trachtenberg, 2008). The increase in K-12 students receiving special education services has been thought to be one of the main contributors to the increase in this population. The Centers for Disease Control and Prevention (2007) found that the number of students in the United States with ASD who received services through special education at the K-12 level, increased by 500% between 1991 and 1998.

Most of the children who received special education services in K-12 come from a very structured and accommodating academic environment (Hawke, 2004). Since its inception in the mid-1970s, students with disabilities in the K-12 environment have been served under the Individuals with Disabilities Education Act (IDEA) (Eckes & Ochoa, 2005; Hawke; Madaus & Shaw, 2006). Under IDEA, schools have been required to, not only serve these students but, actively seek out, identify, and assess students with possible disabilities using a thorough and nondiscriminatory evaluation process (Hawke; Madaus & Shaw). Once identified and evaluated, school districts have been required to develop and implement an Individualized Education Plan (IEP) for each student with a disability (Hawke). IEPs have been used to assess students' progress. Progress is closely monitored by IEP team members who work together to meet students'

needs. This type of structure and level of support changes significantly after high school (Eckes & Ochoa; Hawke; Thomas, 2000).

At the postsecondary level, IDEA has not governed disability access. Rather, students have been protected under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (Eckes & Ochoa, 2005; Madaus & Shaw, 2006; Thomas, 2000). In contrast to the IDEA focus on ensuring the success of students with disabilities, these laws have shifted to a focus of access through the removal of barriers and the provision of accommodations. In higher education, there has been no assurance of success. In reference to higher education, both Section 504 and the ADA have provided examples of reasonable accommodations for qualified students with disabilities; however, the typical accommodations may only address academic barriers and not help with social/relationship or emotional issues (Graetz & Spampinato, 2008) common to students with AS.

The college environment has presented many situations that may be difficult for AS students to navigate that, though having little to do with the academic environment, affect students' ability to be successful. There has been an ongoing debate about what actually constitutes a "reasonable accommodation," and college administrators have struggled to determine when AS students might benefit more from behavioral coaching than from specific academic accommodations (Farrell, 2004).

At the post-secondary level, students with AS, along with other students with disabilities who transition from high school to the postsecondary level, have faced a multitude of challenges associated with changes in their rights and responsibilities, procedures to receive disability services, and the overall learning environment (Eckes & Ochoa, 2005; Gil, 2007; Hawke, 2004; Madaus & Shaw, 2006). To be successful at this next level, it has been crucial for students with disabilities to learn what services they need and how to ask for them. As Gil stated, “Self-determination is a key skill that can be developed to assist students with disabilities in becoming strong self-advocates as they move through their educational experience” (p. 14).

Unfortunately, too often students with disabilities have entered college without good self-determination skills because they have not been as involved as they should have been in their own decision-making (Field, Sarver, & Shaw, 2003; Gil, 2007). Getzel (2008) defined self-determination skills as

a set of personal or interpersonal skills that include acceptance of a disability and how it affects learning; understanding which support services are needed; knowing how to describe one’s disability and the need for certain supports to service providers; and having the determination to overcome obstacles that may be presented. (p. 210)

Being self-determined means “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 1996, p. 24).

Self-determination develops over a life span as children and adolescents learn skills and develop attitudes that permit them to be causal agents in their

lives--they make or cause things to happen in their lives independently

(Wehmeyer & Shogren, 2007). Component elements of self-determined behavior

include:

- Choice-making skills
- Decision-making skills
- Problem-solving skills
- Goal-setting and attainment skills
- Independence, risk-taking and safety skills
- Self-observation, evaluation, and reinforcement skills
- Self-instruction skills
- Self-advocacy and leadership skills
- Internal locus of control
- Positive attributions of efficacy and outcome expectancy
- Self-awareness
- Self-knowledge (p. 437)

Self-determination research has not been readily explored in relation to individuals on the autism spectrum. Researchers have indicated, however, that learners with autism spectrum disorders can meet the unique challenges and acquire these skills with the right educational supports and accommodations (Wehmeyer & Shogren).

Due to the nature of their disability, students with ASD are more likely to learn and practice the component skills of self-determination in a rote manner, without making the connection between the application of these skills and the outcomes in their everyday lives (Wehmeyer & Shogren, 2007). Goal-setting can present a challenge if ASD students are faced with multiple goals because they tend to address these goals sequentially and struggle with prioritizing and changing course if necessary. Problem-solving skills that involve interpersonal or

social situations are complex due to the fact that they have multiple solutions and possible outcomes. These skills are especially challenging for students with ASD because of the difficulties they encounter with social-emotional understanding; however, when provided opportunities to make choices, problem-behaviors are reduced and increases in adaptive behaviors are observed (Wehmeyer & Shogren).

Research on the component elements of self-determination indicate that youth who are more self-determined experience more positive adult outcomes (Wehmeyer & Shogren, 2007). The following four essential characteristics describe the function of self-determined behavior: “1) the person acts autonomously, 2) the behaviors are self-regulated, 3) the person initiates and responds to event(s) in a psychologically empowered manner, and 4) the person acts in a self-realizing manner” (Thoma & Wehmeyer, 2005, p. 51; Wehmeyer & Shogren, 2007).

The development of self-determined behavior can be delayed when a lack of opportunity limits essential practice. Unfortunately, students with disabilities are often nurtured in an environment where they are not readily encouraged to actively participate in discussions pertinent to their own outcomes. In the primary and secondary levels, services for students with disabilities are often decided on and arranged by teachers, other school personnel, and parents who are acting as their children’s advocates (Gil, 2007, Izzo & Lamb, 2002). Students with AS have often not had the opportunity to develop critical problem-solving skills,

because their parents “have been gate-keepers and the problem-solvers for their children” (Graetz & Spampinato, 2008, p. 24). Sometimes, in an effort to protect, these students have been kept so unaware of their own disability that they cannot even explain their disability, much less their needs (Field, Sarver, & Shaw, 2003; Izzo & Lamb; Jones, 1996). This lack of self-awareness has contributed to the academic and personal struggles that students with disabilities face in higher education.

Statement of the Problem

For the first time ever, students with AS have begun to regularly attend colleges and universities as a means to achieving successful adult outcomes. These are precisely the students, however, who struggle with the social interactions within and outside the classroom that have been determined to be critical to college success. Self-determination has been shown to be a predictor of successful adult outcomes for individuals with disabilities, but little is known about how students with AS utilize self-determination skills at the postsecondary level. For the purpose of this study, the researcher assessed the self-determination skills described by students diagnosed with AS who were enrolled in a two-year public community college. The researcher assessed how these students viewed their roles at the postsecondary level in regard to navigating the college environment.

Purpose of the Study

The AS literature has grown and is, in fact, robust in regard to the diagnosis, treatment, and support for children and adolescents. Research about young adults with AS and their experiences in the realm of higher education has, however, been somewhat limited. When AS has been investigated, it has often been from the perspective of educators, parents, and service providers with little being written about the experience of living with AS from the perspective of someone diagnosed with AS. The purpose of this qualitative study was to describe and understand how community college students diagnosed with Asperger's syndrome utilize self-determination skills throughout their college experiences.

Significance of the Study

AS has become a common expression as more individuals have become aware of the disorder or know someone who has been diagnosed with AS. As awareness has grown more students with AS have received services in their K-12 educational settings; and as a consequence, more have recognized college as a postsecondary option (Farrell, 2004). The college experience includes more than academic progression. As Glennon (2001) noted, "The overall goals of any university experience include developing skills for adulthood, forming life-long relationships, identifying a vocational pathway, and/or participating in extra-curricular activities" (p. 185).

To meet the needs of students with AS in higher education, it was important to hear from them, through their own voices, about their experiences in college and, specifically, the role self-determination has played in those experiences. This information was intended to inform K-12 educators of the challenges and successes of postsecondary AS students so that appropriate programming could be implemented early in the transitioning process. The data were also intended to inform colleges and universities about how to meet the needs of this growing population, whether through traditional accommodations or more nontraditional supports and services. Finally, this research was designed to contribute to the growing body of literature about students with AS participating in higher education.

Conceptual Framework

This study was guided by social construction as its conceptual framework. Social construction was first advanced by Berger and Luckmann (1966), who hypothesized that knowledge and meaning were created by social interactions. Power, in turn, is distributed based on these interactions (Foucault, 1977). Social construction of disability then draws on the assumptions that what is believed and valued in society is determined by individuals who are in power (Oliver, 1996) and not by the disabled themselves (Jones, 1996). Albrecht and Levy (1981) summarized their views on disabilities as social problems:

Certain disabilities become defined as social problems through the successful efforts of powerful groups to market their own self interests. Consequently the so-called 'objective' criteria of disability reflects the biases, self-interests, and moral evaluations of those in a position to influence policy. (p. 14)

In one related example, Dudley-Marling (2004) proposed that problems related to learning only exist “in the context of human relations and activity” (p. 482). Likewise, Malloy and Vasil (2002) have argued that AS has been socially constructed within special education in response to society’s needs to address social differences among students. Therefore, individuals with AS, who in the past may have been viewed as unique or eccentric, have more recently been diagnosed using medical criteria as a means to explain their difference (Malloy & Vasil).

To speak of a social impairment in this way implies that there is a clearly demarcated spectrum of normal social behaviour into which all childhood behaviour confidently falls and that failure to correspond to this norm constitutes an impairment. (p. 664)

Oliver (1996) proposed that people with disabilities become excluded from society by means of categorical terminology such as normal and abnormal in addition to the high value placed on the medical profession. This dominance of the medical profession has led to the popularization of the medical model of disability. This model socially constructs disability based on individual pathology. This medical model approach has dominated discourse on AS, focusing on the neurological basis of disorder using rehabilitative therapies as treatment (Malloy & Vasil, 2002). Goodley (2001) argued “that society creates disablement and is

the arbiter of disciplinary powers that (re)produce pathological understandings of different bodies and minds” (p. 210).

In response to the medical model of disability, disability advocates and scholars (Crow, 1996; Oliver, 1996; Shakespeare, 1996) have recommended that the social model of disability replace the medical model. This model allows for the idea that disability is just a difference, similar to eye color, and that oppressive societal structures create the functional limitations of disability. The frame of social construction was used in this study as a means to understand the interactions of students with AS and their postsecondary environment.

Research Questions

This study was guided by the following research questions:

1. What, if any, self-determined behaviors do community college students diagnosed with Asperger’s syndrome express and describe?
2. How do community college students diagnosed with Asperger’s syndrome use self-determination skills to navigate the college environment?

Definitions

Autism Spectrum Disorder (ASD): common term used to name any one of the five Pervasive Developmental Disorders, including: Autism disorder, Rhett’s

disorder, Childhood Disintegrative disorder, and Pervasive Developmental Disorder – Not Otherwise Specified

Asperger's Syndrome (AS): neurobiological developmental disorder manifested by social deficits including communication problems and narrow, restrictive interests, cognitive and language development is normal

Autism: a neurobiological developmental disorder manifested by social impairments, communication impairments, and restrictive repetitive and stereotyped movements, cognitive and language impairments typically exist

High-Functioning Autism (HFA): the term commonly used to describe individuals who presented classic signs of autism in early childhood, but who, as they develop, show higher IQ levels with better behavior and communication skills than usual of autism-- no diagnostic guidelines exist

Comorbidity: when two or more medical conditions coexist

Self-determination: the ability to make independent decisions to the fullest extent possible causing influence over one's outcomes

Locus of control: an individual's perception regarding the cause/s for the events impacting one's life (internal or external)

Assumptions

The following assumptions were made for the purpose of this study:

1. It was assumed that the students interviewed would feel comfortable enough to be open and honest in their responses.

2. It was assumed that the students, all of whom have completed high school with a standard high school diploma, would understand the questions asked by the researcher.

Limitations

1. The nature of the qualitative data collection and sample sized used made it difficult to generalize the findings outside of those being interviewed.
2. Every effort was made to avoid any bias on the part of the researcher. Specific procedures, semi-structured interviews and triangulation of data were employed to reduce this potential limitation to the research.
3. Considering the debate over diagnostic criteria, definition, and even the existence of AS as a separate and distinct disorder, I cannot guarantee the same criteria will have been used in diagnosing participants. The diagnosis each individual respondent received by a licensed clinician was taken at face value.

Delimitations

1. Due to access issues related to confidential disability information, the study was restricted to individuals enrolled in a single community college.

2. The study population and subsequent sample were limited to those students who self-identified as being diagnosed with Asperger's syndrome and had registered with the student disability services office with an official diagnosis.

Organization of the Study

Chapter 1 provided background information pertinent to the study and introduced the problem, significance, and purpose of this study. Chapter 2 presents a literature review with a focus on students with disabilities in higher education, self-determination in relation to students with disabilities, and Asperger's syndrome. The methodology used for data collection and analysis is described in Chapter 3. The interview data are presented in Chapter 4. Next, the data was analyzed and the common themes discovered and self-determination results are presented in Chapter 5. Finally, Chapter 6 contains a summary and discussion of the findings of the study. Implications for students with AS in higher education and recommendations for future research have also been presented.

CHAPTER 2 LITERATURE REVIEW

Introduction

The review of literature presented in this chapter was completed to address issues related to the participation of students with Asperger's syndrome (AS) in higher education. The characteristics of students with disabilities at the postsecondary level and the disability laws impacting the postsecondary transition of students with disabilities were described, including differences in reasonable accommodations. Self-determination and its impact on individuals with disabilities was introduced and discussed in relation to education outcomes. AS was explored through (a) diagnostic criteria, (b) prevalence, (c) differential diagnosis, (d) comorbidity, and (e) the social and communication challenges of individuals with AS. Literature on students with AS in higher education and the programs and services that are available to them were also reviewed. The chapter has been concluded with a discussion of social construction as the conceptual framework for the study.

Students with Disabilities in Higher Education

As the general student population across higher education has continued to grow over the past several decades, so too has the population of students with disabilities. Using data from the National Postsecondary Student Aid Study (NPSAS), the National Center for Education Statistics (NCES) has consistently

reported increases in students with disabilities at the postsecondary level (Horn & Berkold, 1999; Horn, Peter, & Rooney, 2002; Horn & Neville, 2006).

During the 1995-96 academic year, the NPSAS studied a national sample of 21,000 undergraduate students. (Horn & Berkold, 1999). These students were asked “Do you have any disabilities, such as hearing, speech, mobility impairment, or vision problems that can’t be corrected with glasses?” (p. 6). Approximately 6%, or about 1,260, of the students responded affirmatively and provided further specific disability category information. The disability category choices included: visual impairment, hearing impairment or deaf, speech impairment, orthopedic impairment, learning disability, and other impairment or disability. Noticeably absent was any specific category addressing mental or psychological impairments. Of the 6% reporting a disability, 29% reported a learning disability; 23%, an orthopedic impairment; 16%, a vision impairment that was not correctable; 16%, Deaf or hard-of-hearing; 3%, a speech impairment; and 21%, “other health-related” impairment. Based on the categories provided, students with AS would have had to categorize themselves as other health impairment or disability.

A longitudinal study of eighth graders in 1988, revealed that among those who completed high school, students with disabilities (63%) were less likely to be enrolled in some form of postsecondary education two years after graduation compared to students without disabilities (72%) (Horn & Berkold, 1999). Overall, students with disabilities had lower high school gpas, fewer advanced placement

courses, and lower SAT scores. They had a higher likelihood of taking remedial English and mathematics coursework in high school and were less likely to be prepared to attend college (Horn & Berktold).

Differences between students with and without disabilities were also evident in the types of postsecondary institutions in which they enrolled. Using national data of 1988 eighth graders who completed high school, of those enrolled in postsecondary education by 1994, students with disabilities (45%) were more likely to enroll in public two-year colleges than were students without disabilities (33%); at four-year colleges and universities, students with disabilities (42%) were less likely to enroll than students without disabilities (62%). Both groups were equally likely to enroll in for-profit institutions (Horn & Berktold, 1999). In particular, public two-year colleges, commonly known as community colleges, have provided unique opportunities for students with a variety of disabilities.

With their open-door admissions policy, the colleges are often described as the people's or democracy's colleges and are widely credited with opening access to higher education to the most diverse student body in the history of higher education. (Boggs, 2004, p. 8)

This “open door” policy has afforded students with disabilities the chance to experience the academic and social environment of college which might have otherwise evaded them. Community colleges not only have enrolled and served a higher percentage of students with disabilities, but they have also

accommodated a greater variety of disabilities, including the severely disabled (Hawke, 2004).

Once enrolled, students with disabilities have not appeared to progress and complete at the same rate as their non-disabled counterparts. A 1994 national longitudinal survey of those who began college in 1989-90, determined that 64% of students without disabilities had completed a degree or vocational certificate or were still enrolled within five years, in comparison to only 53% of students with disabilities (Horn & Berktold, 1999). Students with disabilities, however, who have persisted and earned a four-year degree have experienced comparable labor market outcomes, including graduate school enrollment, as those students without disabilities (Horn & Berktold).

The NPSAS was distributed again in the 1999-00 academic year to a sample of approximately 50,000 students, and the percentage of students identified with some kind of disability increased to a little over 9%, or about 4,500 (Horn, Peter, & Rooney, 2002). The wording of the disability questions was changed and could have influenced the increase in those reporting a disability, although some of the prior survey questions could have resulted in under-reporting. In this survey, the students were asked:

1. whether they had “long-lasting conditions” such as blindness, deafness, a severe vision or hearing impairment;
2. whether they had “a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying”; and
3. whether they had “any other physical, mental, or emotional condition that has lasted six months or more.” (Horn, Peter & Rooney, p. 17)

Of the 9% identified as students with disabilities, 29% reported an orthopedic impairment, 17% reported a mental illness or depression, 15% reported general health-related problems, and 5-7% reported disabilities in a vision, hearing, learning, or attention deficit. Interestingly enough, when asked, “Do you consider yourself to have a disability?” (p. 17) only 4% of the students reported “yes.” This discrepancy could be due to the fact that students with invisible disabilities, meaning those with non-physical disabilities, often did not associate themselves with disabled populations. These students would include those individuals with AS.

Data collected from the 2003-04 NPSAS showed yet another increase in the students with disabilities population in higher education. From a sample of approximately 80,000 students, 11%, or about 8,800, of undergraduate students in the 2003-04 academic year reported having a disability (Horn & Neville, 2006). Of those reporting a disability, 25% reported an orthopedic impairment, 22% reported a mental illness or depression, and 17% reported a general health-related impairment.

Institutional data on the enrollment of students with disabilities has also been collected. Lewis and Farris (1999) studied 5,040 two- and four-year public and private postsecondary educational institutions. They determined that 98% of public two-year and four-year colleges enrolled students with disabilities during the 1996-97 or 1997-98 years. This was in contrast to much lower enrollments reported for private four-year (63%) and private two-year (47%) institutions.

Almost all medium (99%) and all large (100%) institutions reported having enrolled students with disabilities. Learning disabilities were the most frequently reported disability (about 46%) followed by: mobility or orthopedic impairments (14%), health impairment or problems (11%), mental or emotional disturbance (8%), hearing impairments (6%), blind or visual impairments (4%), speech impairment (<1%), and other (9%). The category of other was explored and found to have included those students with developmental disabilities such as mental retardation and autism (4%).

The increase of students with disabilities participating in higher education over time is related to federal legislation implemented to protect individuals with disabilities from being discriminated against or denied access to educational opportunities. For example, K-12 special education mandates have increased the number of students receiving services (Centers for Disease Control and Prevention, 2007) and, in general, have improved awareness. Students who have become accustomed to disability services during their K-12 educational years know to ask about services at the postsecondary level.

Federal Legislation and Students with Disabilities

In addition to facing all of the usual transition challenges that all students face, such as making hard decisions, working through a new educational process, learning a new academic environment, and creating new social

relationships, students with disabilities must also learn to navigate a new set of disability laws to ensure their equal access.

The federal disability laws governing higher education are different from those special education laws governing the K-12 system, and it is imperative that students with disabilities who are planning to pursue higher education understand the differences between the two (Eckes & Ochoa, 2005; Gil, 2007; Thomas 2000). The Individuals with Disabilities Education Act (IDEA) governs special education in the K-12 systems and at the postsecondary level Section 504 of the Rehabilitation Act (Section 504) and the Americans with Disabilities Act (ADA) govern.

Individuals with Disabilities Education Act (IDEA)

Passed in 1975, the Individuals with Disabilities Education Act (IDEA) was the first nationally adopted special education law. The landmark legislation was based on the philosophy that any student with a disability, between the ages of 3 and 21 (or graduation), should be provided a free, appropriate, public education (FAPE), regardless of the nature or severity of the disability (Madaus & Shaw, 2006). One of the main tenants of IDEA is that students with disabilities must have an IEP.

Included within the IEP is information regarding the student's current level of academic performance, measurable goals and services provided to help reach those goals, specific support and accommodations provided, behavior plans

when necessary, and any other needs identified (IDEA, 2004). The above aspects of the IEP are developed by the student's IEP Team, which includes his/her parents or guardians, special education teacher, a school or district representative, someone who can interpret the child's evaluation results, and when appropriate the child can participate as well as any invited guests who can contribute to the student's education plan.

The IDEA has been reauthorized numerous times, most recently in 2004, and titled the Individuals with Disabilities Education Improvement Act. According to Madaus and Shaw (2006), there have been many key changes in the IDEA 2004 which have been relevant to postsecondary institutions and transitioning students. These include (a) re-evaluations of disabilities, (b) the summary of performance requirement, (c) transition planning, and (d) new criteria for the diagnosis of learning disabilities.

One of the changes under transition planning was that the IEP team must include in their transition planning (a) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and (b) the transition services (including courses of study) needed to assist the child in reaching those goals. (IDEA, 2004, 300.320 (b))

Transition planning has been intended to focus students on preparing for their futures with realistic goals and appropriate preparation to reach those goals. Students transitioning from K-12 to the postsecondary level and their parents are

familiar with IDEA and IEPs and have an expectation of similar services at the postsecondary level. These expectations often result in disappointment if students and parents have not researched the changes in disability law from K-12 to higher education. The laws governing colleges and universities are not special education laws, but rather laws based on prohibiting discrimination on the basis of disability, ensuring equal access.

Section 504 and the ADA

Section 504 of the Rehabilitation Act of 1973 (Section 504) was the first statute created that was intended to directly protect persons with disabilities from discrimination. Section 504 (1973) stated that:

No otherwise qualified individual with a disability in the United States, shall, solely by reason of his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . . (29 U.S.C. § 794[a], as amended)

The regulations defined an individual with a disability as “any person who (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment” (34 C.F.R. § 104.3[j]).

Students with AS meet the above definition because AS is a recognized mental impairment, and it “substantially limits” learning, which is considered a “major life” activity. Section 504 has specified that an individual with a disability must be “otherwise qualified” and, therefore, must also meet “the academic and

technical standards requisite to admission or participation in the recipient's education program or activity" (34 C.F.R. § 104.3 [j]). This definition means that students with AS must be able to academically meet the essential course requirements of their studies and socially must be able to follow the Student Code of Conduct or similar policies related to behavior.

Subpart E of the regulation sets minimum standards by which postsecondary institutions need to abide. These standards include policies on admissions and recruitment, treatment of students, academic adjustments, housing, financial and employment assistance to students, and nonacademic services. Under Section 504, postsecondary institutions that receive federal funding anywhere within the institution, must demonstrate compliance throughout the entire institution, not just in the area receiving the funds (Thomas, 2000).

The Americans with Disabilities Act (ADA) of 1990 extended the protections of Section 504 against discrimination toward individuals with disabilities. The ADA (1990) defined discrimination as:

a failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modification would fundamentally alter the nature of such goods, services, privileges, advantages, or accommodations. (42 U.S.C. 12182 (b) (2) (A) [ii])

Although Section 504 laid the foundation, it was really the ADA that made a deep impact on the lives of individuals with disabilities. In particular, higher education institutions that had made little progress in making their programs and facilities

accessible under Section 504, increased their efforts to meet compliance guidelines (Thomas, 2000).

The ADA has provided protections for individuals with disabilities in the areas of employment, state and local government services, public accommodations and telecommunication. The ADA was broken into five sections referred to as Titles. Title II referred to public programs, services, and activities of state and local governments. This is the title that has concerned postsecondary institutions. The main variation between Title II and Section 504 has been that Title II applied to state and local governments regardless of their size or whether or not they receive federal funding whereas Section 504 has applied to only institutions receiving federal monies.

Title III has referred to places of public accommodations of businesses and nonprofit services that are open to the public such as restaurants, hotels, malls, movie theaters, sports arenas, and hospitals. Also included within this Title were provisions for commercial facilities and private entities including private higher education institutions (Americans with Disabilities Act, 1990). Section 504 and Titles II and III of the ADA cover access to college and university facilities, communication, information, and transportation. They also address reasonable accommodations for individuals with disabilities.

Reasonable Accommodations

Postsecondary success can be dependent on knowing how to access and use appropriate accommodations. It has been the responsibility of the student at the postsecondary level to know and follow the institution's procedures for requesting accommodations. One of the key differences that students with disabilities have faced, upon transition, is the need to self-identify as a student with a disability to receive services. At the postsecondary level, college officials have not been required to identify students with disabilities or assess their needs; therefore, they have not sought out students to ensure they are receiving disability services. This self-disclosure of disability has resulted in a "transfer of responsibility from the school to the individual with regards to seeking special education services" (Eckes & Ochoa, 2005, p. 9).

Most postsecondary institutions have established a disability services department or person designated to support the needs of students with disabilities. Once students self-identify, they may be asked to provide documentation supporting the need for services. Documentation requirements may vary from institution to institution, with some institutions requiring more than others (Office for Civil Rights, 2007); however, the documentation process should not be so complicated or burdensome as to hinder students from receiving proper accommodations (Eckes & Ochoa, 2005). Information about an institution's documentation process should be available in any or all of the

following: catalogs and handbooks, on the institution's website, in a new student orientation, or through a variety of other recruitment materials and methods.

Once eligibility for services has been met, students with disabilities need to request their accommodations through appropriate channels. The type and level of accommodation received in K-12 may not be considered reasonable at the postsecondary level, because colleges and universities have not been required to alter essential course requirements or make modifications that would fundamentally change the program, activity, or service or cause an undue financial burden (Office for Civil Rights, 2007).

At the K-12 level, students and their parents may have become accustomed to a menu style selection process in choosing preferred accommodations or have had the ability to use as many accommodations as possible (Field, Sarvar, & Shaw, 2003). At the postsecondary level, academic adjustments or accommodations have been determined on an individual case-by-case basis depending on the student's disability and needs. Academic adjustments may include priority registration, reduced course load, course substitutions, extended testing time, testing in a distraction-reduced environment, and/or other modification to academic requirements.

Accommodations may also include the provision of necessary auxiliary aids. Section 504 and Title II of the ADA reinforce the obligation of postsecondary institutions to provide auxiliary aides and services to ensure equal

access for students with disabilities. Table 1 presents examples of auxiliary aides.

Table 1
Auxiliary Aides

Examples of Auxiliary Aides and Services	
taped texts	closed caption decoders
note takers	open and closed captioning
interpreters	voice synthesizers
readers	specialized gym equipment
videotext displays	calculators or keyboards with
television enlargers	large buttons
talking calculators	reaching device for library use
electronic readers	raised-line drawing kits
Braille calculators, printers, or	assistive listening devices
typewriters	assistive listening systems
telephone handset amplifiers	telecommunications devices for
	deaf persons

Note. Table is adapted from *Auxiliary Aids and Services for Postsecondary Students with Disabilities: Higher Education's Obligations Under Section 504 and Title II of the ADA* (Office for Civil Rights, 1998).

Auxiliary aides have often been confused with personal attendants and devices by transitioning students with disabilities and their parents. Under IDEA, the K-12 system has been required to provide a FAPE for students with disabilities, and that requirement may have necessitated the use of devices or attendants of a personal nature. However, at the postsecondary level, institutions have not been required to provide such accommodations as "personal attendants, individually prescribed devices, readers for personal use or study, or

other devices or services of a personal nature, such as tutoring and typing” (Office for Civil Rights, 2007, p. 3). Students with disabilities who qualify for reasonable accommodations should take advantage of what is available to them, because “the underutilization of accommodations by college students often seriously impacts students’ persistence. . . and consequently, their retention in postsecondary education” (Getzel, 2008, p. 210). It is critical that students know how to request accommodations, use the accommodations, and follow-up with the appropriate staff if there are any problems.

One of the reasons that accommodations may have been underutilized in colleges and universities is the fact that the accommodation selection process at many institutions has focused on disability type rather than the individual student’s functional needs (Kurth & Mellard, 2006). Kurth and Mellard attempted to discern student perceptions of the accommodation process in their study, hoping to shed light on the usefulness and challenges related to accommodation usage. Surveys and focus groups were used to collect the data.

Participants were recruited through the disability student services offices of 15 community or technical colleges in California, Minnesota, and Kansas. A total of 108 students completed surveys, and 104 participated in focus groups. There were 53 (49%) males and 55 (51%) females. There was a wide spectrum of ages ranging from 18-60, with an average of 30. One disability type was reported by 70 (65%) and two or more disability types were reported by 38 (35%). A variety of disabilities were represented: 42 (39%) learning disabilities, 2

(2%) emotional/behavioral, 2 (2%) psychiatric, 24 (23%) orthopedic, 14 (13%) hearing impaired, 10 (9%) vision impairment, 4 (4%) traumatic brain injury, 6 (6%) chronic illness, and 2 (2%) speech/language disorders.

The data revealed that the top three factors rated as important in selecting accommodations were effectiveness, availability, and increased independence. Participants rated the most effective accommodations to be note takers (87.5%), extended time on exams (85.7%), and assistive technology (81.8%). Those accommodations ranked ineffective by a score of 25% or less were: tape recorders, alternative testing location, taped texts or notes, mental health counseling services, and copies of notes ahead of class. According to Getzel (2008) and Webb, Patterson, Syverud, and Seabrooks-Blackmore (2008), knowledge and use of assistive technology can have a great impact on the potential successes of students with disabilities in higher education.

The focus groups revealed four themes. Students' concerns included: (a) the need for a sense of belonging and a feeling of acceptance, (b) access to the same academic information at the same time as other students, (c) supports for independence or a preference for accommodations that enabled independence, and (d) labeling due to disability or use of accommodations and discrimination.

To ensure that appropriate accommodations are provided, it is important for students with disabilities to become knowledgeable about their rights and learn to be their own self-advocates since professors and counselors at postsecondary institutions are often not aware of specific needs of students with

disabilities (Eckes & Ochoa, 2005; Lock & Layton, 2001). Based on a content analysis of articles from 1995-2006, Webb et al., (2008) found that in addition to utilizing appropriate accommodations, self-determination skills were important in increasing the chances of success for students with disabilities in the postsecondary environment.

Self-Determination

Much of the current literature about individuals with disabilities includes discussion of the importance of self-determination, particularly during the transition period from high school to adult life (Eckes & Ochoa, 2005; Field, Martin, Miller, Ward, & Wehmeyer, 1998; Field, Sarver, & Shaw, 2003; Getzel, 2008; Jones, 1996; Izzo & Lamb, n.d.; Lock & Layton, 2001; Russo Jameson, 2007; Thoma, Nathanson, Baker, & Tamura, 2002; Thoma & Wehmeyer, 2005; Webb, Patterson, Syverud, & Seabrooks-Blackmore, 2008; Wehmeyer, 1996; Wehmeyer, 2004; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007).

Field et al. (1998) described self-determination as

a combination of skills, knowledge and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in society. (p. 2)

Wehmeyer (2004) further explained that “the self-determination construct refers to both the right and capacity of individuals to exert control over and direct their lives” (p. 23). This construct is closely related to the concept of locus of control.

Locus of control refers to one’s belief as to who or what has influence over personal outcomes. Rotter (1975) determined that individuals with an internal locus of control believe that their own choices and actions determine their outcomes. Individuals with an internal locus of control understand the cause and effect associated with those choices and actions. Those with an external locus of control believe factors out of their control such as fate, luck, or other people’s choices or actions, influence their outcomes. Individuals who have an external locus of control remain passive observers in their lives and, therefore, lack self-determination.

The culture of America is strongly rooted in the individual’s ability to exercise power, control, and influence within their community. Yet, people with disabilities throughout their educational experience and into their adult life are consistently limited or denied the opportunity to take risks and make decisions and therefore do not develop self-determination skills. (Izzo & Lamb, 2002, p. 10)

The importance of self-determination for individuals with disabilities was recognized at the federal level and outlined congressionally through the 1992 Amendments to the Rehabilitation Act. The amendments stated that,

disability is a natural part of the human experience and in no way diminishes the right of individuals to:

- a) live independently;
- b) enjoy self-determination;
- c) make choices;
- d) contribute to society;

- e) pursue meaningful careers; and
- f) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.
(Rehabilitation Act of 1973, as amended)

The concept of self-determination, in relation to persons with disabilities, grew as a means of understanding life-long outcomes, both positive and negative (Russo Jameson, 2007). Wehmeyer & Shogren (2007) in discussing the merits of self-determination, wrote “promoting self-determination is not only a moral or ethical response to the demand for equal rights and treatment for people with disabilities, it is also a means to improve educational outcomes for children and youth with disabilities” (p. 434).

Self-determination emerged in special education as a result of the transition-related outcomes pertaining to student involvement and planning, associated with IDEA 1990 (Thoma & Wehmeyer, 2005; Wehmeyer & Shogren, 2007). Since then, numerous studies have been conducted to determine the impact of self-determination on students with disabilities (Carter, Lane, Pierson, & Glaeser, 2006; Russo Jameson, 2007; Shogren et al., 2007; Trainor, 2005; 2007; Wehmeyer et al., 2007).

Though self-determination has been shown to be an effective predictor of success for students with disabilities, students with disabilities have not been entering college with the self-determination skills they need to be successful (Eckes & Ochoa, 2005, Russo Jameson, 2007). Studies specifically related to transition-aged students with disabilities would appear to be of particular interest

to postsecondary educators, as the interventions and related outcomes of that transition group will have a direct impact on their postsecondary experiences. Understanding the extent to which students with disabilities need support for their development is essential. Trainor (2005; 2007) investigated self-determination perceptions and behaviors of transition-aged youth with learning disabilities in two studies.

In the first study, Trainor (2005) conducted a qualitative analysis using focus groups, individual interviews, observations, and document reviews. Purposive sampling was used to select the participants. Data were collected from 15 male students aged 16 or over, who were receiving services for learning disabilities and met eligibility for free or reduced lunch. The participants were categorized by race, but any group differences were subtle. Key findings indicated that the students viewed themselves and their family members, rather than teachers, as key players in their transition planning. The self-determination opportunities at home were thought to be more accessible and productive.

In a similar study, Trainor (2007) used like qualitative methods to examine the perceptions of transition-aged females with learning disabilities regarding self-determination during transition. Participants were seven racially/ethnically diverse females between the ages of 16-18. Each participant received services for learning disabilities and was eligible for free or reduced lunch. Findings indicated that although participants expressed beliefs about being self-determined young women, several key component skills for sound self-

determination were absent. For example, participants discussed choices and decisions they made but were unable to assess the consequences, assign significance, or seek out appropriate resources.

Wehmeyer et al., (2007) studied the role of self-determination in promoting active student involvement in the transition planning of transition-aged youth with disabilities. Participants in the study were recruited from 50 different schools or their assigned 18-21 year old linked program, across 25 school districts throughout 4 states. The sample population included 180 students receiving special education services. The average participant age was 17.73 years old, ranging from 14.4-21.8 with 111 males and 69 females. Participants were represented in disability categories as follows: 81 (45%) mental retardation, 32 (18%) learning disabilities, 18 (10%) autism, 11 (6%) emotional or behavioral disorders, and the remaining were spread across other types of disabilities, less than 5% each. Over all, data analysis revealed that self-determination, and in particular the component skills of self-regulation and self-awareness/self-knowledge, predicted transition knowledge and planning skills, such as team planning skills, decision making, self-advocacy, and goal setting.

Researchers have also investigated the relationship between self-determination and success outcomes of students with disabilities in higher education. Russo Jameson (2007) attempted to determine if there was a link between the success outcomes of students with disabilities at two-year colleges and self-determination. Success outcomes were defined by retention, GPA of 2.0

or higher at the time of the study, and employment success for those who graduated or left the college. Specifically, she wanted to compare how students with disabilities with higher levels of self-determination understood and described their postsecondary experience when compared to those students with disabilities who had lower levels of self-determination.

She used quantitative and qualitative methods to collect data. The study was conducted at a private, primarily two-year, open access institution founded in 1900. The total population included students with disabilities from 1993 to 2002 who formally or informally disclosed a physical, emotional, or learning disability (n = 303). Of the total population, 255 were selected to be a part of the initial mailing, and 48 surveys were completed and returned. Based on the survey data collected, Russo Jameson (2007) found that the students with disabilities with positive success outcomes measured higher levels of self-determination. Follow-up interviews were conducted with four participants and revealed that those measuring low self-determination reported negative postsecondary experiences and those with higher levels of self-determination described highly self-determining behavior and more positive experiences.

Russo Jameson's (2007) results coincide with feedback given by students about college success. Skinner (2004) asked 20 college graduates with learning disabilities, through semi-structured interviews, what it takes to be successful in college. The study took place at a mid-sized liberal arts college in the southeast. Participants included 10 males and 10 females with a median age of 26.6

(ranging from 22 to 54), and interviews were conducted in person and via the telephone. Responses revealed eight common themes regarding success: (a) importance of knowledge of one's disability and concomitant accommodations, (b) limited explanation of results of psychoeducational evaluations, (c) a dearth of information related to disability law, (d) importance of self-advocacy, (e) significance of accommodations and course alternatives, (f) importance of support systems, (g) recognition of the need to persevere under challenging circumstances, and (h) positive effects of goal-setting. Overwhelmingly, self-determination played a significant role in the success of the graduates. Four of the eight themes (a, d, g, and h) were directly related to self-determination with the others being loosely associated.

In a similar study, The Virginia Commonwealth University, Rehabilitation Research and Training Center (as cited in Thoma & Wehmeyer, 2005) asked college students to identify which self-determination skills were necessary to be successful in college. Students with various disabilities, from diverse ethnic groups, attending different types of institutions participated. The following were named as most critical to attaining success in college as a student with a disability: (a) understanding the nature of one's disability and the acceptance of that disability; (b) understanding strengths and limitations; (c) learning to succeed despite disability and other barriers; (d) setting goals and determining how others can contribute to helping set and achieve goals; (e) acquiring problem-solving skills, also knowing rights and responsibilities; and (f) acquiring self-management

skills. They also felt that forming relationships with professors, disability staff members, friends, and mentors was important. Knowing where to locate campus resources and the willingness to take advantage of such resources were also deemed essential to being successful. Finally, personal skills such as self-advocacy, self-evaluation, perseverance, and coping skills were mentioned as critical to advancing through one's program.

Lock and Layton (2001) agreed that self-advocacy plays a critical role in college success. Working with a group of college students with learning disabilities, Lock and Layton assisted in the development of self-advocacy plans, which highlighted learning styles and useful accommodations. The students used the plans as a reference when discussing disability accommodations with their professors. Informal interviews revealed most of the students knew more about their own disabilities and were able to articulate their needs with greater confidence. This type of self-advocacy is key for students with AS. They need to learn what they need and how to advocate for it. Particularly in college, assertiveness skills, effective verbal and written communication, negotiation skills, compromising, and knowing how to navigate internal systems and bureaucracies are necessary for self-advocacy (Wehmeyer & Shogren, 2007).

The literature reviewed on self-determination could be placed into three distinct categories: (a) nonintervention or descriptive studies, (b) perceptions of self-determination of those with disabilities, and (c) efficacy of interventions that promote self-determination (Chambers et al., 2007). While research in these

areas has increased, the results of self-determination studies reviewed were not comprehensive in reflecting the strengths, challenges, personal strategies, and individual experiences of students diagnosed with AS at the postsecondary level.

Asperger's Syndrome

Hans Asperger, a Viennese pediatrician and researcher, observed a small group of young boys, with normal cognition, who displayed a pattern of behaviors exhibiting social and communication deficiencies; he named this condition 'autistic psychopathy' (Attwood, 2007; Fitzgerald & Corvin, 2001, Wing & Potter, 2002). These behaviors were demonstrated by having trouble with normal age-appropriate social interaction, problems with non-verbal communication, and unusual interests.

Asperger's original work was written in German and remained relatively unknown until the early 1980s when Wing introduced the English-speaking world to the term Asperger's syndrome in 1981. She used the term to describe those with autistic-like characteristics, but with social and language skills higher than those typical of autism. Her observations differed slightly from Asperger's, and she recommended the term be used for "children and adults who have autistic features, but who talk grammatically and who are not socially aloof" (Wing, 1981, p. 124). In the early 1990s, Frith translated and published Asperger's original work, *Autistic Psychopathy in Childhood*, into English (Wing & Potter, 2002).

Surprisingly, the term AS and its related diagnostic criteria were embraced by researchers, clinicians, and the general public. “Descriptions of Asperger syndrome in the media created strong resonance in the general public. . . . Asperger syndrome has a special cachet that hints at superior intelligence and perhaps even genius” (Frith, 2004, p. 673). People related to the characteristics of AS and were unofficially diagnosing themselves or other people they knew who seemed to match the stereotypic behaviors outlined in the disorder. The diagnosis “has great appeal for parents as it provides a holistic explanation of their child’s behaviour difficulties” (Stiefel, Shields, Swain & Innes, 2008, p. 2).

Diagnostic Criteria

AS has been described as a developmental disorder characterized by impairments in social reciprocity, difficulties in communication, and a set of restricted interests or preoccupations. At the time of this study, several diagnostic sets of criteria were being used to diagnose AS. No real “gold-standard” has been agreed upon, and diagnostic procedures have varied greatly (Kopra, von Wednt, Nieminen-von Wednt, & Paavonen, 2008; Stiefel et al., 2008). The most commonly used criteria in the United States in 2009 are from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR)* (APA, 2000) and are displayed in Appendix A. These criteria are also used throughout Canada and in scientific studies (Kopra et al.).

In 1992, two years prior to entering the DSM-IV, AS was added to the *International Classification of Diseases and Related Health Problems (ICD-10)*. Descriptions and criteria for AS can be found in two *ICD-10* publications (WHO, 1992; 1993) and are displayed in Appendixes B and C. The *ICD-10*, used commonly in Europe and Australia, is a worldwide diagnostic system. Before being included in the *ICD-10* or in the original *DSM-IV* in 1994, the term AS was used for many years throughout Europe based on Asperger's original and Wing's subsequent descriptions (Woodbury-Smith, Klin, & Volkmar, 2005).

The Gillberg criteria (Appendix D) revised from Gillberg and Gillberg (1989) and the Szatmari et al. (1989) criteria (Appendix E) are also well-known diagnostic criteria. The Gillberg criteria, from Sweden, were the first AS criteria to be published, followed closely by that of the Canadians, Szatmari, et al. The Gillberg criteria has been widely used in clinical practices throughout Northern Europe, and the Szatmari et al. criteria has been adopted in parts of the United States and in Canada (Kopra et al., 2008). The Gillberg criteria followed by the Szatmari, et al. criteria are considered to be closest to those of Wing's (1981) descriptions and those in Asperger's original studies (Attwood, 2007).

There are some similarities and overlap in the different sets of criteria, but there are also some noticeable differences. The *DSM-IV-TR* and the *ICD-10* are the most like each other having almost identical items of social interaction impairments, idiosyncratic and repetitive patterns of routines and interests, and they each include an absence of cognitive and early language delay as part of

their criteria. Early language delay is measured by the lack of spontaneously used meaningful words by 24 months and phrases by 33-36 months. Many researchers and clinicians have found this differentiation misleading and exclusionary (Gillberg, 2002; Howlin, 2003). In fact, the Gillberg (2002) criteria and the Szatmari et al. (1989) criteria both include language abnormalities as part of their criteria.

The *DSM-IV-TR* and *ICD-10* also recognize AS as a subcategory of the PDD and, therefore, both exclude AS if the individual meets the criteria for autism. The Gillberg (2002) criteria alone include a requirement of motor clumsiness, a characteristic noted in many studies and in Wing's reports of her (1981) original research. The *ICD-10* acknowledges that motor clumsiness is common, but it is not required for diagnosis. Only in the Szatmari et al. criteria is solitariness included. The degree of severity or complexity of symptoms are not addressed in any of the four sets of criteria.

Although the *DSM* is the most widely used in Northern America, criticism of the *DSM's* criteria has been widespread. Many researchers and clinicians have argued that the *DSM-IV-TR* criteria would actually exclude some of the original cases described by Asperger himself because of its comparatively narrow interpretation (Fitzgerald & Corvin, 2001; Leekam, Libby, Wing, Gould, & Gillberg, 2000). Some have gone so far as to state that an AS diagnosis is not possible using the *DSM-IV-TR* criteria considering the precedence rule, whereby autism supersedes AS in a diagnostic hierarchy (Mayes, Calhoun, & Crites,

2001; Tyron et al., 2006) and because of the absence of language delay (Gillberg & Gillberg, 1989; Szatmari et al., 1989; Wing, 1981).

Woodbury-Smith, Klin, & Volkmar (2005) disagreed and found that the DSM-IV/ICD-10 criteria could lead to a diagnosis of AS when they conducted a collaborative study using a *DSM-IV* multicenter field trial. A total of 977 cases from 20 sites around the world were utilized in the study. Of the 977 cases 48 were identified with a diagnosis of AS, including 38 males and 10 females with a mean age of 12.7 and a FSIQ mean of 95.9. Using *DSM-IV/ICD-10* diagnostic categories by addressing the “rule out autism” and the “onset rule,” analysis indicated that 11 (23%) cases would be reassigned a diagnosis of autism by either and 33 (68%) would be diagnosed as AS. These results contradict the opinions of those who believe that an AS diagnosis using *DSM-IV-TR* or *ICD-10* is almost impossible.

Leekam et al. (2000) compared the *ICD-10* criteria with Gillberg’s criteria using algorithms designed for the Diagnostic Interview for Social and Communication Disorders (DISCO). Their study included 200 children and adults between the ages of 32 months and 38 years, with a mean of 12.7 years, who met the *ICD-10* criteria for either childhood autism or atypical autism and 3 (1%) who met the criteria for AS. In contrast, when using Gillberg’s criteria, 91 or (45%) met the diagnostic criteria for AS.

The major differentiation between the two methods of diagnosis in the Leekam et al. (2000) study was the ICD-10’s requirement for “normal”

development of cognitive skills, language, curiosity, and self-help skills. Overall, the authors of the study questioned the clinical and theoretical value of defining subgroups. Instead they suggested that a dimensional view of the autistic spectrum was more appropriate than a categorical approach. They also believed that “in clinical work, attempts too adhere to rigidly to specific diagnostic criteria can lead to the exclusion of individuals from services they need” (Leekam et al., p. 26).

Based on a comparative study of diagnostic methods for AS, Kopra et al. (2008) found that there was poor overall agreement between these four most frequently used diagnostic methods with the most agreement between the *DSM-IV-TR* and the *ICD-10* and the least agreement between the Gillberg and Szatmari et al. criteria. Such poor agreement questions the validity of the comparability of studies on AS. According to Attwood (2007), the differences in diagnostic criteria methods used can have an impact on the prevalence studies. For example, studies have differed with some showing ICD-10 criteria as more stringent than Gillberg’s but another showing ICD-10 and DSM-IV as producing higher rates of diagnosis. In both of those studies, Szatmari et al. criteria showed the highest rates of diagnosis (Kopra et al.).

Prevalence

Wing and Potter (2002) defined prevalence as referring “to the number of individuals in a specified population who have the condition being studied at a

specified time, such as one particular day, regardless of when it began” (p. 152). Up until very recently, autism was considered a rare disorder estimated at 2 to 4 per 10,000. At the time of this study, however, estimates reached as high as 60 per 10,000 or more depending on the research methods used and if other ASD were considered (Prior, 2003; Williams, Thomas, Sidebotham, & Emond, 2008; Wing & Potter, 2002).

The Centers for Disease Control and Prevention (CDC) have estimated the number of children with some type of ASD to be 6.6 per 1,000 or 1 in 152 (CDC, 2007). The British Medical Council estimated in 2000 that 1 per 1,000 children was diagnosed with autistic disorder and 2.5 per 10,000 children were diagnosed with AS. The National Institute of Neurological Disorders and Stroke (2005) reported similar AS numbers with the conservative estimate that 2 in 10,000 had the disorder.

The prevalence of AS has been estimated to be much higher at 9.2 per 10,000 by Gillberg, Cederlund, Lamberg, & Zeijlon (2006) and 16.6 per 10,000 by Williams et al. (2008). Gillberg’s (2002) estimate was even higher with an estimate of 3 to 4 individuals of every 1,000 projected to develop a full clinical picture of AS by age 10. The highest rates of ASD have been reported in Japan, Sweden, the United States, and the United Kingdom (Prior, 2003), with AS more common in males (four to six males per one female) than females (Gillberg, 2002).

One of the factors often considered for this increase in the prevalence of AS and other ASD have been changes in diagnostic criteria and practices (Prior, 2003; Wing & Potter, 2002). Although diagnostic guidelines have been established and available, researchers and clinicians have not always followed strict diagnostic criteria and may instead interject global judgment by using criteria in the literature and popular media, professional opinion, or other factors when making a diagnosis (Mayes et al., 2001; Scuitto & Cantwell, 2005; Stiefel et al., 2008; Tryon et al., 2006).

Another factor that may have contributed to the increase of ASD is the symptom commonality ASD has with other conditions (Gillberg, 2002; Prior, 2003). Because social phobia can lead to suspicion of AS, and obsessive-compulsive disorder has many characteristics that resemble AS, clinicians need to avoid confusing psychological disorders that result in a lack of close friendships with AS (Tantam, 2000). In the past, children whose diagnosis may have met the criteria for another diagnosis might have been excluded from AS; however, multiple diagnoses have grown in acceptance, and ASD has come to be associated with such conditions as anxiety, obsessive-compulsive disorder (OCD), depression, and attention-deficit hyperactivity disorder (ADHD) (Bellini, 2004; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Ozonoff et al., 2005; Tantam, 2000).

Factors outside the clinical and research environment, e.g., an increase in the availability of special educational services related to ASD, may also have

played a role in the growing prevalence of ASD (Prior, 2003; Wing & Potter, 2002). It has been contended that AS has emerged to serve the needs of special education because the popularity of AS as a diagnostic category grew as special education moved away from centralized, state-funded and run institutions to autonomous professionals and agencies that contract for services (Malloy & Vasil, 2002). The recognition of ASD by IDEA and the subsequent general acceptance by education administrators may have encouraged clinicians to be more willing to make a diagnosis when these additional services were dependent upon the diagnosis (Prior, 2003).

Stiefel et al. (2008) have found that referrals for AS assessment at their preschool developmental clinic have increased significantly. The referral rate for primary aged children from July 2002 to July 2007 increased from 3% to 17% in just 5 years. They believed that referral rates were increasing due to a greater public awareness. Books, websites, and other media have provided readily available information about the disorder and diagnostic criteria. Movies, television, and news reports have heightened the awareness of spectrum disorders (Prior, 2003; Wing & Potter, 2002).

Stiefel et al. (2008) noted that as the popularity and recognition of AS and other such related spectrum terms have grown, the diagnosis has been applied with increasing liberality. They have argued that clinicians are often faced with professional conflicts and ethical dilemmas surrounding a diagnosis, particularly when parents request a specific diagnosis or are faced with prior diagnoses with

which they disagree. This greater public awareness has led to increased pressure on clinicians because “services, other people’s moral attributions, the sufferer’s own self-perception, and many more consequences are determined by diagnosis--or the withholding of a diagnosis” (Tantam, 2000, p. 48).

Differential Diagnosis

Despite the fact that Asperger’s syndrome has been included in diagnostic manuals since the early 1990s, there has been an ongoing debate over the exact definition of AS and what symptoms constitute a diagnosis. A question has also remained for many clinicians and researchers as to whether AS is indeed a separate and distinct syndrome from autism (Mayes et al., 2001). The question has arisen because several of the characteristics associated with AS have been noticeably common in autism, specifically those of high-functioning autism (HFA).

Appendix F contains the autistic disorder diagnostic criteria. According to the criteria, AS and autism both include significant impairment in social interaction, accompanied by restrictive, repetitive and stereotyped behaviors or interests. Although autism does have additional criteria such as communication and symbolic play problems before the age of three (APA, 2000), the stark similarities in diagnostic criteria has led to controversy over the validity of AS as a separate and distinct disorder from autism.

Szatmari et al. (1989) were some of the first researchers to investigate the diagnostic validity of AS. They examined the early history and current outcome of

AS children compared to HFA individuals and children with clinical referrals regarding difficulty interacting with other children. The study consisted of 28 AS individuals (23 males, 5 females) with an average age of 14 (ranging 8 to 18), 25 HFA individuals (19 males, 6 females) with an average age of 23 (ranging from 7 to 32), and 42 socially impaired individuals, referred to as outpatient controls (34 males, 8 females) with an average age of 14 (ranging 7 to 17). Parent interviews, child interviews, school history records, and early histories as described by the parents were used to collect the data. After performing statistical analysis, no substantive, qualitative difference was found in a comparison of the three groups.

Since 1989, numerous studies have been conducted to determine if there was a difference between AS and autism or HFA (Bennet et al., 2008; Fitzgerald & Corvin, 2001; Howlin, 2003; Macintosh & Dissanayake, 2004; Sciotto & Cantwell, 2005; Tryon et al., 2006). Many of the studies have focused on early language delay which has been one of the key distinguishing features between the definition of AS and autism according to the *DSM-IV-TR* and *ICD-10*. (Bennet et al.; Howlin; Sciotto & Cantwell).

Bennett et al. (2008) conducted a study in Southern Ontario that assessed 19 children with AS and 45 with HFA at 4-6 years of age and again every two years after that until the children reached the ages of 15-17 years old. Communication, socialization, and daily living skills were measured along with the total number of autistic symptoms. Using regression analysis, they found that

specific language impairment accounted for the greatest variation in outcome scores in adolescence compared with the standard diagnosis of AS versus HFA.

Accordingly, Bennett et al. (2008) expressed their belief that AS was differentiated from HFA primarily based on a history of language delay or impairment and that therefore,

the best way to think of these conditions is not as different disorders but rather as parallel and potentially overlapping developmental pathways; once children with HFA develop fluent speech and are without structural language development (SLI), they jump to the developmental pathway of the children with AS. (p. 618)

Howlin (2003) also focused on early language delay for determination of differential diagnosis. Her study compared 34 adults diagnosed with HFA who had shown early language delays with 42 adults with no reported delays in words or phrases who were diagnosed as AS. Participants were 18 years or older, had a nonverbal IQ of 70 or above, and met criteria for age of onset, communication and social impairments, and stereotyped behavior. Gender, nonverbal IQ, and age were matched. Participants were selected from patients at a specialist diagnostic and assessment clinic for adults with developmental disorders. The results showed no significant differences between the two groups for impairments in social and communication skills, ritualistic/stereotyped patterns, and motor clumsiness, regardless of early language delay. Both groups scored similarly and fell below chronological age on language comprehension and expression. Social outcome ratings also failed to show any differences.

Sciutto and Cantwell (2005) investigated the influence of a child's IQ, presence of language delay, the influence of a child's IQ, and desire to engage others in social interaction on clinicians' diagnosis of AS by creating a fictional psychological report, an excerpt from which 74 clinicians read. Before distribution, the fictional report was reviewed by DSM-IV expert raters and categorized as autistic disorder. The clinicians were then asked to recommend a primary diagnosis and one or more rule-outs for the child. The most frequent diagnosis made by the clinicians was AS (68%), followed by autistic disorder (14%), PDD-NOS (10%), and OCD (4%). The most common rule-out was autism (47%), PDD-NOS (32%), OCD (28%), AS (19%), and schizophrenia (10%).

Results indicated that delay of language did pose a factor in the diagnosis, as it decreased the chance of an AS diagnosis. It did not rule it out, however, since 55% of clinicians still gave an AS diagnosis with the language delay. Also, when a language delay was combined with a higher IQ and a desire to engage others in social interaction, the likelihood of an AS diagnosis significantly increased. The IQ and social intention factors did not alone appear to influence diagnosis. These findings indicated that clinicians use *DSM-IV* diagnostic criteria as one of any number of factors considered when making a diagnosis.

Mayes et al. (2001) agreed that IQ did influence diagnosis. They examined a large clinical sample of children with diagnoses of autism or AS to see if any met AS criteria. Using *DSM-IV* criteria, the participants were evaluated by a psychologist at a local university affiliated psychiatry department. The

psychologist used behavior rating scales and questionnaires completed by parents and/or teachers, clinical observations, IQ testing, parental interviews, and a review of historical data to determine diagnosis. The research sample included 157 children between the ages of 19 months to 14.4 years, with an average age of 5.1 years. The male to female ratio was 122:35. IQs ranged between 14 and 143 with a mean of 65. The evaluations were reviewed independently by a psychiatrist and met 100% agreement with the review of the psychologist.

Although the study included participants with diagnoses of autism and AS, the results showed all 157 children met the criteria for autism and none met the criteria for AS. A total of 47 of the participants had an IQ above 80, and 24% had no significant delay in language. However, all the children met the autistic criteria for social impairment and restrictive and repetitive behavior and interests, and all had communication impairments. The researchers noted that “clinicians appear to equate Asperger’s disorder with high-functioning autism or mild autism with normal or near normal intelligence” (Mayes et al., 2001, p. 268). These findings supported the lack of distinction between autism and AS and the likelihood that children diagnosed with AS may have met the autism criteria and still receive a diagnosis of AS.

According to Tryon et al. (2006), most studies have revealed that clinicians have not universally applied the hierarchy rule of the *DSM-IV-TR*. Instead, clinicians regularly used the term, AS, in reference to those who have

autistic symptoms but no history of cognitive or language delays. Tryon et al. have agreed that autism is a spectrum disorder and AS is actually HFA. They have, in fact, recommended that AS be deleted from the next *DSM* version. They have cited as reasons (a) clinicians' lack of application of hierarchy, (b) the unreliability of PDD subtypes, and (c) the mounting empirical evidence that AS is HFA. They have expressed the belief that high and low functioning autism should still be included.

Few distinguishing features between AS and HFA have been scientifically proven. Researchers have shown that most, if not all, individuals diagnosed with AS actually meet the criteria for autism (Mayes et al., 2001; Tryon et al., 2006). The literature revealed few qualitative differences between AS and HFA that would distinguish AS from HFA (Macintosh & Dissanayake, 2004). In fact, in clinical practice the terms have often been used interchangeably (Attwood, 2007; Attwood, n.d.).

Some distinctions have been found between the two disorders. For example, the average age of diagnosis for AS has been age 11 compared with 5.5 for autism (Frith, 2004; Toth & King, 2008). It has been noted that hiding or compensating for AS may be easier for a toddler or even an adult, particularly one with a high IQ with appropriate available supports. (Frith). Any differences have had more to do with degree or severity of impairment than with any significant difference (Fitzgerald & Corvin, 2001; Szatmari et al., 1989). A majority of researchers and clinicians have questioned the relevance of the issue

of whether or not AS is separate and distinct from autism. Others, however, have expressed the belief that the distinctions between autism and AS have implications regarding educational placement (Frith), an understanding of prognosis, comorbidity, treatment, and future studies (Macintosh & Dissanayake, 2004).

Comorbidity

Comorbidity refers to presence of more than one diagnosis. Several researchers (Bellini, 2004; Ghaziuddin et al., 1998; Ozonoff et al., 2005; Tantam, 2000; Williams et al., 2008) found comorbid psychological disorders, such as affective disorders, anxiety-related disorders, and conduct disorders, to be more common in individuals with AS than had originally been anticipated. Learning disorders were also found to be common for those with AS (Myles & Simpson, 1998; Tantam; Williams et al.).

There has been intense pressure in society to “fit in.” For individuals with AS or other ASD, this stress can lead to anxiety and other psychiatric issues (Howlin, 2000; Tantam, 2000). Also, victimization, such as verbal teasing or physical bullying is common

and may lead to long-standing frustration, poor self-esteem and suspiciousness of others. This can be compounded by a growing awareness of how others view oneself and so, paradoxically, people with Asperger syndrome may become more distressed by their condition as they become older and less disabled by it. (Tantam, p. 56)

According to Bellini (2004), high-functioning adolescents with ASD exhibit significantly higher anxiety levels than the general population. His study incorporated 41 adolescents diagnosed with ASD and their families. The sample participants included 19 adolescents with HFA, 16 with AS, and 6 with PDD-NOS. The 35 male and 6 female participants ranged from 12 to 18, with an average of 14.22. Of the participants, 11 had been previously diagnosed with anxiety, and 16 were taking medications for anxious symptoms. Intelligence was normal with an average IQ score of 99.94. Results showed social anxiety levels at 49% for the sample group compared to 14% from previous general population studies. The types of anxiety experienced were diverse. Assertive social skills were found to have a negative relationship with social anxiety. Moderate relationships between empathic skills and different social anxiety measures were also found.

Ghaziuddin et al. (1998) described the occurrence of psychiatric disorder in a group of patients diagnosed with AS according to the *DSM-IV/ICD-10* criteria. A total of 29 males and 6 females with an average age of 15.1 and an average full-scale IQ of 102.7 (VIQ 105.9, PIQ 97.5) were recruited to participate in the study from referrals to the University of Michigan Medical Center. Of the participants, 23 (65%) presented with symptoms of an additional psychiatric disorder either at the time of evaluation or after a two-year follow-up evaluation. Children were most likely to present symptoms of ADHD, whereas adolescents

and young adults were most likely to present symptoms of depression, including major depression, dysthymia, and bipolar disorder.

Ozonoff et al. (2005) used the *Minnesota Multiphasic Personality Inventory--Second Edition (MMPI-2)* to explore personality and psychopathology in high-functioning adults diagnosed with ASD, based on *DSM-IV-TR* criteria. The *MMPI-2* is a self-report measure and consists of 567 true/false questions. The *MMPI-2* was administered to 20 adults with AS or HFA, with FSIQ of 70 or greater and to 24 college students who were age, IQ, and gender matched for comparison.

The ASD group was recruited from the University of Utah Child and Adolescent Specialties Clinic. Those who participated were compensated \$20 for their time. Eight individuals from the ASD group were also diagnosed with a comorbid psychological disorder: major depression (3), anxiety (2), depression and anxiety (2), and ADHD (1). The control group was recruited from an introductory psychology course at the University of Utah. Those participants were compensated with extra credit for the class. Large group differences were discovered with the ASD group scoring higher on several of the *MMPI-2* scales, “reflecting social isolation, interpersonal difficulties, depressed mood, and coping deficits” (Ozonoff et al., 2005, p. 90). The proportion of the ASD group scoring in the clinical range on the *MMPI-2* scales was between 25% and 35%. These scores were consistent with the clinical picture of AS and HFA in adulthood.

Social and Communication Challenges

Social and communication challenges have been identified as two of the main tenants of AS and “typically, a consideration of the diagnosis is triggered by the failure to adapt to a new social challenge” (Tantam, 2000, p. 47). Social impairments can manifest themselves as an “extreme form of egocentrism with the resulting lack of consideration for others” (Frith, 2004, p. 676). Individuals with AS have difficulty forming successful long-term interpersonal relationships, as it is hard for them to imagine someone else’s feelings or thoughts (Frith).

This inability to interpret the thoughts and intentions of others has been referred to as Theory of Mind. Theory of Mind (ToM) describes one’s ability to “recognize and understand thoughts, beliefs, desires and intentions of other people in order to make sense of their behaviour and predict what they are going to do next” (Attwood, 2007, p. 112). Baron-Cohen (1995) coined the term “mindblindness” to describe this phenomenon. ToM has been particularly difficult for individuals with AS because “the child or adult with Asperger’s syndrome does not recognize or understand the cues that indicate the thoughts or feelings of the other person at a level expected for someone of that age” (Attwood, 2007, p. 112). An impaired ToM can manifest itself in the following ways, impacting everyday life:

- a) difficulties reading the messages in someone’s eyes
- b) a tendency to make a literal interpretation of what someone says
- c) a tendency to be considered disrespectful and rude
- d) remarkable honesty
- e) a sense of paranoia

- f) an inability to see that another person may have the knowledge and a desire to be of help
- g) delay in the development of the art of persuasion, compromise and conflict resolution
- h) a different form of introspection and self-consciousness
- i) problems knowing when something may cause embarrassment
- j) anxiety
- k) a longer time to process social information, due to using intelligence rather than intuition
- l) physical and emotional exhaustion. (p. 127)

This lack of intuitiveness can make developing and maintaining relationships extremely difficult leading to life-long interpersonal struggles.

Saulnier and Klin (2007) investigated the social and communication abilities and disabilities of those with HFA and AS in relation to age and IQ. The researchers used a sample from a large federally-funded project on the neurobiology of higher functioning ASD individuals. The study included 32 participants with HFA and 35 with AS, all of whom were males between the ages of 7-18 with a Verbal IQ (VIQ) greater than 70.

Ability was compared to socialization and communication domains, and although AS participants had significantly higher VIQ scores and less symptomatology than individuals with autism, the scores showed major adaptive impairments despite cognitive ability. Both groups scored two standard deviations below their VIQ on the communication domain and three standard deviations below their VIQ on the socialization domain. Communication and socialization were also shown to decrease with age, indicating an inability to make gains in adaptive skills commensurate with chronological growth. "These

data highlight the magnitude of deficits in real-life communication and socialization skills, which can be colloquially described as ‘street smarts’ that play a central role in functional prospects for these individuals” (Saulnier & Klin, 2007, p. 792).

Rubin and Lennon (2004) also found similar social communication challenges in individuals with AS and HFA in the developmental domains of capacity for joint attention and capacity for symbol use. According to them, the capacity for joint attention consisted of:

- (a) determining the attentional focus, perspective, and intentions of others;
- (b) perceiving emotional states and considering plausible causal factors;
- (c) initiating and maintaining conversational exchanges that are sensitive to the social context, the interests of others, and the previous knowledge of those involved;
- (d) recognizing and repairing breakdowns in communication exchanges on the basis of misinterpretations or the emotional reactions of others. (p. 273)

The capacity for symbol use included:

- (a) understanding and using more sophisticated language as a means to clarify intentions;
- (b) understanding and using nonverbal cues (e.g., gestures, facial expression, body proximity, and intonation) as a means to clarify intentions such as emotion, humor, sarcasm, and nonliteral meanings;
- (c) understanding and adhering to social conventions and cultural norms for initiating, exchanging turns, and terminating interactions;
- (d) using language as a tool for guiding behavior, collaborating with others and emotional regulation. (p. 273)

AS individuals demonstrate strengths in expressive and receptive language and verbal memory. They display vulnerabilities in the perception of nonverbal social cues. These strengths typically lead to a preference in activities with a verbal component. AS individuals often have a verbose conversational

style and show areas of interest around 'fact gathering' activities compared to hands-on, mechanical activities (Rubin & Lennon, 2004). Finally the rhythm and tone of speech may be varied in AS individuals but does not always match the communication function, e.g., humor, emotion, and sarcasm.

Müller, Schuler, and Yates (2008) conducted a qualitative study that examined the social challenges of adults with AS and other ASD from their own perspective. Participants were recruited by telephone and through personal contacts associated with ASD and parent support groups. The participants had self-reported communication issues with formal or informal diagnoses and no diagnosis of mental retardation. Ultimately 13 formal AS, two informal AS, two HFA, and 1 PDD-NOS participated in the study. The 18 adults were interviewed and asked to describe their experiences in navigating their social worlds, to make recommendations for effective social supports, and share strategies for improving social connectedness. Participants were provided a small stipend for their time.

Semi-structured interviews were given at the location of the participants' choice and lasted between one and two hours with breaks if needed. Data were taped and transcribed verbatim. Qualitative analysis of the transcripts revealed 15 major themes and 11 minor themes. Major themes were denoted if 50% or more of the participants noted the topic and minor themes were denoted if 25% to 49% noted the topic. The six major features of the social experience included: (a) profound sense of isolation, (b) difficulty initiating social interaction, (c)

challenges in communication, (d) longing for greater intimacy, (e) desire to contribute to community, and (f) effort to develop greater social/self-awareness (Müller et al., 2008, p. 178). Intense isolation was the highest ranked theme with all but one participant reporting such feeling. Childhood and adulthood isolation were discussed “with the pain of isolation increasing as they grow older and become more conscious of being ‘different’, ‘alone’, or ‘out of place’” (p. 177). The majority also participated in ongoing efforts to improve their social/self-awareness by reading books or articles about ASD, attending autism support groups, and participating in social skills groups to improve body language, pitch, and intonation. The findings of this study were in contrast to the stereotyped ASD individuals who have been described as socially aloof and unaware of their deficits.

Asperger’s Syndrome and Higher Education

Prior to entering college it is likely that students with AS have received intensive support from family, friends, and educators that have contributed to their successes (Welkowitz & Baker, 2005). Making the transition from high school to college can be particularly challenging for students with AS as they often struggle greatly with the environmental and social changes with which they are faced.

Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. The roles include employment, participating in post-secondary education. . . and

experiencing satisfactory personal and social relationships. (Halpern, 1994, p. 117)

Transition challenges can result from difficulties related to executive functioning. Executive functioning refers to: (a) organizational and planning abilities, (b) working memory, (c) inhibition and impulse control, (d) self-reflection and self-monitoring, (e) time management and prioritizing, (f) understanding complex or abstract concepts, and (g) using new strategies (Attwood, 2007, p. 234). Difficulties in these areas are frequent and contribute to the academic and social problems experienced by those individuals with AS (Attwood).

Academically, students with AS may struggle with the format and requirements of the course curriculum. Traditional formats of instruction expose all students to content material at the same time and subsequently test knowledge at the same time; however, this format assumes that all students progress at a similar rate, but they rarely do (Tincani, 2004). Additionally, cumulative learning, common in higher education assumes that students will be able to build on one topic as they move to subsequent topics. This is difficult for students with AS.

Also, students' knowledge is typically assessed less frequently in postsecondary settings, with perhaps just a mid-term and final and a couple papers or a project. The delayed consequences of procrastinating and "the absence of effective time management skills, common to many college students, compounds the problem" for students with AS (Tincani, 2004, p. 129). Overall,

“poor note-taking skills, limited participation opportunities, low attendance, infrequent assessment, and nonindividualized instructional pacing contribute to academic failure” (p. 129).

Once registered and enrolled in classes, additional non-academic issues may arise. For example, classroom conduct may present a problem as students with AS struggle with appropriate class behavior. It is not uncommon for AS students to correct professors or ask too many questions monopolizing class discussions (Moore, 2006). “Classroom problems are especially likely to occur in those people with Asperger syndrome who have a particular impairment in non-verbal interpretation, since they are likely to find the social situation in the classroom difficult to understand” (Tantam, 2000, p. 54).

In addition to the new academic challenges at the postsecondary level, AS students may also have difficulty facing the social pressures associated with attending college, such as making friends and mastering their new independence (Dutton, 2008; Webb et al., 2008; Welkowitz & Baker, 2005). AS students, particularly those who go away to college, can feel lost and confused due to a lack of supervision coupled with changes in routine and living arrangements, exposure to drug and alcohol consumption and to new sexual norms.

Social situations can present a multitude of issues. Although individuals with AS often have a strong desire to have close friendships (Tantam, 2000), developing relationships can be very challenging with AS because “social contacts often centre around special interests and skills, rather than involving

close, spontaneous friendships” (Howling, 2000, p. 79). Poor nonverbal communication can pose problems. Welkowitz and Baker (2005) commented on the potential problem for AS college students that “an inappropriate eye gaze or out-of-sequence comment might be seen as inappropriately sexually aggressive” (p. 180). The need to respond to social situations may create the most stress for students with AS, because they do not know how to appropriately respond (Glennon, 2001). These stressful situations can create a tendency to retreat into isolation (Welkowitz & Baker).

To avoid stressful situations at the postsecondary level, Glennon (2001) has suggested that AS students familiarize themselves with their new environment by touring the campus prior to attendance. While touring campus, students should visit locations they will frequent on a regular basis such as the library or cafeteria so that they will have a reference for expectations. Identification of safe places on campus which can serve as a retreat if necessary is also recommended. Meeting with support staff and professors ahead of time to discuss and arrange accommodations can also ease the anxiety according to Glennon.

College can be overwhelming, so to combat potential pitfalls, Graetz and Spampinato (2008) have recommended that transitioning students with AS contact the disability services office early to learn what accommodations and/or services are available, explore career options related to their interests, work on coping skills, and consider community college enrollment while adjusting to the

new level of independence. Community colleges can offer the size, structure, and support AS students need to make a successful transition (Myles & Simpson, 1998).

There are no definitive statistics on students with AS at the postsecondary level because institutions have used different diagnostic and categorical measures to track their students (Farrell, 2004; Lewis & Farris, 1999). Anecdotally, however, colleges and universities across the nation have been experiencing increases in their AS student population (Dutton, 2008; Farrell; Moore, 2006; Trachtenberg, 2008). Community colleges, in particular, have been recipients of increasing numbers of students with AS, because the students and their parents are unsure of students' abilities to handle the demands of a four-year institution (Moore).

Gwendolyn Dungy, the executive director of NASPA, reported in an interview that "colleges and universities are 'very aware' of the problem, as the first big wave of children diagnosed with autism-related disorders moves beyond high school" (Dutton, 2008, para. 8). Institutions are struggling but still working to find a way to appropriately serve the first generation of AS students going to college in large numbers (Moore, 2006; Trachtenberg, 2008).

Smith (2007) attempted to ascertain what services and accommodations were available to students with AS at the postsecondary level. Participant institutions were recruited through membership in the Association on Higher Education and Disability (AHEAD). At the time, 1,706 institutions were members

of AHEAD, and a random sample of 102 institutions was selected as possible participants.

The sample institutions were emailed a survey instrument to be completed by a staff member of the disability student services (DSS) office. There was a low response rate (28.4%), with 5 surveys returned by mail and 29 returned by fax. The most common accommodations listed were alternate testing site and extra time on exams (25%), DSS advisor for mentoring (19%), tutoring (15% of the time by DSS offices), and other (16%). Some of the other accommodations named were: housing preferences, attendance flexibility, peer note takers, priority registration, and reduced course load.

Though all institutions indicated that they did not provide support group services specifically for AS students, over half (56%) of the institutions had counseling services available for all students. The institutions did provide faculty education via workshops, one-on-one discussions, and individual faculty inquiry. Results indicated that accommodations and services being provided to students with AS at the postsecondary level were designed primarily for other types of disabilities. Based on her literature review, Smith (2007) recommended that colleges and universities should explore group support services and study their effectiveness.

Programs and Services for Students with Asperger's Syndrome

According to Glennon (2001), students with AS require non-traditional supports to be successful at the postsecondary level. Though some colleges have developed specific services to serve this population, others have struggled with how to provide assistance (Farrell, 2004; Graetz & Spampinato, 2008). Disability practitioners have debated whether services such as mentoring or coaching qualify as a reasonable accommodation. Dillon (2007) has stated that colleges may not be prepared, or feel it is an institutional responsibility, to provide special services such as mentors or coaches for students with disabilities.

Others believe such services should qualify as an accommodation because they remove the barrier presented by the disability. King, a disability specialist, equated coaching services to that of providing an interpreter for a hard-of-hearing student (Moore, 2006). However, most disability professionals have expressed the belief that students are personally responsible for learning such social/survival skills. Many have argued that some services of a personal nature needed by students with AS are beyond the scope of what colleges can or should do.

Although there has been disagreement over the extent of responsibility that should be assumed by colleges and universities for accommodations (Farrell, 2004), many postsecondary disability service providers want to provide an environment and services that foster success for all their students with disabilities, including those with AS. They simply do not know where to begin.

Dillon (2007) recommended investigating ideas and support that might be obtained from vocational rehabilitation agencies. These agencies have long been in the business of offering individualized services to persons with disabilities to assist with work-related issues. They can bring “experience dealing with these unique issues, as well as familiarity with models of support that recognize empowerment and self-determination yet provide the needed degree of support a give student would need” (Dillon).

A handful of colleges and universities have established dedicated programs geared toward helping ASD students navigate college life. Some mentoring type programs have been provided without cost to students as a service. Other programs have established fees that can range between \$3,200 and \$4,700 per semester. In all of the programs researched, the associated colleges and universities did not consider the services to be an accommodation, noting that colleges are not legally required to provide such personal accommodations (Farrell, 2004). These programs have assisted students with AS develop time management, organizational, social, and independent skills. The specialized services may include: assistance interpreting body language and maintaining appropriate physical space/eye contact, coaching with making small talk, field trips to practice social skills, and even help with dating (Farrell; Dutton, 2008; Moore, 2006; Trachtenberg, 2008).

Many programs have used paid graduate assistants to essentially befriend the students and help them adjust to their new physical and social surroundings

(Moore, 2006; Welkowitz & Baker, 2005). Others, like that of the Essex campus of the Community College of Baltimore County, have hired local special education teachers to help students with AS manage their time and assignments (Moore). These programs offering such personalized services have grown in popularity, highlighting the need for such assistance. The University of Pittsburgh's program, Achieving in Higher Education with Autism and Developmental Disabilities (AHEADD), began in 2002 with a state grant to work with local colleges on transition issues (Farrell, 2004; Dutton, 2008; Moore). Since then, the program has continued to expand and in 2009, AHEADD reported branches in Albany, Boston, Dallas, Long Island, Miami, Pittsburg, and Washington D.C. (AHEADD, 2009). The success of these types of programs has been evidenced by student reports. One student who contracted with AHEADD increased his GPA from 1.5 to 3.6 after utilizing services (Dutton).

Despite all the challenges facing them at the postsecondary level, some students with AS may be looking forward to college to develop new friendships that were absent from high school experience (Graetz & Spampinato, 2008). College might also offer a place to explore individual interests without judgment and allow for the experience of personal growth (Graetz & Spampinato). Students with AS can be successful in college, and often exhibit outstanding abilities in their specific areas of interest (Dillon, 2007).

Social Construction

Social construction will provide the conceptual framework for the present study and will be used to explain the individual experiences reported by participants. Social construction draws on the concept that society creates meaning and value through subjective means of social interaction. This framework has been popular in cultural studies since its introduction in the late 1960s (Berger & Luckmann, 1966) and has been used in reference to ideas on race, class, gender, religion, and other topics of sociological interest. Wendell (1996) described the influence of culture on the social construction of disability.

The power of culture alone to construct a disability is revealed when we consider bodily differences--deviations from a society's conception of a "normal" or acceptable body--that, although they cause little or no functional or physical difficulty for the person who has them, constitute major social disabilities. An important example is facial scarring, which is a disability of appearance only, a disability constructed totally by stigma and cultural meanings. Stigma, stereotypes, and cultural meanings are also the primary components of other disabilities, such as mild epilepsy and not having a 'normal' or acceptable body size. (p. 44)

AS could be similarly viewed using Wendell's description of disability in that individuals with AS have been labeled because they communicate, socialize, and learn differently from the majority.

Foucault (1977) posited that societies organize people based on categorical terms and in doing so establish relationships based on power. These categories and relationships are also supported through the use of language. Berger and Luckmann (1966) discussed knowledge, stating that it "objectifies this world through language and the cognitive apparatus based on language, that is,

it orders it into objects to be apprehended as reality. It is internalized again as objectively valid truth in the course of socialization” (pp. 82-83).

The language used to describe disability has had a great impact on the construction of disability in society. Gergen (1999) addressed the role of language as follows: “Language is a major ingredient of our worlds of action; it constitutes social life itself” (p. 49). The word “disability” itself brings about negative connotations. Linton (1998) stated “the prefix dis- connotes separation, taking apart, sundering in two” (p. 30). Using Linton’s ideas, disabled then could be said to refer to a lack of ability or to be the opposite of, or separate from, the able-bodied. Disability has been explicitly defined by the dominant culture as “(a) lack of adequate power, strength, or physical or mental ability; incapacity and (b) a physical or mental handicap, esp. one that prevents a person from living a full, normal life or from holding a gainful job” (dictionary.com, 2009). Albrecht & Levy (1981) discussed the disability definitions as follows:

We contend that disability definitions are not rationally determined but socially constructed. Despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments. (p. 14)

These definitions have not, however, been used in exploring the notion of disability coexisting with any kind of positive outcomes or even as a valued measure of diversity.

Malloy and Vasil (2002) agreed and asserted that AS emerged as a diagnostic category in the special education field so therapists, teachers, and

parents would have a shared language with which to discuss a child's needs.

They also noted that the rise of AS coincided with changes in school and special education organization.

The social construction of disability has been expressed through a variety of models. These models have helped define disabled identities throughout modern culture. The medical and social models of disability are two of the most prominent and are described below to further clarify the conceptual framework of social construction.

Medical Model of Disability

Disability theory and practice have been dominated by the assumption that disabilities are pathological in nature. The medical model of disability has been used to focus on physical differences (Shakespeare, 1996). In this model, it has been theorized that the physical condition of one's disability is the primary factor restricting the lives of the disabled (Crow, 1996).

The medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden [or] personal tragedy. Society, in agreeing to assign medical meaning to disability, colludes to keep the issue within the purview of the medical establishment. (Linton, 1998, p. 11)

This model has been built on the following definitions of impairment, disability, and handicap presented by the World Health Organization (WHO):

Impairment: . . . any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability: . . any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: . . a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents fulfilment of a role that is normal, (depending on age, sex, social or cultural factors) for that individual. (WHO, 1980, pp. 27-29)

This approach supports the idea that a person with a disability is one who is deficient and who can and should be healed through medical intervention, allowing for assimilation into normal society. In this model, college students with AS must assume individual responsibility for such activities as negotiating the campus, organizing themselves for their classes, and making friends.

Under the medical model, persons with disabilities are viewed as “sick. . . [and] when people are sick, they are excused from the normal obligations of society: going to school, getting a job, taking on family responsibilities, etc.” (Kaplan, n.d., para. 7). The medical model approach has dominated rehabilitation paradigms, including those for AS interventions for two reasons: (a) Persons with disabilities are perceived by society as helpless and (b) rehabilitation agencies and professionals benefit from people with disabilities needing help through the expansion of their work and role in society (Swain, French, & Cameron, 2003). Finally, the medical model of disability has been supported by contemporary American ideals that value physical, intellectual, and emotional perfection above all else. People with disabilities then become the opposite of what is valued by those in power.

The medical model reflects wider cultural assumptions around individuality, personal autonomy and self-determination within a society in which great value is placed upon 'standing on your own two feet', 'staying one step ahead', 'standing up for yourself', 'walking tall' and 'making great strides.' (Swain et al., p. 22)

The metaphors used above, again use language to express the collective consciousness of society. "Disabled people are often defined as that group of people whose bodies do not work; or look different or act differently; or who cannot do productive work" (Shakespeare, 1996, p. 95).

Malloy and Vasil (2002) observed that AS has been defined by the medical model as a developmental disorder. They have argued that using the medical model approach with AS and other PDD is not effective, because through the diagnostic and labeling processes there is a danger of losing individuality.

Once a diagnostic label is attached there is a risk that all the child's characteristics are filtered through this diagnosis or explanatory mechanism resulting in a tendency to view the child's behaviour as symptoms, rather than as expressions of his or her unique personality. (p. 661)

The neurological basis of the disorder, along with potential treatment for correction, has been of the utmost interest in the medical and educational communities.

Disability scholars (Crow, 1996; Oliver, 1996; Shakespeare, 1996) have argued against the medical model of disability construction, noting that "disability as a long-term social state is not treatable medically and is not certainly curable. Hence many disabled people experience much medical intervention as, at best,

inappropriate, and, at worst, oppressive” (Oliver, p. 36). They instead supported the social model of disability.

Social Model of Disability

While the medical model has assumed that disability is caused by physical entities that exist in the world, the social model has posited that disability is interpreted and determined by those of social and political power (Oliver, 1996). When viewed using this model, the biology of disability is separated from “the handicapping social environment in which the person with disability exists” (Jones, 1996, para. 15), and any impairment is then caused by the social and cultural limits of society, not the disability itself. This model permits the exploration of issues related to the inter-connectedness between disability and society.

The social model of disability emerged to combat the medical model as a result of the oppression felt by persons with disabilities. This model has been used to challenge the medical model in that the problems faced by persons with disabilities are viewed as a result of attitudinal or physical barriers which have been socially created (Oliver, 1996; Shakespeare, 1996). Although one’s impairment may have a biological cause, as with AS, the social model “recognizes social discrimination as the most significant problem experienced by persons with disabilities and as the cause of many of the problems that are regarded as intrinsic to the disability under other models” (Kaplan, n.d., para. 12).

The social model of disability introduced a clear distinction between impairment and disability. The Union of the Physically Impaired Against Segregation (UPIAS) defined impairment and disability as two distinct terms. Impairment, like the medical model, described the physical difference that denotes someone as different from the norm. Disability, however, was defined as:

. . . the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS, 1976, cited in Swain et al., 2003, p. 23)

These definitions and distinctions in terminology reflect the idea of disability being socially constructed. Under the social model view of disability, the reduction or elimination of these barriers is possible through social change (Shakespeare, 1996).

Instead of focusing on the physical or mental difference, the social model perspective requires a consideration of not only the communication, social, and learning differences of students with AS, but also the unique postsecondary environments which they attend. Consequently, the social model of disability, under the framework of social construction, seems an appropriate lens for which to frame this study.

Summary

Although college has increasingly been made a viable option for individuals with AS, these students face a variety of challenges related to the barriers presented by their diagnosis in the postsecondary environment. The legal rights and responsibilities of students with disabilities in higher education, along with the determination of reasonable accommodations, should be of particular importance to students with AS. Much research has been presented illustrating the positive role self-determination has had on individuals with disabilities, particularly those who are transitioning from high school. Programs designed specifically for postsecondary students with AS have increased in popularity and may contribute to a new service model view. Finally, the medical and social models of disability within social construction theory were reviewed and presented as the conceptual framework of this study.

CHAPTER 3 METHODOLOGY

Introduction

This chapter describes the study methodology used in this research investigation. An overview of the research design and rationale for its use is introduced followed by the research questions used to guide the study. Next, site location and participant selection are discussed. The data collection procedures employed and the interview protocol are described along with a description of the data analysis. The researcher's perspective is detailed, and research trustworthiness is discussed. Finally, ethical considerations of the study and a summary are provided.

Research Design and Rationale

In this study, I, the researcher, attempted to understand how community college students with Asperger's syndrome (AS) utilize self-determination in relation to their college experience. Most studies about students with disabilities have relied on quantitative methods; however, a qualitative approach was chosen for this study for several reasons. First, collecting information about the utilization of self-determination of community college students with AS through conventional quantitative design would have been difficult. As Hartley and Muhit (2003) explained,

the low prevalence rates of different impairment groups, make it extremely difficult to draw any statistical conclusions from a quantitative study and the heterogeneity of these groups further confounds quantitative research design and makes controlling for variance a logistical nightmare. (p. 108)

Second, using the traditional quantitative approach to disability research has contributed to the dominance of the medical model of disability framework as opposed to addressing the more social aspects related to disability (Hartley & Muhi). The qualitative paradigm, on the other hand, allows researchers to explore disability through a different lens, “by focusing on participants’ personal meanings, qualitative research ‘gives voice’ to people who have been historically silenced or marginalized” (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005, p. 199). Additionally, Brantlinger et al. expressed the belief that “descriptive information from qualitative studies leads to an understanding of individuals with disabilities. . . .” (p. 196); therefore, a qualitative design approach was determined to be more appropriate to address the research questions in this study. Table 2 further details the differences between quantitative and qualitative methodology.

According to Cresswell (1994), “a qualitative study is defined as an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting” (p. 24). Cresswell defined five types of qualitative research: (a) the biography, (b) phenomenology, (c) grounded theory, (d) ethnography, and (e) case study. Both phenomenology and case

study research were explored by the researcher as possible methods for this study.

Table 2
Comparison of Quantitative and Qualitative Methods

Descriptors	Quantitative	Qualitative
Philosophical foundation	Deductive, reductionalist	Inductive, holistic
Aim	To test pre-set hypothesis	To explore complex human issues
Study Plan	Step-wise, predetermined	Iterative, flexible
Position of researcher	Aims to be detached and objective	Integral part of research process
Assessing quality of outcomes	Direct tests of validity and reliability using statistics	Indirect quality assurance methods of trustworthiness
Measures of utility	Generalizability	Transferability

Note. Table is adapted from *Sampling for Qualitative Research* by M.N. Marshall (1996), p. 524.

When researching methodology types, I originally thought to employ a collective case study model; however, after further consultation with my dissertation chair, I decided upon the phenomenological approach to in-depth interviewing. This qualitative approach design was chosen due to its ability to capture the essence of the lived experience of community college students diagnosed with AS and focus on the details of their understandings. Multiple methods of data collection are used with this approach to produce rich

descriptions about the personal experiences and perspectives of the participants (Patton, 1990).

Research Questions

This study was guided by the following research questions:

1. What, if any, self-determined behaviors do community college students diagnosed with Asperger's syndrome express and describe?
2. How do community college students diagnosed with Asperger's syndrome use self-determination skills to navigate the college environment?

Site Location

This study took place at Valencia Community College, a large metropolitan, public two-year institution located in Central Florida. The college is a multi-campus institution serving the two-county district of Orange and Osceola counties. Housed under the division of Student Affairs, each of the four main campuses offering credit courses has an office or staff personnel designated to serve students with disabilities. The site was chosen due to my position as the college-wide director of the Office for Students with Disabilities. This afforded me direct and indirect access to potential participants and disability related information that is typically confidential to those outside of disability services.

Participant Selection

Random sampling leading to a large number of participants was not necessary due to the qualitative nature of this study. Seidman (1998) described two criteria for determining how many participants in a qualitative study are enough: sufficiency and saturation. Sufficiency was defined in terms of whether “there are sufficient numbers to reflect the range of participants and sites that make up the population so that others outside the sample might have a chance to connect to the experiences of those in it” (pp. 47-48). Saturation referred to a time when “the interviewer begins to hear the same information reported” (p. 48) by multiple interviewees. Based on the experience of this researcher, saturation would be extremely difficult to achieve with this population of community college students because of the unique characteristics of the individuals diagnosed with AS. Thus, sufficiency was chosen as a means to determine an adequate number of participants.

To reach sufficiency, purposive sampling was used to select participants for this study. This method of sampling is best used when the researcher has designed an in-depth study based on the experience and knowledge that a particular group of individuals may offer (Patton, 1990). Purposive sampling can also utilize a key informant or snowballing strategy to gain access to information and participants (Marshall, 1996). A key informant is someone with a particular expertise that allows him or her to identify a group of participants for a study. Snowballing occurs when the participants in a study are able to recommend

other participants. In this research, the use of a key informant would have been ineffective because of the confidential nature of the students' disability information. Similarly, in the college setting, students with AS do not often know other students with AS because of the size of the AS population and students' desire to remain anonymous. Unlike the Deaf community, for example, individuals with AS do not necessarily have a cultural identity associated with having AS; therefore, students in this study would not necessarily be able to identify other students with AS.

Academic advisors within disability services at the site institution served as gatekeepers in this study. The advisors were able to fulfill these roles because they had established relationships with their students. The population of students with AS at this community college was very small, and the advisors were able to identify the students with AS who might be interested in participating as well as determine which of these students would be best suited to provide information in an interview. I conferred with these advisors to identify potential participants.

During this process, advisors reached out to their students diagnosed with AS and informed them about the study. If the students were interested and gave permission to be contacted, I did so to further explain the research study and solicit participation. The advisors identified 12 potential participants for the study. Of the potential participants, three did not return the phone calls of advisors, one potential participant indicated he would need to think about it, but never followed up. Another potential participant responded negatively but gave permission for

his mother to be interviewed in his place. He commented that she would know all of the answers. Finally, two potential participants were eliminated for not meeting the study parameters.

Participants needed to meet the following criteria: (a) be 18 years or older, (b) act as their own legal guardians, (c) be registered with the disability office with an official diagnosis of AS provided by an appropriate licensed professional, and (d) have been enrolled at the site institution for at least one academic term prior to the interview term. A total of five participants were selected for the study. The participants selected were provided an investigation packet which included information about the study, including purpose and procedures, an informed consent form (Appendix G), and relevant contact information.

Data Collection

The primary means of data collection for this study was through the use of semi-structured interviews, centered on 14 areas of researcher interest, which were explored with each participant. Individual follow-up questions were used to clarify personal statements. The flexibility allowed with the semi-structured format works well with the phenomenological design and the nature of the individualized data being collected. Figure 1 details the interview cycle (Reysoo & Heldens, 2007, slide 5) that was followed.

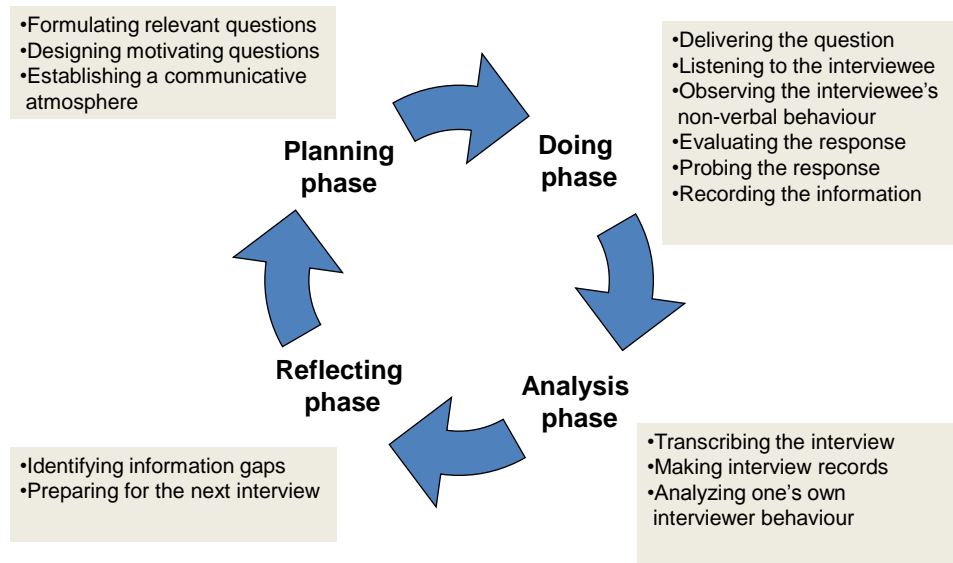


Figure 1. Interview Cycle

Note. Figure is adapted from *Qualitative Interview* by F. Reysso and J. Heldens, 2007.

I contacted selected participants to arrange a date and time for the interviews. The interviews took place in a face-to-face format over a two and a half week time period. The length of the interviews varied depending on the individual. One interview was just under 15 minutes; the other four interviews were approximately 30 minutes in length. The interview format followed that recommended by Kvale (1996) to include: a briefing prior to the interview, the interview, and a debriefing after the interview. The initial briefing allowed the researcher to explain the purpose of the study and its implications for future students with AS pursuing higher education. The recording and transcribing

procedures were described, and assurances were provided as to the voluntary nature of participation, as well as the confidentiality afforded all participants. At the conclusion of the main interview, a debriefing provided the participants with next step information and an opportunity to share any feelings or concerns that may have arisen during the interview process.

Every interview was audio recorded and professionally transcribed verbatim. Kvale (1996) noted that “in most studies the tapes are transcribed by a secretary, who is likely to be more efficient at typing than the researcher” (p. 169). Using personal funds, I employed a certified captionist as transcriber to ensure the accuracy of the typed data. The transcriber was employed part-time by the disability office to caption for Deaf and hard of hearing students, so she was very experienced in transforming oral speech to written text. She signed a confidentiality statement (Appendix H) to ensure student privacy during the duration of her work and returned all original materials to me upon completion of transcripts. Additionally, I took observational field notes during the interviews to capture expressions, body language, and other impressions.

In addition to in-depth interviews and observation notes, document reviews of the participants’ academic and disability records were used for triangulation purposes. These records not only provided basic demographic information, but helped to confirm or contradict information obtained through the interview process, such as: GPA, course selection, how often the students met with advisors, and use of accommodations. This document review, along with the

field notes, allowed me to better interpret the sincerity and truthfulness of the responses. According to Seidman (1998), participants may not be forthcoming on every question, or they may alter comments in an attempt to present a certain image.

All effort was made to create a comfortable atmosphere during the interviews. I attempted to establish rapport with the participants by introducing myself in person prior to the interviews if possible and by communicating via email and/or phone prior to the interview date. An explanation of confidentiality and a thorough description of the process were shared with each participant. Finally, it was made clear to the participants prior to the interview that there were no “correct” answers and that at any time they could choose not to respond to a question and/or conclude the interview.

Interview Protocol

The interview protocol (Appendix I) was developed based on my personal knowledge of the field, the current literature, particularly the component elements of self-determined behavior identified by Wehmeyer and Shogren (2007), analysis of the research questions, and input from my dissertation chair. Follow-up prompts or probes (Patton, 1990), distinguished in italics, were used if the participants’ responses were not sufficiently thorough to produce rich data. Table 3 displays the linkage between the research questions and the interview protocol areas.

Table 3
Relationship of Research Questions to Interview Protocol

Research Questions	Interview Protocol Areas
1. What, if any, self-determined behaviors do community college students diagnosed with Asperger's syndrome express and describe?	1, 2, 3, 7, 8, 13, 14
2. How do community college students diagnosed with Asperger's syndrome utilize self-determination to navigate the college environment?	4, 5, 6, 7, 9, 10, 11, 12

In regard to Research Question 1 as to the self-determined behaviors expressed and described by participants, interview protocol areas 1, 2, 3, 7, 8, 13, and 14 were used to collect information. This information was used to examine the goal-setting skills, choice-making skills, decision-making skills, self-knowledge, self-efficacy, and independence of community college students with AS.

Research Question 2 was concerned with participants' utilization of self-determination skills to navigate the college environment. Interview protocol areas 4, 5, 6, 7, 9, 10, 11, and 12 were used to gather information related to self-advocacy, self-regulation, self-awareness, problem-solving skills, and internal locus of control. Due to the nature of the interview format and open-ended question design, any one interview question had the potential to inform either research question. For the same reason, component elements of self-determined behavior could overlap. These elements were categorized for each research

question based on the primary component of self-determined behavior that would most likely be explored through the related interview protocol questions.

The order of the questions in the interview protocol was chosen to guide the participants through the interview in a cohesive manner aimed at facilitating conversation. Questions 1-3 were introductory questions about attending college designed to ease any anxiety the interviewee may be feeling. Questions 4-6 focused mainly on the participants' experiences in the academic realm. The next four questions, 7-10, delved into participants' knowledge and understanding of their disability and its impact on their interactions. Finally, the last four questions, 11-14, allowed the participants to share more individual reflections of their experiences.

Data Analysis

After the data were collected and verified as complete, data analysis began. According to Patton (1990), "the first decision to be made in analyzing interviews is whether to begin with case analysis or cross-case analysis" (p. 376). In this study, cross-case analysis was used by grouping the responses from participants based on question category for analysis. Using the cross-case analysis, data notes were organized based on the interview protocol areas and research questions used to guide the study.

Coding the notes began by reading through all the interviews and observational notes, making comments in the margins and/or using sticky notes

to record reflections about the data. A similar process was carried out for document reviews. According to Patton (1990), the process of labeling topics is the first step in organizing the data. A personal shorthand coding and highlighting system was used to achieve this step in establishing a data index. The purpose of coding is to “facilitate the retrieval of data segments categorized under the same codes” (Coffey & Atkinson, 1996, p. 28); however, “Coding is much more than simply giving categories to data; it is also about conceptualizing the data, raising questions, providing provisional answers about the relationships among and within the data, and discovering the data” (p. 31). Coding the data for simplification or reduction allowed me to more easily explore emergent themes to in order to generate meaning.

Trustworthiness

Qualitative researchers must work to ensure the data collection process is trustworthy (Brantlinger et al., 2005). The four general criteria used to establish trustworthiness in qualitative research are credibility, transferability, dependability, and confirmability (Denzin & Lincoln, 1994).

Credibility, often referred to in quantitative studies as internal validity, refers to truthfulness of the data collected and presented. This study employed several strategies to ensure that truthfulness was achieved. Data triangulation, peer debriefing, member checking, and researcher reflexivity helped establish credibility (Brantlinger, et al., 2005; Merriam, 1998). Data triangulation is “the

process of corroborating evidence from different individuals, types of data, or methods of data collection in descriptions and themes in qualitative research” (Creswell, 2002, p. 651). In this study, in-depth interviews were the primary source of data collection, along with observations, and document reviews.

Peer debriefing, a “process of exposing oneself to a disinterested peer for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (Lincoln & Guba, 1985, p. 308) was used to probe biases and clarify interpretations. I consulted on my study and debriefed with my dissertation chair and a colleague in disability services from a neighboring research university. Each provided critical feedback.

“Member checking is a process where the researcher asks one or more participants in the study to check for accuracy of the account” (Creswell, 2002, p. 280). For this study, member checking was completed by emailing the participants their interview transcripts for review and allowing the participants to have the opportunity to amend or clarify their statements. The interviewees were invited to email back any comments to the researcher or set an appointment to discuss further in person. Participants were given two weeks to respond to the email. Finally, reflexivity was carried out by a disclosure of my values and assumptions. I maintained a personal journal throughout the length of the study to capture my feelings and other reflections about the processes and interactions.

Transferability references the ability of the research to be generalized from one setting to the next. Studies primarily using interviews for data collection have often been questioned as to their generalizability (Kvale, 1996). Brantlinger et al. (2005), countered this position in their explanation, “Qualitative research is not done for purposes of generalization but rather to produce evidence based on the exploration of specific contexts and particular individuals” (p. 203). The data analyzed from this research should not be generalized to a greater population outside the participants; however, it was the goal of this researcher to have the reader discover the relevance and use of the data collected and presented, which provides “perspective rather than truth” (Merriam, 1998, p. 209). Thick descriptions of the research context and procedures helped establish transferability.

Dependability, similar to reliability, refers to the likeliness that similar results would be obtained if the study was repeated or replicated. To make sure this study can hold up to dependability measures, the methodological procedures were clearly outlined. These procedures included the process of selecting participants, data collection methods including the interview protocol, and data analysis practices. Finally, confirmability is focused on the extent to which the study could be corroborated or confirmed by others to determine if the findings are supported by the data collected. A thorough description of changes as they occurred in the study and a research audit were employed to help maximize dependability and confirmability.

Researcher's Perspective

The interpretation of results should consider the personal background and perspective of the researcher (Patton, 1990). The qualitative nature of the study, including the researcher as the instrument, necessitated the consideration of potential biases (Charmaz, 2005); therefore, it was important to understand my background. I have worked in disability services for the past seven years both at the student service level and at the administrative level. My experience working directly with students with disabilities has given me a strong perspective on the importance of self-determination for college students with disabilities. Through professional experience and personal interest, I have gained knowledge of disability law and formed opinions on what I believe constitute reasonable accommodations for students with disabilities, including those with AS.

My interest in this topic of study has stemmed from my interactions with students with whom I worked who had been diagnosed with AS and conversations I have had with colleagues about their experiences. Since I began my employment in disability services, I have seen the population of students with AS grow, and I have been privy to many of the struggles experienced by these students at the postsecondary level which may present as a bias. I believe that although faculty and staff may have been willing to accommodate these students, they often have not known how to meet their needs. In search of strategies, I have attended several workshops via national conferences on the subjects of AS and self-determination.

One major concern with which I contended in this investigation was the increasing awareness of AS and the concurrent growing interest in the subject as a research topic. I had been concerned about the timeliness of my study and have been anxious to complete it before others delve into this area of concentration. Upon researching the subject of college students with AS, I found information on the student perspective to be lacking. Despite the fact that students with AS have become a “hot topic” among disability service providers in higher education, there appears to have been a disconnect between what experts are saying and what the students are feeling. It was my hope that my study would shed light on the experiences of students with AS in college, particularly in regard to self-determination.

Ethical Considerations

Prior to conducting the research, institutional review board criteria from both the researcher’s academic institution, and the research site institution, was met (Appendix J). In an effort to reduce the risk of coercion, participants were invited to participate in the study on a voluntary basis. Each potential participant was informed that participation, or lack thereof, in the study had no impact on current or future services received through the Office for Students with Disabilities. Only students who gave permission to be contacted were solicited by me.

The informed consent form was used to explain the overall purpose of the study, its design procedures, the benefits, and possible risks from participating in the investigation. This consent also included an explanation of voluntary participation and informed students of the right to withdraw from the study at any time. These explanations were used to counteract any unintended coercion (Kvale, 1996). The consent form included contact information for me, my dissertation chair, and that of the University of Central Florida Institutional Review Board. Confidentiality of each participant was maintained by using pseudonyms and not revealing any identifying information.

The audio recordings and subsequent transcription of the interviews were available only to me, committee members, and the hired captionist, who signed an agreement of confidentiality. Participants were provided an opportunity to review the transcripts of their interviews for accuracy. The audio recordings and transcripts were kept in a secure location until the completion of the research investigation. At that time, the recordings and transcripts were destroyed.

Originality Score

The University of Central Florida (UCF) College of Graduate Studies requires each student completing dissertation or thesis to submit their work for originality. The method of choice for UCF Graduate Studies is the tool Turnitin (iParadigms, 2009). An acceptable score defined by the graduate advisor for this investigation was between 0 and 10%. Upon initial submission of the proposal,

the researcher received a score of 20%. The initial score was immediately reduced to 12% after the removal of quoted material. An item by item review allowed for a further reduction in the total score to an estimated <3%. The document was approved as original work by the researcher's graduate advisor.

Summary

The research design chosen and rationale, guided by the research questions, have been presented in this chapter. The site location, participant selection, and data collection processes were also discussed. The interview protocol was described in relation to the research questions and data analysis procedures were explained. The qualitative nature of the methodology used necessitated an exploration of the researcher's perspective and a discussion of trustworthiness. Lastly, ethical considerations for the study were provided and the Originality Score requirement was detailed. The interview narratives and related data are presented in Chapter 4.

CHAPTER 4 THE VOICES OF ASPERGER'S SYNDROME

Introduction

The purpose of this research study was to investigate the self-determined behaviors that community college students diagnosed with Asperger's Syndrome (AS) express and how they utilize those self-determination skills in relation to navigating the college environment. In this chapter I have described my experience conducting the interviews and collecting supplemental information through observations and document reviews. Each participant interview is then described in detail using rich explanations from the participants themselves. A summary concludes the chapter.

Conducting the Interviews

The primary mode of data collection for this study was semi-structured interviews. As outlined by the American Psychiatric Association (2000), individuals with AS may lack "social and emotional reciprocity" (p. 84). These are important components in carrying out a productive interview. For some of the participants in the present study, it appeared difficult for them to articulate their thoughts about a particular subject. The open-ended nature of the questions proved challenging for participants, and several directed prompts were used to solicit more information when more detail was desired or alternately when a broader, more general response was necessary. The quality of the student

interviews obtained for this research project was not as robust as I would have liked considering the qualitative intention of this study.

As the interviewer, I believed that my background and experience in working with community college students had prepared me well to interview this population of students. My experience includes several years experience working one-on-one with students, teaching classes, participating in focus group training, and serving as a member of a focus group facilitator team. Additionally, I am knowledgeable about AS and have worked with individuals who have AS in the past; however, nothing prepared me for the “joys and frustrations” of interviewing this particular group of students.

The joyous part of this process was definitely having the opportunity to meet with students enrolled with disability services and to hear from them, in their own words, about their experiences in college and their feelings about certain subjects. At times I wished the scope of my study was larger, because it would have been interesting to broach additional topics with the participants. They seemed to have fascinating insights, and their sincerity and straightforwardness was refreshing. An unexpected pleasure was the fact that their perspectives, at times, could be quite amusing.

On the other hand, I had moments of frustration during the interviews as well. For one particular student, there were often long pauses before answering a question and several “I don’t know” responses. Other participants, however, seemed more engaged and were quite loquacious in their own ways. In fact, a

couple of times I had to refocus participants' attention when they extended answers that were of interest to them and veered from the question topic. Throughout the interviews, I attempted to provide the participants with positive feedback on their responses and maintain a friendly and patient demeanor despite some internal frustrations at the occasional lack of detail given.

Despite the fact that the majority of the participants gave the impression that they were eager to talk, it was often difficult to get them to elaborate on a topic once they said what they felt was adequate. To provide the participants an opportunity to express themselves in a non face-to-face communication situation, I asked follow-up questions, and for clarification on some of their initial responses, via email when I sent them their transcripts to review. This supplementary communication led to additional information and highlighted that email, and other types of electronic communication, may allow individuals with AS to communicate on a more level playing field.

Observational Field Notes

During the interviews, I tried to capture additional data via focused observations. Notes taken on a legal pad were categorized into four areas: (a) personal observations, (b) non-verbal, (c) impressions, and (d) other. Under personal observations, I detailed superficial attributes such as appearance and dress and recorded my overall first impressions. The non-verbal area was utilized to note participants' tone, level of eye contact, and body language. My personal

thoughts about the participants during, and immediately following, the interviews were listed under impressions. These impressions consisted of notes on subjective ideas about their personalities and comfort level as well as notes about particular comments that they made. The other section was used to highlight certain responses that warranted further examination or to list unique details about a participant such as an additional disability diagnosis. This section was also used to record pre- and post-interview information that seemed noteworthy.

Document Reviews

As described in Chapter 3, document reviews of the participants' educational records were utilized for purposes of triangulation. These document reviews were an invaluable resource during the course of this research investigation. They provided not only verification of an AS diagnosis but allowed a fuller picture of the participants' self-determination through an analysis of their academic records. These records revealed some of their disability history, how often they met with their advisors and why, as well as GPA and course history. In essence, the review of documents filled in some of the information gaps left by various participants due to communication difficulties.

Participant Profiles and Interview Descriptions

A total of five students, including three males and two females, were interviewed in the course of this investigation. There were four Caucasian students and one Hispanic student. The students ranged in age from 19 to 21. All five students had a diagnosis of AS, and four had one or more co-morbid diagnoses. One student, who had recently graduated from the community college, was currently attending a four-year public university. One student had transferred from another two-year college. All five students lived at home with family. To protect their confidentiality, pseudonyms were given to all of the participants and any individual they referenced during the course of the interviews.

Olivia

Olivia was a 19-year old Caucasian female who was diagnosed with AS when she was a senior in high school after she was referred for an assessment due to social and interpersonal issues. She was pursuing her Associate in Arts degree with a pre-major in Art Studio/Fine Art. She had recently transferred from another two-year college in the state and has just completed her first semester at Valencia Community College. Olivia made the decision to transfer specifically for the art and theatre classes offered at Valencia Community College. Her combined overall GPA from the two institutions was a 2.8.

Olivia, a pleasant looking young woman with a slight figure, arrived for the interview on time and alone. She wore glasses and had long, wavy light brown hair which was pulled back into a loose pony-tail. She was dressed very casually in shorts, a tank top, and sandals. She did not appear to be wearing any make-up. Throughout the interview, Olivia sat on a small sofa with her legs crossed. She tilted her head slightly and swayed faintly at times. She had difficulty maintaining eye contact and glanced only occasionally at me. Overall, she exhibited poor verbal communication. She was unable to articulate her ideas thoroughly, and much prompting was needed during the interview due to many incomplete sentences and long pauses before responding.

Olivia stated that her major was chosen “Cause it’s what I like, my hobby” (Transcript Record [TR] 1, p. 2). Despite the fact that she was clear on her career goal path in art and theatre, she could not articulate a timeframe in which to realistically accomplish those goals. Her chosen major matched her interest and career goals, as she expressed a desire to be an animator for Disney. She also shared that she enjoyed “being on stage. . . acting and singing” (p. 2) and had participated in several plays while in high school. I found her interest in theatre at odds with her introverted demeanor. Olivia was soft-spoken, and her affect and mood remained flat during the entire interview, with few exceptions.

Although Olivia said of friends, “Well, I don’t have that many” (TR 1, p. 3). When asked to elaborate on what she liked to do with the friends she had, she talked about watching movies together and re-enacting song and dance

numbers. When describing these experiences, her voice did modulate becoming more upbeat and increasing in volume. This discussion was also the only time during the interview I recalled a change in her facial expression. She became more animated, and a large smile graced her face.

Olivia reported that the decision to attend college was made by her parents when she was “little” (personal communication, August 30, 2009). Olivia had visited the disability office on two different occasions, both of which were attended by her mother. Her first visit was for her initial intake appointment. Her second visit was follow-up meeting to process her accommodation form letter for her professors. During her initial appointment, she did note AS as her disability type on the intake form which she completed by herself. The only accommodation that Olivia requested was extended time on exams.

When asked about how she became involved with disability services at the college, Olivia stated, “Well, I guess one day I found out about this Asperger’s thing,” (TR 1, p. 4) and she shared that it was her mother who told her about the availability of disability services in college. She has utilized taking her exams in the Testing Center with extended time as her only accommodation. She also indicated that she had used private tutoring in the subject of math. Olivia had been previously enrolled with disability services at her previous college and reported having used extended time on exams and tutoring as her accommodations.

When asked to discuss the process of being diagnosed with AS, Olivia said, "I don't remember exactly," (TR 1, p. 4) but thought "It was a couple of years ago" (p. 4). When describing AS, she spoke in terms of "they" and "their," distancing herself saying, "Well, I think it's just that they say things differently, their behavior is a little different, and that's all" (p. 4).

Olivia connected her AS diagnosis to her struggles in math, although her disability documentation did not evaluate for any learning disabilities. Olivia had difficulty articulating any critical challenges or successes of her college experience unrelated to basic academics. She simply related her challenges and successes in terms of struggling with math and conversely passing her courses. She did indicate that her mother and her tutor had contributed to her success. When asked about any benefits to having AS, Olivia again connected her response directly to her academics through accommodations noting, "Well, like I can take my time during math tests" (TR 1, p. 6).

Olivia did not appear to have a systematic way of managing her coursework and assignments saying, "It depends. Sometimes I write them down; sometimes they're on the syllabus. I just do it when I do it" (personal communication, August 30, 2009). She did use the assistance of an advisor to help register for the right classes. She reported being registered for four courses; however, she was not able to indicate the differences between being a part-time versus a full-time student. Olivia indicated that she was not aware of the

resources available to her at the college but would be interested in learning about them.

When describing her interactions with classmates, Olivia commented, “If someone says hi to me, I say hi and that’s, I’m not really. . . I don’t really talk that much” (TR 1, p. 3). She was not very enthusiastic about group work but resigned to it as a necessary inconvenience. Her communication with faculty was similarly described “Well, I mostly just say hi, and if I have a question, that’s pretty much it” (p. 2).

Olivia was the most difficult participant to interview as she provided several “I don’t know” responses and little elaboration on the queries to which she did respond. There were many moments of silence during the interview. Of note, Olivia was my first interview. There is a possibility that her responses and interactions were based on her responding to my heightened level of focus. Though I made an effort to be very personable, I may have appeared to be task oriented and a little too direct at times. I noticed as the interviews progressed, I became more confident and casual in my interview delivery which may have impacted the subsequent interviewees.

Brian

Brian was a 20-year old Caucasian male, who had attended Valencia Community College since the fall of 2008 with continuous enrollment. At the time of the study, he had a 3.5 GPA. He was an Associate in Arts degree-seeking

student with plans to attend the local university, where his brother attends, after completing his program. His choice of majors, graphic design, aligned well with his interests as he admitted to being “obsessed with technology” (TR 2, p. 9).

Brian had undergone numerous evaluations since early childhood stemming from delayed speech and language development, learning difficulties, and struggles with socialization. Brian explained, “Well, I wasn’t listening, and I had a hard time keeping eye contact with people. They thought I had real actual autism” (TR 2, p. 8). He also described an infection which was addressed that was affecting his hearing and focus. He indicated that he “got some mental therapy and then they diagnosed Asperger’s Syndrome and that’s how it came to be” (p. 8). In addition to AS, Brian had a history of Attention Deficit Hyperactivity Disorder, for which he took medication to manage the condition, and an anxiety disorder.

Brian arrived a few minutes early for his scheduled interview, having been dropped off by his older brother. He came prepared for the interview and brought his signed consent form with him. Brian had straight brown hair worn in a short hairstyle. He was tall, over 6 feet, and lean with a pale complexion. He had narrow pointed features and piercing blue eyes. He wore dark jeans with a black graphic t-shirt and fashionable black sneakers. He appeared stylishly casual yet neat and well-groomed at the same time. Throughout the interview, he maintained good eye contact. He had a strong voice and seemed confident in his responses with few hesitations. During the interview Brian fidgeted at times. For

the most part, however, he appeared quite relaxed, spreading his arms over the back on the sofa. Brian struck me as very self-aware and quite assured. His responses were open and reflective.

When describing individuals with AS, Brian used the personal pronoun “we” to include himself and used a creative analogy that made perfect sense to him.

Well, how I would describe it is that we are just obsessed with certain things that other people aren't, and it's very different. It's like comparing, for example, a Windows computer to a Macintosh. Not always going to get along. Not always compatible on the same levels but they're pretty much the same because they do a lot of similar things. (TR 2, p. 9)

He then explained that some of his “rituals” (TR 2, p. 6) included taking naps, reading educational books, reading online information, and walking around the room. Brian reflectively remarked that a benefit to having AS is that one has “a very humble soul” (TR 2, p. 13) because of the developmental and social challenges related to having AS, particularly during the time of puberty.

With Asperger's Syndrome, 'cause early on the stages, um, you're not mentally aware of your condition first of all. And second of all, it's very difficult because your brain is underdeveloped in the first stages of Asperger's, and it could be very difficult going through that middle age when you're in middle school. (TR 2, p. 13)

Brian began his communication with the disability office well before his first term of enrollment, and since that time he has met regularly with his advisor. Of note, Brian listed learning disabilities rather than AS as his disability type on his intake form. During his first few appointments he was joined by his father, but has since typically attended his appointments alone. In his interview, he

described his father as “a great guy” (TR 2, p. 2) and his “inspiration” (p. 2) for attending college.

When asked why he chose to attend a community college, Brian said,

I mean I really wanted to go to community college so I'd get prepared for a *regular* college. . . so that I can get all my prerequisites taken care of so that when I merge to have my major completed at [local university], I have all the prereq classes taken already, so I don't have to take them there. (TR 2, p. 2)

During his intake appointment with the disability office, Brian was asked to describe his specific difficulty when taking exams. He responded, “It takes me longer to finish tests, because I analyze the text too much” (personal communication, July 8, 2008). He also noted on a self-assessment that he was not comfortable working in groups. He reported positive interactions with the disability office and his advisor.

. . . as soon as I walked into this office they welcomed me with open arms. They gave me a full read through of my rights and a full read through of all my accommodations and what these guys had to do for me and as soon as I got that I was like wow, these guys, they really do their job well I'd say, very impressed. (TR, 2, p. 7)

For his accommodations, Brian received copies of notes and extended time on exams. He was able to explain why he qualified for these accommodations “It's hard for me to read and copy information at the same time,” (TR 2, p. 8) and “I'm easily distracted by outside influence, [so] I take my tests at the testing center” (p. 8). Although Brian could not name specific disability laws, he did know that if his accommodations were not met there could be “prosecution” (p. 11).

Brian spoke of his experiences with faculty positively as well.

They're actually very experienced teachers and I talked with [Derek] he's the director of his own class, you know, in traditional media and he also has another class, digital designing. Hmm. . . He says that he's dealt with kids like you know, that for, and it's not really that big of a deal cause its computer class and there's not really a lot of note taking as far as it goes. And most of it is just book reading so it's really easy. (TR 2, p. 3)

Brian described Derek as "a really good guy" (p. 4). Brian also, did mention one professor who he did not think worked well with him. His response to the situation was to seek out his advisor immediately who made arrangements for Brian to be dropped from the class. When describing his discussions with professors about his disability and making arrangements for accommodations, Brian commented

I keep things I'd say very simple because um, it's not that I'm afraid you know, about what kind of opinion they'd have towards me having Asperger's Syndrome. It's just um, I don't know, for the sake of them not knowing, I feel that would improve their attitude toward me a little bit. Whether or not they dislike the disability but you know, I just tell them the regular accommodations. I don't tell them the fact that I have Asperger's. (p. 11)

The nature of Brian's major usually produces many of the same students taking several classes together. Brian said, "I love my classmates so much" (TR 2, p. 5) and that having good relationships with your classmates is "Very important. . . If you are going to succeed in a class, the first step is to know your classmates" (p. 5). However, Brian admits that he hasn't always been okay with group work partly because he is concerned with judgment. He explained that it is,

Hard for somebody like me to work with a group, because I'm more like focused on individual work and like doing things myself but usually sharing my ideas with the group is, you know, kind of difficult and at the same time if we're all doing like specialized work, it's easier for me but same time, you know, I'm kind of slacking off a bit because, you know, I'm worrying

what the other groups, you know, whether they're going to accept my work or not. (p. 5)

Brian named "meeting with friends, getting out there and meeting people" (TR 2, p. 11) as the greatest barrier he has faced so far. He indicated that he had experience being bullied in middle school and was a little cautious meeting new people. He stated, "I have just one simple strategy whenever I'm meeting somebody new. If they're interested in something that I'm interested in, then it's an okay" (p. 12). This strategy has worked for him and he now regularly hangs out in the cafeteria "with the guys. . . playing games and cards and stuff" (p. 12). Brian stated that he has shared with his friends that he has AS, recalling, "they didn't know it. After I told them and they said 'oh my gosh, really? I wouldn't be able to tell, like seriously, that's amazing'" (p. 6).

Brian commented on his overall college experience so far.

It's been a very positive. People are very you know, positive at this school I'd say. And they're very supportive. They're very, you know, intellectual. They know about, you know, what disability I have and how it affects me but they're not whatsoever discriminating. They don't have a negative opinion about it. (TR 2, pp. 10-11)

He also gave advisement to other students with AS.

I first off, I'd walk up to the student and I'd say, well what is it that you like to do and they'd tell me and I'd say well they've got a bunch of great people here, a bunch of good students who are good in that area and I think you'd get along perfectly with them. (p. 14)

At the conclusion of the interview I thanked Brian for his time and explained my expected timeline for any follow-up. I offered my hand to shake and Brian surprised me by opening his arms wide for a hug. I hugged him briefly and

again thanked him as I walked him out of the office. At that time Brian invited me to lunch to share some more of his ideas. I was a little taken aback by his invitation, despite what I believe was a platonic gesture, I felt a bit uncomfortable. I responded to him by indicating that I could perhaps meet him in the cafeteria, a convenient and neutral venue, to continue our conversations.

Joshua

Joshua was a 20-year old Caucasian male who graduated from Valencia Community College in the term prior to his interview and was now attending a four-year public university in the state of Florida. He was planning to attend the local university; however his program major (Information Engineering Technology) was no longer offered, so he was attending another university via online courses instead. There was an alternate program available; however, it was not online, and Joshua noted a preference for taking online courses because, "I usually don't have to deal with students' attitudes" (TR 3, p. 1).

Joshua explained that his interest in information technology stemmed from his desire to

maintain computers and basically like [to] wrangle with them and let's see, well I wanted to like get rid of any errors in them. Try like, make sure they behave themselves (p. 1). . . to work with them and keep them under control. (p. 3)

I was informed by Joshua's advisor, who explained the study to him, that he was immediately interested but did first ask if the interview could take place

over the phone. When his advisor explained to Joshua that it was important that the interview took place in a face-to-face format Joshua suggested using a web-cam. Ultimately, Joshua had agreed to be interviewed in a traditional format.

Joshua arrived for the interview accompanied by his mother, who he relies on for transportation, although he had recently acquired his learner's permit. Before we began, I had a brief conversation with Joshua's mother who assured me that she was not staying and that Joshua would be participating independently. Joshua was just shy of average height with light brown hair, soft brown eyes, and a sparse mustache. For the interview, he was dressed in khaki slacks, a short-sleeved red button-down shirt, black Velcro sneakers, and white athletic socks. He had a bit of a rumpled look about him and wore rectangular silver glasses.

At the start of the interview, he provided minimal eye contact with his eyes landing on mine quickly and then darting away again. As our conversation progressed, his eye contact improved noticeably. He appeared comfortable on the small sofa and became increasingly relaxed as the interview progressed. His responses were projected in a strong and direct tone. He had clear opinions on almost every topic discussed and appeared very sure of himself. Unlike Brian, who did not want to name the professor with whom he had some difficulties, Joshua used the full names of professors whether his comments were positive or negative.

Joshua could not name a specific person who influenced his decision to go to college but rather pragmatically commented that he had, “heard that people who go to college generally get paid more in jobs, so there’s a good reason to go to college” (TR 3, p. 2). Joshua said he chose to attend a community college, “to get my first two, like my first two years done in some kind of general studies so I could pretty much go anywhere I wanted to” (p. 2) and because “it’s cheaper” (p. 2). He also commented about the size of the nearby local four-year university saying, “That place can almost be a city--it’s that big” (p. 2).

Joshua was an extremely bright young man who scored exceedingly well on the entrance placement test and earned several college-level course credits by taking specialized exams in those content areas. His schooling was sponsored by the local vocational rehabilitation agency. He began at the community college in the summer of 2007 and graduated exactly two years later with a perfect 4.0 GPA. Surprisingly, he had not mentioned his GPA during the interview even when asked about his successes. He hoped to complete his bachelor’s degree in two years as well. Some of Joshua’s academic success can be attributed to his time management strategies. He described his use of a planner to organize his time and completion of assignments.

There’s a to-do list here and then there’s like a general note area here for each day. I fill in items in the to-do list and um, I try to bring each thing to completion before I work on the next. I use the A, B, C, priority method. A is like it must be done. It’s very important. It usually has to do with something academic, health. Some of it must be done immediately. B priority is something that it’s probably might be something with the family or with friends, but it’s not important. It’s not super important and it can be

rescheduled. C is like only for myself, or if it's something very minor like it could be possibly with friends or something. (TR 3, p. 7)

Joshua and his parents initiated contact with the disability office prior to his graduation from high school. Joshua participated in the intake process, completing most of his intake form independently, with his mother completing a couple of portions including an inquiry about medications. Joshua did name AS as his disability type. Throughout his enrollment, he met regularly with his advisor to review his course schedule and request his disability accommodation forms. He utilized extended time on exams in a distraction-reduced room and indicated that this was beneficial. He also qualified for copies of notes but indicated that "it usually wasn't necessary" (TR 3, p. 9). Despite his extensive history with disability services, Joshua was unable to describe how he became involved with disability services.

Joshua was diagnosed with AS as a young child and also had a co-morbid diagnosis of Attention Deficit Hyperactivity Disorder and Anxiety Disorder. He takes medication to manage the latter condition. Joshua described AS as "a lack of socialization" (TR 3, p. 8) He also reported that AS did at times impact his learning.

Well if a class requires a lot of interaction between students, that would create a negative impact but if it's something like that self paced course in trigonometry, that's--I didn't have to team up with anybody, then I could just zoom through that at maximum speed and uh, and get it right, you know. Do a very good job. (p. 8)

He described his preferred learning style and explained in detail why he felt self-paced courses worked so well for him.

I was able to set my own schedule and let's see, I was able to set my own schedule uh, and I know I didn't have to work with others. And I guess because it was self paced. Um, I didn't have to listen to the teachers like lecture in front of a white board or well there was this one DVD that you actually, the teacher had to actually have us watch. But that was it. It was like other than that there were no lectures. I just read from the book and I feel like I learn better, I'm a visual learner. That's probably why I did so well because it was very visual, hardly anything auditory. (p. 9)

Like Brian, when asked about legal provisions for individuals with AS, Joshua could not name any specific laws but said, "you're not allowed to discriminate against us. . . if you were given accommodations you have to obey them" (p. 9).

In describing his interactions with professors, Joshua noted that "there were some really awesome teachers here" (TR 3, p. 2) and proceeded to name a couple of specific instructors with whom he had taken classes. He had invited one professor to his 20th birthday party, as the date held some significance to the subject taught. Unbeknownst to the disability office, Joshua also made individual arrangements in a few of his classes to have his mother act as a note-taker. It was, in fact, those classes and professors that Joshua spoke so positively about. Joshua was also able to negotiate additional accommodations such as working alone rather than in a group.

. . . then we also discussed like notification forms and discussed, some were easier to convince than others. Professor [Smith] for example, she was very easy to convince. Initially she wanted people to be working in groups but we managed to convince her to you know just to let me work alone as a single individual you know. (p. 4)

That was important to Joshua because for him:

Group work is very difficult I think because, well, probably I think that was before I had my [INDISCERNIBLE] therapy. I might not have been so good with just verbal communication in general. But even probably, because I'm an extreme introvert, I prefer to work alone rather than with anyone else. (p. 4)

Joshua also described a situation when a professor insisted he work in a group. She had explained that she knew he would do a good job and that group work was part of the learning process. Joshua called others in his group "slackers" (p. 4) and described the experience as "uncomfortable mainly because they weren't up to par with me. I was always like several steps ahead of them" (p. 5).

Any additional interactions with his classmates were not sought. "I try to avoid it as much as possible" (TR 3, p. 5) because "um, well I figure they're busy, I'm busy. I like, socializing is not very important to me. It never really was" (p. 5). When asked about friends outside of school, Joshua said he didn't "hang out" (p. 5) but did have one email pen-pal who lived in Malaysia who he met through a LEGO fan website four years previously. Joshua had a unique fixation on LEGOs and even noted that his original career goal had to do with LEGOs saying, "I think, originally I wanted to work for the LEGO Company as either a set designer or a master builder" (p. 1). He later referred to LEGOs as "child's interest" (p. 3). Describing online communication, Joshua stated that he prefers it "because I can really think about what I am saying." (p. 5) Joshua had not shared with his pen-pal that he had AS.

Joshua named group work and adjusting to his first term, “getting back into the swing” (TR 3, p. 10) as his greatest challenges. He described his successes in terms of specific assignments.

Hm, probably, I guess probably the experience I get with Microsoft Power Point in like creating presentations for various like classes, most Spanish and Asian humanities. I think like those two classes would be like getting through all levels of Spanish and the Asian humanities courses, those are my success, those are my favorite classes I’ve ever taken here. (p. 10)

Joshua insightfully recognized some advantages to having AS.

Let’s see, I think like one thing you usually, like you usually don’t tell lies. I don’t tell lies. I don’t play like mind games with people. Like say one thing then say another or something like that. I don’t do something like that. I’m very straightforward. I don’t beat around the bush. (p. 10)

He also noted that individuals with AS are organized, have “the desire to bring tasks to conclusion,” (p. 11) and they “don’t waste time with excessive socialization” (p. 11).

At the conclusion of the interview, Joshua used an office phone to let his mother know that he was ready to be picked up. Sometime during our interview a student with a young child entered the office suite and was sitting in the waiting area. Joshua immediately turned to tell me about this occurrence and let me know that he was not comfortable with kids. In response to his concern, I offered him a seat at a computer station across the room. He took advantage of this offer and promptly logged on to email his pen-pal.

Sarah

Sarah was a 21-year-old Caucasian female who was first diagnosed with AS at the age of 17. She was a dual degree seeking student pursuing an Associate in Science (AS) degree in Film Production Technology as well as an Associate in Arts (AA) degree. Having attended Valencia Community College since the fall of 2006, she had already completed her credit requirements for an AS degree and was only a couple of classes shy from completing her AA degree as well. Sarah sought assistance from the disability office at the beginning of her second term. She completed her own intake form; however she did not name AS as her disability type. Like Brian, she checked off learning disabilities and also hand wrote OCD (Obsessive-Compulsive Disorder), for which she takes medication to manage that condition. She also had been previously diagnosed with a social anxiety disorder.

Sarah arrived on time for her scheduled interview. She came alone but indicated that her mother had dropped her off. Sarah was of average height and had a full figure. She had a round face with soft-features, pretty blue eyes and pale, smooth skin. She wore rectangular silver glasses and did not appear to be wearing make-up. Her curly shoulder-length dark blonde hair still appeared to be damp when she arrived. She wore jeans, a dark green t-shirt with navy sleeves, and stylish sneakers of a popular brand name.

I had personally worked with Sarah on a few prior occasions and was able to establish rapport immediately. She maintained good eye contact throughout

the interview. Her tone was generally flat but did fluctuate on certain topics. I interpreted her body language as open, although she did not seem to be very comfortable on the small sofa, never fully leaning back. At times, Sarah's face appeared very blank and did not match her verbal interaction. However, it was all the more striking when her typically expressionless face would light up with a pretty smile and a twinkle in her eye when she found something amusing. For example, when she was talking about the different diagnosis she received prior to be identified as an individual with AS, she became more animated, finding apparent humor in the efforts of her medical team.

Sarah had been involved with disability services for many years; however, she was not familiar with any of the laws applicable to college students with disabilities. Describing her involvement with disability services, Sarah said,

Um, since I was six I was in uh, I wasn't in special ed but I was, had a lot of problems. Like I was always going to for these brain tests and hospitals and stuff because they didn't know what I had. And then, when I was in 6th grade then I got put in special ed classes until about 9th grade. Then I was in the learning strategies classes. But the reason they didn't keep me in special ed was, it was good for the small classes and to communicate with the teachers better. But, I was ahead of the work they were doing. So I was getting frustrated. So that's why they put me, they had me in learning strategies where I could go there if I needed to be like--safe. And then I'd have all the work from the regular classes. (TR 4, p. 6)

She reported that it was her high school guidance counselor who had referred Sarah to the local vocational rehabilitation agency for assessment. That agency, in turn, referred her to the college disability office. She indicated that she visited the office to see her advisor "whenever there's a problem" (TR 4, p. 7).

Sarah had utilized several accommodations in the past including copies of notes and extended time on exams. Sarah also pursued, and was awarded, course substitution for her math courses based on documentation of a mathematics disorder.

When asked about her professional goals, Sarah noted that she already had her AS in Film, although she had not applied for graduation on time and would officially graduate at the conclusion of the following term. She also said that she wanted to be involved more in, “digital media kind of stuff” (TR, 4, p. 1). She was not very specific, however, indicating only that she would like to work in “web graphics with behind the scene videos” (p. 1). She also expressed that she was pursuing the additional AA degree so that she could attend the local four-year public university if she ever decided to continue her education. She cited that both of her parents had attended college and encouraged her to do so. Hearing that she would soon complete her degrees, I asked what she planned to do when she finished. Sarah replied, “Um, I’m looking. I already have a job placement looking for me, a place to go. We’re trying Universal, and PBS, and all the big places” (p. 1).

When asked to describe why she chose the major of film, Sarah reported she has been interested in film since middle school. She went on to explain,

I don’t know if you know but people with Asperger’s Syndrome, they have, um, this one special interest thing and so sometimes like you’ll just get it and then one day out of nowhere and then you have it for like a few years and then all of a sudden it stops. But all of mine have been in film but

different parts of it so I figured I'd get a job because I know a lot about it already. (TR 4, p. 2)

Sarah described her experiences with faculty as "pretty much good" (TR 4, p. 3) but indicated that "they'll get a little impatient with some things" (p. 3). She shared some of the difficulties that she had encountered in the classroom.

Um, well sometimes I'm afraid to say stuff in the class 'cause I don't want it to come out sounding rude and then I don't want them to like get mad. And um, a lot of times with tests, I have this problem because I read this problem and I don't really understand what they're asking and if I ask them they can't tell me what the question means. They can only repeat the question. So I usually end up writing for the answers, I write what all the answers actually mean because I don't know what they're asking. And that takes me longer to finish tests. (p. 3)

Sarah explained that she had talked with her professors about her necessary accommodations. "After the end of the first class, I give them the form and I tell them that I have this problem with tests, and I need a note-taker and sometimes I don't use the note-taker though" (p. 3). Sarah said that she didn't "normally ask for help much," (p. 4) but like Joshua, she also advocated for herself and negotiated additional accommodations from one of her professors.

I've noticed when I went into, I was in biology last summer, not this summer but the last summer. And she give me this test on scantron and I gave, it came back and I had like a 60 something and then I told her to look at the test because I always look at the answer on there. And she graded it and I had a 90 something so I realized that there's a problem with me transferring over and that's when she gave me the no scantron testing thing. (p. 4)

Sarah had earned average grades resulting in a GPA of 2.7. She had never failed a class but had earned several Cs and Ds throughout her coursework. At times she had difficulty managing her assignments.

I usually don't have to study because I remember everything. But, for stuff like, I hate when they give a lot of work that's due on the same day. Then I have problems. And my mom will say well just do this now and do this tomorrow but I can't because I think of the whole thing that has to be due on the one day and I freak out. (TR 4, p. 4)

Sarah described her classmates as "more like acquaintances rather than friendships (TR 4, p. 11). . . I usually don't talk to them unless we're in a group" (p. 5). When working in groups Sarah said,

. . . it's hard sometimes because if there is already a leader of the group, then I stay quiet and I don't do anything but usually if there, if everybody is half equal, I usually do the power points because I'm good with graphics. (p. 5)

Like Joshua, instead of cultivating friendships with classmates, Sarah said she talks to people on the internet. She also similarly meets friends through common interests.

Um, I'm on a forum for a singer that I like. And I'm, make friends that live, one girl lives in Finland and one girl lives in Russian and then one girl lives in North Florida. They're far away but it's easier to communicate with them from typing. 'Cause you don't have to watch their facial expressions and you don't have to listen ... (p. 5)

Sarah elaborated further about the difficulty in interpreting facial expressions.

I usually don't know if they're mad or, I have this one friend who lives in Ohio . . . and she, I'm always asking her, okay are you mad? Are you sad? Are you tired? She's like, [Sarah], I'm just tired. I'll tell you when I'm mad. (p. 6)

Unlike Joshua, Sarah shared that she eventually did divulge to friends that she is someone with AS.

I usually tell them, like not the first thing I say. It's not something you want to go, hey guess what? But like after I talk to them for a while, then I'll say if I seem weird, this is why. They're usually like I don't care, I don't um, a

lot of them are just like so what, if you're my friend now. So I try to make friends with them first and then tell them. (p. 6)

Sarah explained, with much humor, the process of being diagnosed with AS.

They were thinking it was everything. First they said, first they said it was ADHD. Then they said it was OCD. Then they said it was sensory perception. Then they, I went like a million things before someone said hey, all these together is one thing. They said they usually don't find out until you're older anyway. Then my mom read the books after the doctor said that, and my mom read the book and she's like, and you have all this stuff and nobody knew anything. (TR 4, p. 8)

Sarah was very well-informed about AS and, like Brian, used the personal pronoun "we" when talking about persons with AS.

It is, we don't show, we don't show a lot of expressions or body language but we're listening. A lot of people don't think, they're why aren't you paying attention. But we are, we're just not, it's hard to show that we're listening. And, it's, it's like, people say you're off in your own world but we're not because we know what's going on. It's just we look like we're off in our own world. But we hear and we see everything that's going on and we comprehend what's going on but it's just we're not showing it with our body. (p. 8)

Sarah described particular difficulty related to having AS in her speech class.

Uh, I was in speech and I had a lot of trouble because he would take points off if we're not giving body language and if we're not changing the pitch in our voice and that's hard to do. I gave him the papers on it and I ended up getting a B in there but that was just because I had to tell him all this stuff. (p. 8)

Sarah, in fact, utilized one of her speech assignments to educate the class when she presented her informative speech on AS. During the course of her research Sarah discovered "why some things were happening to me when I was younger" (p. 9). She elaborated further,

Uh, I would get in trouble and I would never know why I was in trouble but it was because of something I said and apparently, we speak bluntly. So if someone says, so if, like when I was younger if someone would say, do I look fat in this dress and I'd be like well it's not the dress, you know. We're not trying to be mean. We're just saying the truth. (p. 9)

Sarah described other challenges related to having AS. "Well there's a lot of stuff that sometimes when we hear, we take it literally. And its, some of it is not meant to be taken literally. And that can be a problem" (p. 9). Despite the challenges associated with AS, Sarah was able to articulate benefits as well.

Um, you notice more detail. . . like in accounting or something. Uh, there's also, if your interest is like, say your interest is astronomy or something and you can get, if you learn everything about that, you'll be like um a professor without a degree and then when you go to college and you actually get the degree and you can probably get really high in your career because of that. (pp. 11-12)

Sarah noted her greatest barriers in school to be juggling multiple assignments at the same time and pursuing her math course substitution. Her greatest successes included her work in the film program and the related technical certificates she earned. She highlighted, as positive attributes of her experiences, the consistency of the coursework and her major professor.

Rafael

Rafael was a 19-year old Hispanic student who had a long history of receiving disability services. In addition to a diagnosis of AS, he had also been diagnosed with a mathematics disorder; however, his co-morbid diagnosis did not seem to present an insurmountable barrier, as he completed his math course

with an A. He was pursuing his Associate in Science degree in Nursing with hopes to complete his Associate in Arts degree as well and eventually pursue his Bachelor in Science in Nursing at the local university. His choice of major seemed at odds with someone diagnosed with AS, as the field of nursing requires strong social and communication skills. Despite the potential incompatibility, he had successfully completed three semesters of coursework and earned an overall GPA of 3.9. Like Joshua and Sarah, Rafael's education was sponsored by the local vocational rehabilitation agency.

Rafael arrived for his interview on time. He introduced himself without hesitation and offered his hand during our introductions. Rafael was a mature-looking young man with a round face and full cheeks. He had loosely-curved brown hair accompanied by prominent side-burns, soft brown eyes, and olive-toned skin. He wore a short-sleeved button down camp shirt in a brownish-green tone with cargo jeans and white athletic sneakers. He had on silver rectangular glasses and a large silver watch.

Rafael presented himself as a friendly, easy-going young man who smiled often and maintained fairly good eye contact throughout the interview. He would occasionally gaze off into the distance and stare when he was considering a question or response, but overall he exhibited a strong visual connection. He used a normal volume when speaking; however, his affect was typically flat. I noticed almost immediately that Rafael had an uncannily similar speech pattern to Joshua, just slightly less nasal sounding. Rafael appeared very relaxed during

the interview, but at times he did fidget with his hands and click his finger-nails against each other.

During the interview, Rafael shared a strong interest in art and computers. “Um, I’m sort of an artist. Yes and I’m also good with computers. And I’ve dipped my hand into computer art and animation” (TR 5, p. 1). His hobbies and social pursuits seemed to revolve around these interests. He described a few activities in which he had participated outside of school including attending the play of a friend who was a film major, attending the Renaissance Fair with another friend, and playing video games with his best friend.

Rafael admitted that although his parents encouraged him to attend college, he wanted to go so that he would “get a high paying job” (TR 5, p. 2). He further stated that

. . . it was basically suggested by my parents that I uh yeah, try the community college first and then uh, yeah, then I’m so far liking it. It’s very, I’ve adapted well here and it’s been very good and I’m doing exceptionally well. (p. 2)

He went on to explain that the idea of college did make him a little nervous and that he felt a community college would be a good first step. He also added that it was “much cheaper” (p. 2) and that “it’s a more friendlier setting to newcomers” (p. 2). Rafael was not involved in any extracurricular activities but was familiar with campus resources. He reported regular use of the library, the computer lab, the testing center, and the student lounge.

Rafael found out about the college's disability services at a booth that was set up during Freshman Orientation. With the assistance of his parents, he initiated contact with the disability office prior to his first term of enrollment. He reported a positive experience with the disability staff. Like Brian and Sarah, Rafael chose learning disability as his disability type when he completed his intake with the disability office and did not indicate AS. He does not recall exactly when he was diagnosed with AS, but knew it was when he was very young, "around elementary school" (TR 5, p. 6). He elaborated further,

Um, well, I did not even know it was called Asperger's Syndrome. It's basically I'm drawing a blank. Um, all I know, all I can vaguely remember is that, you know, I was in different kinds of classes. Yeah, basically my whole school, my career, almost my whole school career. And I haven't like, didn't really know what I really had until high school. Yeah, that's when I got knowledge. (p. 6)

He explained what it was like to transition from exceptional education classes to mainstream classes.

Uh, okay, yes, um, well in high school when I uh stopped taking special education courses and yeah started taking uh regular courses it was kind of pretty difficult. The assignments were definitely more intense yeah to what I got basically my whole life. And the classes definitely were bigger, yes and um, I felt kind of a little out of place. But with time and um work, I've managed to get to where I am now. (p. 7)

Rafael had difficulty describing AS but associated it with learning differences.

Well, it's kind of a bit of a learning, some kind of deficiency with learning but it's, I wouldn't really know the full effect I mean. I remember my mom telling me that I really advanced out of it. But it's like you know a learning difficulty you know. It makes someone a little different in how they learn and stuff but yeah, I think it can be overcome--definitely. (p. 7)

He felt that having a good imagination and the ability to “think out of the box” (p. 10) were benefits of having AS. Like the other participants, Rafael could not name or describe any of the laws that impact students with disabilities in higher education.

Although Rafael expressed that he did not feel that AS impacted his learning, he was utilizing accommodations in the academic environment. He used extended time on exams, seating in the front of the room, and use of a tape recorder as his accommodations. He indicated that he would use copies of notes but that he had not needed them because the material was usually available electronically through the college’s online course management system. Contrary to his statement about AS not impacting his learning, Rafael reported that he has benefited from all his accommodations. He elaborated his method of informing his professors about his accommodations.

Well uh, on the uh first day uh of class I before, pretty much before the class officially starts, yes, I go up to my professor and then I pull out the paper, the form, and I inform them that I have a paper for them from the office of students with disabilities. Then they check it and then I discuss with them the accommodations and then we pretty much both work things out. (TR 5, p. 5)

Rafael did not report any concerns regarding working with faculty. He noted that the faculty are good practitioners, “very friendly” (p. 2) and easy to work with. He said that he did not typically initiate conversation with faculty, but did say hello if he saw them around campus.

Rafael appeared to be very self-sufficient in planning for his course selection.

Um well, I well, I found out about the, that education plan program on the computer yeah, and uh also with that, with that course packet, uh the degree packet, yeah basically following the directions then reading and careful planning and also the education plan which is really helpful. (TR 5, p. 6)

Rafael paid close attention to how he scheduled his classes as part of his time management strategy. This method was based in part on his dependence on his parents for transportation. Though he was the only one of the five participants who had a driver's license, he mentioned that his dad still gives him lessons.

On managing his coursework and assignments, he said,

Oh okay, well uh, I know what I have to do and I make like kind of like a schedule on what I have to do. And which assignments take priority first based on deadlines and um, make time for assignments on based on their difficulty, like how much I have to spend time with it. And I basically get the job done. (p. 3)

He expressed a need to stay very organized, "I've developed this thing, this kind of like need to keep on top of things to make sure everything is running smoothly and okay and uh, and uh, yeah, and keeping, keeping things under control" (p. 9).

Rafael shared that he had made a few friends, with whom he had common interests, but that he generally kept his communication with classmates to basic pleasantries. He had, however, been required to work with classmates on group projects. He described adjusting to the experience of group work.

Okay, well there were a few types of experiences. One is where yeah like I was in a group and basically did my job and pretty much easy going. Everyone did theirs. That was just it. Nothing special. The, another type was uh, where I basically had to take control. Yes. I was the leader of yeah, group leader for a project in developmental psychology and I pretty much yeah, handled myself very well. Um, I, I guided, uh my group members and um, and helped them form a plan of what we all needed to do and then got together and worked on the project and helped everyone prepare for the presentation and basically working with people and making sure they're okay with what they have to do. (TR 5, p. 4)

Rafael described his challenges and successes in very simplistic terms.

He named his greatest challenge, which he had overcome, as knowing where things were and locating his classrooms. He also worked with a professor to correct a miscalculated grade. His greatest successes have been passing all of his coursework and eating in the student café for the first time. On being a community college student with AS, Rafael stated, "I never really found it a problem. Yeah, basically in my life I just feel like a regular guy" (TR 5, p. 10).

Summary

This chapter introduced the participants who shared their lived experiences at one particular community college. The participant profiles were presented in a narrative format to allow the reader to gain a sense of who the participants were as individuals. Chapter 5 contains the research findings, including the major and minor themes revealed, and a discussion in response to the research questions which guided the study.

CHAPTER 5 RESEARCH FINDINGS

Introduction

The first portion of this chapter will identify and describe the themes revealed by the data collected by the interviews presented in Chapter 4. Major and minor themes will be outlined and discussed in detail. Next the findings will be discussed in relation to the component elements of self-determination in the context of each of the two research questions. Lastly, a summary of the chapter will be provided.

Major Themes

Cross-case analysis (Patton, 1990) was used to identify patterns and themes within the research findings. Data collected from each participant were analyzed and placed into categories. The interview protocol was used as a guideline to group similar ideas. Major themes, themes identified by four or more participants, included:

1. Community college students with AS are academically successful.
2. Support from disability services and use of accommodations are important to community college students with AS.
3. Personal interests influence academic choice of major for community college students with AS.

4. Community college students with AS rely on family influence and support.
5. Community college students with AS have difficulty developing social connections on campus.

Theme 1

Community college students with AS are academically successful.

What appeared evident based on the research interviews, and in particular the document reviews, was that the students did not struggle academically. I refer to academic success in terms of GPA, continuous enrollment, and progression towards completion or program completion. Three of the students had exceptionally high GPAs ranging from 3.5 to 4.0. Even the students with more average GPAs did not report any major academic struggles. When asked about any difficulty with assignments, Olivia stated, “Well, I don’t think I’ve had any problems” (TR 1, p. 3).

Most of the students attributed some of their success to characteristics associated with having AS. For example, study rituals, the desire to complete tasks in a timely manner, as well as being extremely organized by using daily planners and having specific time management strategies benefitted the students academically. Most students did not however make a direct connection between their learning and having AS. When questioned about how AS may impact his learning, Rafael commented,

I really wouldn't know but I feel no problems. I mean, if I, I mean usually I think learning is about hard work and yeah, I mean if you don't get it you just keep getting it, keep trying to get it, like make different directions and basically eventually you'll get it. (TR 5, p. 7)

Additionally, four of the five students had been enrolled at the institution for multiple terms without any stop-outs. These four began taking classes the fall term immediately following their graduation from high school. Olivia, who had just completed her second term, was currently registered for the subsequent term at the time the interview was conducted. This continuous enrollment, coupled with full-time course loads for most of the students, had placed them on a path to graduation.

Sarah, who did have a few C and D grades, managed to not only complete the credits of one program major, but was quite close to completing the requirements of a second major with a solid 2.7 GPA. Brian had also successfully progressed towards his degree goal and was approximately two terms from completion. Joshua had already completed his degree at the community college and was enrolled in a four-year public university.

Two of the students did have a diagnosed mathematics disorder which could have impacted their progress; however, each had overcome that barrier in different ways. Sarah petitioned the college's Course Substitution Committee to review her disability documentation and make a recommendation for a course substitution in the area of math. Her request was awarded, and at the time of the interview she was in the process of completing the classes that would count

towards the substitution. Rafael also had a mathematics disorder. Rather than applying for a substitution, he decided to attempt his math coursework with accommodations. He was able to successfully complete his requirement.

All of the participants associated their greatest successes of attending college thus far with their academic performance. Olivia and Rafael commented generally, indicating that simply passing their classes was a major success. Brian described being “very proud” (TR 2, p. 12) of his achievements in his digital media class as well as the completion of essay assignments in a composition course. Joshua was very specific when discussing his academic performance successes, describing the creation of PowerPoint presentations for different classes. Sarah stated that her work in the film program and the certificates she earned during the program had been her greatest successes.

Theme 2

Support from disability services and use of accommodations are important to community college students with AS.

To be eligible to participate in this study, students needed to be registered with the disability services office at the research institution. However, any further involvement or contact with the office was not required. Despite the fact that students were not mandated to meet with their disability advisors, all of the participants regularly did so. Several of the participants depended on their advisors to advise them on course enrollment to meet their program

requirements, to determine accommodations, and to make appropriate referrals to other offices.

The advisor support also extended past assistance with course selection and registration. In particular, Brian, Joshua, and Sarah had well-established relationships with their advisors. Sarah communicated with her advisor about more than just academic advisement and accommodation arrangements. She looked to her for support and coaching in other areas. Brian noted in his interview that when problems arose he went to his advisor for guidance.

Early contact with disability services also indicated the importance the participants placed on disability services. Brian, Joshua, and Rafael each made their initial contact with disability services prior to their first term of enrollment. Olivia connected with disability services during her first term and Sarah did so at the beginning of her second term. Another indicator that the participants found their connection with disability services to be important was their recommendation to other students with AS. Olivia said she would tell someone to “go to disability services and they will help” (personal communication, August 30, 2009). Likewise, Sarah indicated that she would recommend that a new student with AS visit disability services.

Accommodations were described in detail by several of the participants and played a significant role in their success. Although it was espoused in the literature that the use of traditional accommodations might not be helpful or suffice for college students with AS (Farrell, 2004; Glennon, 2001; Graetz &

Spampinato, 2008; Smith, 2007), all five of the participants reflected positively on the helpfulness of their accommodations. The accommodations most often utilized were extended time on exams in a distraction-reduced environment, copies of notes, and seating preferences. Additionally, some participants were able to negotiate individual accommodations with their professors without the involvement of disability services. Joshua was able to work independently, rather than in a group, for an assigned group project and Sarah was able to demonstrate to one of her professors that scantron forms were not accurately capturing her knowledge.

Interestingly, although all of the participants made a connection with the disability office and reported positive experiences, few were able to describe how they became aware of disability services at the college. Several seemed to indicate they felt their parents were involved with the process. Others just guessed, “Hm, I don’t know. Perhaps there was something on the application form or something that said if you have disabilities please check here. I don’t exactly know really. I’m afraid I don’t know” (TR 3, p. 8).

Theme 3

Personal interests influence academic choice of major for community college students with AS.

According to the American Psychiatric Association (2000), individuals with AS can be described as having a “preoccupation with one or more stereotyped

and restricted patterns of interest that is abnormal in intensity or focus” (p. 84). For all five of the participants, this abnormal focus of their interests contributed to their selection of majors and their enjoyment of their programs of study. Table 4 outlines each student’s degree major and their corresponding self-described area of interest. Coincidentally, all of the participants’ interests relate either directly or indirectly to computers. Additionally, the technology is linked to a softer fine arts application using personal creativity.

Table 4
Student, Degree Major, and Interest

Student	Degree	Major	Interest
Olivia	Associate of Arts	Fine Arts/Theatre	theatre (acting), art, animation
Brian	Associate of Arts	General Studies (Graphic Design)	computers, classical music
Joshua	Associate of Arts	General Studies	computers, LEGOS design
	Bachelor of Science	Information Engineering/Technology	
Sarah	Associate of Science	Film Technology	film, digital media
	Associate of Arts	General Studies	
Rafael	Associate of Science	Nursing	science, computers, computer art, animation
	Associate of Arts	General Studies	

These interests, in fact greatly impacted choice of institution for a few of the participants. Olivia specifically transferred to Valencia Community College

because of the classes offered in her field of interest. Similarly, Sarah chose Valencia because of its film program. Joshua, who just began attending a four-year public institution, made the last minute decision to go to a different institution than he had originally planned to because of his major being cut. There were a couple of programs very similar to what he wanted to study, but he chose to change schools rather than modify his focus in another program. Some of the participants were able to articulate their understanding that their focus of interest, and choice of major, was affected by having AS. Sarah explained,

. . . people with Asperger's Syndrome, they have um this one special interest thing and so sometimes like you'll just get it and then one day out of nowhere and then you have it for like a few years and then all of a sudden it stops. But all of mine have been in film but different parts of it so I figured I'd get a job because I know a lot about it already. (TR 4, p. 2)

Many of the participants spoke at length about their interests and program majors. They often used technical jargon when describing specific experiences. It appeared that the participants were knowledgeable about their program requirements and of what is necessary to prepare academically and practically for their field.

Theme 4

Community college students with AS rely on family influence and support.

During the course of this research, it became clear that familial involvement played a role in the college experience for community college students with AS. In particular, parents influenced the decision not only to attend

college but which college to attend. Olivia commented that her parents made the decision for her that she was to attend college. In the cases of Brian, Joshua, and Rafael, their parents encouraged them to attend a community college as their postsecondary choice.

In several cases, parents appeared to manage their child's disability information. They were often the ones to maintain disability documentation and played a key role in the participants registering for disability services. In fact, during the interviews, when asked about information regarding disability and diagnosis, Joshua and Rafael both referenced their mothers for additional information. For example, Rafael said, "My mom may know more," (TR 5, p. 6) when he did not know the answer to one of my questions.

In numerous instances, parents attended advising sessions with their children, as well. Brian's father attended the first few meetings he had with disability services, and Rafael's parents also helped him with his initial communication with the office and with his documentation, "[they] got the necessary paperwork and that stuff" (TR 5, p. 5). However since then, both have regularly acted independently. On the other hand, Sarah's mother/brother attended appointments with her on many occasions. Similarly, Joshua's mother stayed involved in his academic and disability services. Olivia had only had two appointments with the office at the time of the interview, and both had been attended by her mother. All of the participants, except Brian, had completed a Student Consent to Release Educational Records form, which allowed

designated individuals to have access to their records. Each of the four who completed the form gave their parents access to their academic and disability information.

Of all the participants, Joshua seemed most reliant on his mother for support. Joshua's mother assisted in completing his initial intake form with the disability office and often attended his meetings with his advisor. Additionally, Joshua's mother would speak directly with his advisor at times. I had a similar experience. Initial arrangements for Joshua's participation in this research project were coordinated by his mother. Finally, Joshua's mother was the only one who attended class with him to assist with notes. This arrangement was made privately and did not involve disability services.

Transportation was another big area of support by the family. All of the participants lived at home with family and relied on others for their transportation needs. Olivia, Joshua, and Rafael depended on one or both of their parents to take them to and from classes. Brian often made arrangements with his brother, who attended the local university. They coordinated schedules to make the commute convenient. Sarah was transported by either her mother or brother, who also attends Valencia Community College. The participants ranged in age from 19 to 21, yet only two had driving experience. Rafael had his driver's license, although he admitted to still receiving driving lessons from his father, and Joshua had just received his learner's permit.

Theme 5

Community college students with AS have difficulty developing social connections on campus.

Several of the primary characteristics related to a diagnosis of AS have to do with impairments in social interaction. These difficulties appeared to impact the social connections of the participants. Most of the students mentioned having few friends and expressed awareness of their discomfort in interacting with others. For some there was a desire to make friends. Olivia admitted that she did not have many friends and did not usually interact with classmates. When asked about her personal goals, Sarah revealingly stated “friends” (TR 4, p. 1). However, for one participant making friends was clearly not a priority. Joshua commented, “... Socializing is not very important to me. It never really was” (TR 3, p. 5).

Despite an obvious desire by most of the participants to cultivate friendships, it was apparent that several had difficulty making new friends or maintaining current friendships. Brian stated making friends had been his greatest barrier in college. Rafael had managed to “make a few friends” (TR 5, p. 4) in college by striking up conversation with classmates and finding similar interests. Similarly, Olivia and Brian both enjoyed friendships based on enjoying like activities. Olivia briefly mentioned that she had friends outside of school and that they liked to watch movies together. Brian purposely sought out those with similar interests as a basis for making new friends. He had made friends in

college through his efforts and commented that he and his friends generally hung out in the cafeteria playing video games and cards. He also mentioned that he did have friends outside of school and that they liked to do group activities on the weekends.

For two of the participants, email communication seemed to allow an added comfort level with maintaining friendships. Joshua and Sarah each had developed long-standing relationships with internet pen-pals. In both cases, they met these friends through fan websites. In Joshua's case he met the one friend he mentioned during the interview on a LEGOS site. Sarah named a few internet friends during the interview, some of which she met on a site dedicated to a singer she liked. Sarah discussed the benefits of communicating online but still struggled with interpreting the message of her friends and often needed reassurance by them about their feelings and intent.

Although none of the participants reported any negative experiences with classmates, in fact Rafael stated that his classmates were "generally friendly when you get to know them" (TR 5, p. 4), few interactions with classmates were sought out by the participants. Joshua made clear his preference for online courses because he did not have to interact face-to-face with his professors or his classmates. Joshua said that he did not care to socialize and in fact tried to avoid interacting with his classmates. Sarah said that she typically did not talk to her classmates unless they had to work together in groups. Not surprisingly, most of the participants indicated that they were not comfortable with assigned

group work. Brian said that, "It's hard for somebody like me to work with a group, because I'm more like focused on individual work and like doing things myself" (TR 2, p. 5). Joshua agreed, saying, "I'm an extreme introvert, I prefer to work alone rather than with anyone else" (TR 3, p. 4). Olivia and Rafael were a little more resigned than the others to participating in group work. Both said that working in groups was not their preference, but if it was necessary they did it with few issues.

One opportunity that college students have to connect with peers and the college community is to partake in extra-curricular activities. These activities may include participation in clubs and organizations, student government, intramural sports, and other campus-sponsored events. Extra-curricular activities were an area where community college with students with AS clearly lacked involvement. None of the participants reported regular involvement in any type of extra-curricular activities. Joshua did note that he attended a Phi Theta Kappa informational meeting, but that was the extent of his involvement. Brian stated that he had not participated in any activities as of yet but he thought he might join a club in the coming year depending on his interests.

Minor Themes

Throughout the analysis process, I recognized concepts that did not appear to be common across the entire group but were significant for two or three participants. These concepts were identified as minor themes.

1. Faculty connections are noteworthy and impact the educational experience for community college students with AS.
2. Attending a community college prior to a four-year college is considered a good idea by community college students with AS.

Theme 1

Faculty connections are noteworthy and impact the educational experience for community college students with AS.

A few of the participants seemed to have more positive experiences and make a greater connection to the college based on the development of key faculty relationships. During the interviews three participants mentioned professors by name, and two students referred to their professors by first names. Regardless of subject matter, favorite classes appeared to be associated with professors. For example, Joshua's affinity for his Asian humanities and foreign language professors were clearly unrelated to his major of interest. In his case, these were also the professors that he stated worked with him individually on his unique requests, such as having his mother attend class with him to take notes and allowing him to work in his own group for a group assignment. His Asian humanities professor made such an impact on him that he invited her to his 20th birthday celebration, which he had learned has significance in Asian cultures.

Brian and Sarah described their classroom experiences and interactions with the lead faculty members of their programs positively. Brian's digital media

professor reassured him from the beginning that he has worked with students with disabilities in the past, and that they would not have any problems. Brian had taken multiple classes with this professor. Sarah spoke about the teaching style and support provided by her film instructor. “He hires people who are professionals and they come into his classroom, and they teach us. And then, we go to sets but Chris is always there. It’s always the same group of people” (TR 4, p. 11).

Negative experiences with faculty also impacted the college experience for a couple of the students. Brian and Joshua both described interactions with faculty that were not positive. Brian viewed one particular professor as “very irresponsible” (TR 2, p. 4) and unwilling to work with him regarding his accommodations.

All of my accommodations and stuff like that, and she didn’t follow any of them. On my second day of class, she even asked me to take notes. We got off at the wrong start there and I switched classes immediately after that. (p. 4)

Joshua criticized one faculty member by describing her as “a real nobody professor” (TR 3, p. 7) who was “very disorganized” (p. 7). He stated that the class “was like one of the worst classes I’ve ever taken” (p. 7). Joshua also made comparisons between the professor who accommodated his difficulty working in groups and one who did not. He was told that he could not work independently on the group project in his statistics course, and he was not happy about that. According to Joshua, the professor told him that people do not always like to

work in groups but that it was a worthwhile experience and she was confident he would do just fine. He completed the assignment but viewed the experience and the professor negatively.

Connections with high school teachers and counselors also influenced the experience of two of the students. Brian and Sarah both described relationships from high school that impacted their attendance and support in college. Discussing high school, Brian said, “I had some really good counselors that worked with me there” (TR 2, p. 7). Likewise, Sarah talked about how her high school counselor put her on the right track for college by referring her for assessment at the local vocational rehabilitation agency.

Theme 2

Attending a community college prior to a four-year college was considered a good idea by community college students with AS.

For many of the participants the decision to attend a community college was encouraged by their parents; however, several of them described why they agreed and felt the decision was right for them. Brian recognized that by attending a community college first and completing his program pre-requisites, he would be better prepared academically for a “regular college” (TR 2, p. 2). Joshua agreed and noted that completing his general studies would then enable him to “go anywhere” (TR 3, p. 2) to finish his studies at the bachelor’s level. This preparation for the next level was important even for those who did not plan to

transfer immediately. Sarah and Rafael were primarily seeking two-year Associate in Science degrees that would hopefully lead to employment. Both commented, however, about completing their Associate in Arts degrees as well so they would be academically prepared if they ever decided to pursue a four-year degree.

Joshua and Rafael noted that attending a community college was less expensive and therefore a good value. Joshua also specifically commented that the community college was *not* the local university which he described as big enough to be its own “city” (TR 3, p. 2) Rafael similarly expressed concern over the size of the local university, which made him nervous. He chose to attend the community college first because it seemed “friendlier” to him. Rafael was happy with the decision he made saying, “I’ve adapted well here and it’s been very good and I’m doing exceptionally well.”

Self-Determination Results

There were two research questions which guided this investigation. These questions focused on the self-determination behaviors of community college students with AS. Data collected from in-depth student interviews, observations, and document reviews were used in this study to address the research questions. This study attempted to answer the following research questions:

1. What, if any, self-determined behaviors do community college students diagnosed with Asperger’s syndrome express and describe?

2. How do community college students diagnosed with Asperger's syndrome use self-determination skills to navigate the college environment?

The following component elements of self-determined behavior, outlined by Wehmeyer and Shogren (2007), were used as areas of interest in analyzing the data.

- Choice-making skills
- Decision-making skills
- Problem-solving skills
- Goal-setting and attainment skills
- Independence, risk-taking and safety skills
- Self-observation, evaluation, and reinforcement skills
- Self-instruction skills
- Self-advocacy and leadership skills
- Internal locus of control
- Positive attributions of efficacy and outcome expectancy
- Self-awareness
- Self-knowledge (p. 437)

The responses of the participants varied greatly, highlighting both strengths and weaknesses in self-determined behavior, sometimes within the same element. Therefore, each component element was assessed individually.

Research Question 1

What, if any, self-determined behaviors do community college students diagnosed with Asperger's syndrome express and describe?

The following component elements of self-determination were used to assess the self-determination behaviors expressed and described by community

college students with AS: (a) goal-setting skills (b) choice-making skills (c) decision-making skills (d) self-knowledge (e) self-efficacy and (f) level of independence.

Goal directed behavior entails one's intentional actions that facilitate the ability to reach a desired outcome. The students in this study did appear to possess strong goal-setting skills pertaining to academics. There was an obvious alignment between their fields of interest and their degree choice and major. Appropriate course selection and continuous enrollment also indicated meaningful progress towards their goals. A couple of the students had already completed their degree goal requirements and the others seemed well on their way.

On the other hand, little information was garnered about the participants' personal goals, although each was asked to discuss their personal aspirations. The participants clearly struggled with their responses when asked about their personal goals. Sarah was the only student who attempted an answer, and she simply stated that she would like "friends" (TR 4, p. 1). The question about personal goals was either universally misunderstood or the participants were not able to associate themselves in a personal nature. The intent of the question was to discover students' goals for family, self-sufficiency, desired living arrangements, as well as travel, personal health improvement, and other individual goals.

Choice-making skills involve the ability to identify and effectively communicate a preference between two or more options. The participants expressed clear interests in several areas and were able to articulate those preferences. Choice of major was an obvious area where participants were able to indicate what they chose and why. Since all of the participants based their major on individual interests, it is reasonable to assume that their choices were not influenced by others. Some participants were able to provide a preference for teaching style as well. Joshua was clear in expressing his preference for an online format over classroom lecture style courses and opted to register for online courses when available. Similarly, Sarah expressed her enjoyment of the continuity her film program provided.

Decision-making is the process of analyzing various forms of information and selecting a conclusion based on the best possible solution. For many of the students, the decision to attend college was influenced by family members; however, all except Olivia indicated that they participated in the decision to attend college. Most were able support the decision with their own perceptions of the importance of college and even the advantages of attending a community college. They used information collected from family, the media, and general knowledge in explaining their conclusions.

There were varying levels of self-knowledge expressed by the students as evidenced by an understanding of their disability. Participants who had a significant history of disability services were more knowledgeable about AS. It

was evident that Brian and, particularly, Sarah were very aware of AS and its impact on them as individuals. Others were able to articulate general characteristics about AS. Joshua described AS as, “a lack of socialization” (TR 3, p. 8). Olivia was able to make a few general statements about individuals with AS such as “they say things differently” (TR 1, p. 4) and “their behavior is a little different,” (p. 4) but she was not able to make a personal connection between AS and herself. Similarly, Rafael had trouble describing AS and how it impacted his learning.

Self-efficacy refers to one’s belief in his or her ability to be successful. Most of the participants expressed positive self-efficacy. They reported doing well in classes and overcoming challenges which most likely contributed to their confidence. There was also noticeable pride in their voices when they spoke about their accomplishments.

The participants did not display very high levels of independence. All of the participants still lived at home, and none expressed a desire to change those arrangements at the time of the interviews. None of the participants drove, nor did they coordinate their own means of transportation. For example, none of the students took advantage of utilizing the large city bus system. Rather, they depended on family members to get them to and from school. The participants also lacked job history, placing economic reliance on family.

Research Question 2

How do community college students diagnosed with Asperger's syndrome use self-determination skills to navigate the college environment?

The component elements of (a) self-advocacy (b) self-regulation (c) self-awareness (d) problem-solving skills and (e) locus of control were used to reveal how community college students with AS navigate the college environment.

Self-advocacy is the act of representing one's self. In order to effectively represent one's self, there needs to be awareness about applicable rights and responsibilities. Unfortunately, none of the participants were able to name any of the laws impacting students with AS in higher education. Two of the students were able to explain that the college could not discriminate against them and was required to provide their accommodations. The other students said they were not familiar with the laws and had nothing else to share on that subject.

Participants were able to practice self-advocacy within the college environment on several occasions. The participants regularly met with their advisors for their accommodation forms, and most of them appropriately discussed their need for accommodations and coordinated arrangements with their professors on a term by term basis. In two instances when an accommodation was not being fully met, the students made appointments with their advisors to explain the situation and request assistance in arriving at a resolution. Finally, part of self-advocacy is the development of leadership skills. Surprisingly, a couple of the participants, who admitted they did not like to work

in groups, described themselves as the emergent leaders in their groups in that they had taken control of the division of labor and kept their groups on task.

Self-regulation, which incorporates self-observation, self-evaluation, self-reinforcement, and self-instruction enables individuals to assess their surroundings, respond appropriately, and self-correct as necessary. Many of the students were able to reflect on their own behavior and developed strategies for improvement. For example, Sarah commented that she used the disability office as a refuge when she became overwhelmed with things going on around her. Academically, several participants had effective time management strategies that allowed them to stay current with their assignments.

A strong self-awareness through an understanding of one's strengths and weaknesses is crucial to being a successful student in college. A few of the students were able to reflect on struggles they had in the past and how they adapted. Brian was able to state the accommodations for which he qualified and, more importantly, why they were needed. Sarah was also able to describe why she struggled in her math courses and ultimately pursued a course substitution. Regarding her disability, Sarah had an understanding of her difficulties in reading the facial expressions of others.

The majority of the students used effective problem-solving skills to navigate their college environment. They were able to address some problems individually. For example, both Joshua and Sarah were able to make individual arrangements with their professors when faced with problems in evaluation

methods. Joshua was also able to work through possible solutions when he learned his program had been cut at the institution he planned to attend. Rather than change majors, Joshua determined the best solution was to attend another institution via distance learning.

In other cases, the participants sought assistance. A key component to problem-solving is knowing where to go for help. Most of the students were able to name several resources available at the college which they relied on for assistance including: the library, the computer lab, the testing center, and disability services. Some students were able to extend their problem-solving skills and advise others. Sarah referred one of her internet friends who was having difficulties in math to visit her college's disability office and was coaching her through the course substitution process.

With an internal locus of control, as opposed to an external locus of control, there is acknowledgment that one has control over his or her own future. Most of the participants participated in a decision-making process about attending college with the mindset that attending college would lead to a rewarding career and financial security. A valuable way to gauge an individual's locus of control is to determine one's sense of personal responsibility. The participants displayed the belief that their own efforts directly impacted their academic endeavors.

Summary

Presented in the first part of Chapter 5 was an analysis of the interview data. While interviews with each participant exposed unique personalities and ideas of self, common themes were revealed. The major themes included (a) community college students with AS are academically successful, (b) support from disability services and use of accommodations are important to community college students with AS, (c) personal interests influence academic choice of major for community college students with AS, (d) community college students with AS rely on family influence and support, and (e) community college students with AS have difficulty developing social connections on campus.

Additionally, the following minor themes were also identified (a) faculty connections are noteworthy and impact the educational experience for community college students with AS, and (b) attending a community college prior to a four-year college is considered a good idea by community college students with AS.

The second part of the chapter addressed the research questions and how the data informed the self-determination of community college students with AS. Chapter 6 will relate the research findings to the previous literature, discuss the result of the study, make recommendations for practice, review the limitations, outline the implications for practice and policy within the community college, and make recommendations for future research.

CHAPTER 6 SUMMARY, DISCUSSION, AND RECOMMENDATIONS

Introduction

In this chapter, the conceptual framework used for this study is reintroduced and discussed in relation to the findings. The research questions are also discussed using the literature review as reference. Recommendations, limitations of the study, and implications for practice for key stakeholders are presented. Finally, suggestions for future research are detailed followed by the chapter summary.

Conceptual Framework Revisited

The conceptual framework of social construction, described in Chapter 2, provided an important perspective to the findings of this study. Within social construction, both the medical and social models of disability were explored, and the latter was the preferred framework for this investigation. The social model purports that the impairment of a disability is created by social oppression carried out by those in the majority who have power (Oliver, 1996). In that framework, students with AS have been disabled based on the value society places on social interaction and communication.

The findings of this study revealed that the students had a unique way of communicating with others and interacting with their surroundings. Although they faced challenges based on their personal characteristics, which have been

grouped together and outlined as a disorder, the overarching concepts of social construction allows for the possibility that these students did not, in fact, view themselves as disabled. Therefore, there was not necessarily an expectation that their personalities, or even their behaviors, needed to be accommodated to meet the norms of society which in their cases were those of institutions of higher education.

The participants seemed to understand that they had been labeled as individuals with a disability, but interestingly, the participants expressed unique understandings of what it means to be disabled. Olivia stated, "I don't feel I have a disability. To me someone with a disability has trouble physically or mentally. I feel like a regular kid" (personal communication, August 31, 2009). Joshua also shared his perspective on what it means to have a disability.

When it comes to verbal communication, social skills, and processing speed, I think I do have a disability. However, in some ways, I think I am more able than the average student at some things, such as math and visual-spatial skills. I am also a very motivated person who likes to get things done, and this attitude often helps me plow through difficult assignments. (personal communication, August 31, 2009)

Sarah had mixed feelings about the label of disability.

Sometimes I do and sometimes I don't. When I am at home I don't feel like I have anything wrong with me because everything is normal. When I talk to my friends online I am normal. Sometimes when I am out places I feel like I do have a disability because everyone seems different. It is hard to make friends in person because you can see when you are different face to face. Even with Skype I feel normal, still seeing my friends that way with web cam and voice I am normal. I don't really know how to explain it. (personal communication, September 1, 2009)

Rafael stated, “I really, I really even though I technically do, of course, I really don’t. I just feel like a person, and you know I think I can do anything. I really feel no detriment” (TR 5, p. 11). Brian’s response focused on labels and categories, so in turn more captured the medical model of disability. “I do consider myself to have Asperger’s syndrome because I share almost every aspect of the diagnosis, considerably my lack of certain interests and my daily rituals” (personal communication, September 9, 2009).

All of the participants did receive academic accommodations based on disability status; however, all of the participants except Olivia, had one or more co-morbid diagnosis that would have justified the use of traditional academic accommodation regardless of a diagnosis of AS. The only adjustment that could be interpreted as based on the social diagnostic criteria of AS was the allowance of not working in a group, and that adjustment was negotiated by Joshua and his mother without the involvement of disability services.

It was not clear whether or not the social model of disability had been internalized by the participants of this study who were ‘diagnosed’ by the medical community. Olivia, who had the most recent diagnosis, was the most direct in her response in not believing she had a disability. However, one can understand the confusion for someone who has not accepted the diagnosis but has been encouraged to register with disability services and receive academic accommodations based on disability status. Some participants seemed to express a feeling of normalcy even though they admitted to “technically” being

disabled based on the criteria of the disorder. This acceptance of a label promulgates the power of the medical model of disability. Others inherently felt “different” from those around them and seemed to look for understanding outside of a diagnostic label.

Discussion of Results

The intent of this research investigation was to contribute to the literature where information about the self-determination of students with AS in postsecondary education was lacking. There were two research questions which guided this investigation.

1. What, if any, self-determined behaviors do community college students diagnosed with Asperger’s syndrome express and describe?
2. How do community college students diagnosed with Asperger’s syndrome use self-determination skills to navigate the college environment?

These questions focused directly on the self-determination behaviors of community college students with AS and indirectly on the overall college experience of students with AS. The self-determination results described in Chapter 5 were categorized by component elements of self-determination for clarity and analysis. Because the component elements of self-determination were not independent of one another, and could inform either research question, the conceptual definition of self-determination was considered as “a combination of

skills, knowledge and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective. . . ." (Field et al. 1998, p. 2).

The literature indicated that students with disabilities were not often entering college with the self-determination skills needed to be successful (Eckes & Ochoa, 2005; Russo Jameson, 2007) due to lack of involvement pertaining to their own outcomes at the K-12 level (Gil, 2007). The findings of this study were not as definitive. The reader should keep in mind that this research study included five participants whose diagnosis manifested itself in ways unique to each individual. Therefore, analysis of the data sometimes produced contradictory results.

Research Question 1

What, if any, self-determined behaviors do community college students diagnosed with Asperger's syndrome express and describe?

The participants in this study expressed and described a variety of self-determined behaviors associated with their college experience. In the literature, it was surmised that self-determination was connected to positive adult outcomes for individuals with disabilities (Wehmeyer & Shogren, 2007). All of the participants in this study were registered with disability services. The process of enrolling with the office requires one to self-identify as a student with a disability.

Self-identification, in and of itself, causes one to display a level of self-determined behavior as it shows acceptance of one's disability and exhibits self-awareness in knowing that assistance will be needed. It also shows the ability to access appropriate resources.

All of the participants were supported to some degree by their parents in this process. For some students their parents seemed to assist in the beginning, but after they became more comfortable the students were able to manage their own interactions with the office. On the other hand, two of the participants were not even able to describe this process and did not seem to know how they became involved in disability services. One wonders whether, if parents had not been involved, would these participants have followed through or even initially sought out services.

Wehmeyer and Shogren (2007) suggested that goal-setting and prioritizing are difficult tasks for students with AS. The findings did not necessarily support that determination. The findings showed that all of the participants were able to set, follow through, and meet their established goals. Of the five participants, three were very organized and had developed effective strategies for prioritizing their assignments and time.

Knowledge of one's disability and how it impacts learning is vital to self-determination (Getzel, 2008). Unfortunately, students with disabilities often cannot describe their disability or how it impacts them (Field et al., 2003; Izzo & Lamb; Jones, 1996). Four of the five participants were able to at least minimally

describe characteristics of AS, and two of them were very knowledgeable on the subject. Additionally, three of them were able to connect their learning styles to having AS.

Research Question 2

How do community college students diagnosed with Asperger's syndrome use self-determination skills to navigate the college environment?

The participants in this study utilized their connections and resources, self-advocacy, their strengths, and support from others to navigate the college environment. Students with disabilities are not typically involved with the arrangement of their accommodations in the K-12 environment (Gil, 2007; Izzo & Lamb, 2002), making it difficult to transition into a higher education environment where they are the primary party responsible for such actions. The participants of this study were able to connect with disability services, the office responsible for assisting with the determination and arrangement of accommodations. They met regularly with their advisors and participated in the request process each term.

Self-advocacy is crucial to the development of self-determination (Lock & Layton, 2001). The participants in this study utilized self-advocacy as one of the ways in which they navigated the college environment. A couple of the participants were able to negotiate arrangements for alternate assessments with their professors individually. When they were unsure about appropriate strategies

to use in addressing a concern, they contacted their advisors for recommendations or referrals.

The students in this study were, for the most part, aware of their strengths and limitations regarding both the academic and social environments. They were able to detail the subjects in which they excelled and struggled, and they chose majors connected to their strengths and interests. Additionally, some of the participants were able to articulate how they learned best. Socially, two of the participants were able to reflect on their interactions with others and how they cultivated and maintained friendships.

Welkowitz and Baker (2005) stated that students with AS have used intensive support from family and others involved in their education throughout K-12. This statement appeared true for the participants of this study. However, the level of support received bordered on cultivating dependence. The students in this study relied heavily on family for encouragement, support, and assistance in their pursuit of higher education. Although it appeared that independence was encouraged, autonomy had not yet been achieved for the participants of this study.

Other

In the course of answering the research questions pertaining to the self-determination of community college students with AS, reviewing the research data indirectly informed the researcher about the overall college experience of

these students as well. The participants appeared to find enjoyment in their programs of study, commenting positively on individual classes and curriculum, their professors, and even classmates for one participant. They reported helpful interactions with disability services staff and had developed strong relationships with their advisors. Most were satisfied with their decision to attend a community college and talked about the good reputation of the college. Although cultivating friendships proved difficult for the participants, many had managed to establish relationships with a few fellow classmates. Overall, the participants seemed comfortable in their environment and reflected fondly on their college experiences.

Recommendations

The investigative results of this study, coupled with my knowledge of AS and professional higher education experience, has led to several recommendations. These recommendations, made to students, their family members, high school educators, college faculty, postsecondary disability service providers, and higher education administrators, are intended to improve the self-determination outcomes and college experience of community college students with AS.

Students

Students diagnosed with AS prior to college have the opportunity to prepare themselves for being a college student with a disability. At the K-12 level, students with AS should be involved in their own transition planning as early as possible. They need to understand their disability and how it impacts their learning. Knowing their individual areas of strengths and challenges and learning how to strategize for the best possible outcomes are important.

It is recommended that students with AS, nearing the postsecondary level, should visit colleges of interest and consider not only the academic programs available but also what supports are available to them. Several of the participants in this study commented that they were encouraged to attend a community college. They agreed it was a good place to start and reported positive experiences. It is recommended that students with AS pursuing higher education consider two-year colleges when beginning their educational degrees. Participants relied heavily on family support, and a two-year college is often closer to home; thus, a community college would more readily allow for the type of support required.

Once in college, students with AS should seek out support services such as those offered by disability services, career services, and student development services. All of the participants in the study contacted disability services early in their educational careers. Despite the fact that not all of the participants considered themselves disabled, each spoke positively about their interactions

with disability services and the helpfulness of their accommodations. In addition to academic and disability advisement, the disability advisors reportedly provided social and motivational support.

Career exploration should begin early in the college careers of students with AS. The participants in this study expressed clear academic interests, and their degree programs were congruent with their interests. However, related professional goals were less obvious. It is recommended that students with AS consult with career services for assistance in preparation for and transition into the workforce. This assistance may include completing career assessments, job market research, creating a resume, and practicing interview skills. The participants had no prior job experience. Participation in internships or other work type experiences is recommended.

Participants in the study expressed difficulty making friends; the friendships that did develop were often based on mutual interests. It is therefore recommended that college students with AS seek out participation in clubs and organizations related to their interests. These groups often provide organized student activities where students with AS could meet other students who have similar interests.

Family

Family plays a key role in the success of college students with AS. Participants in this research investigation received long standing support from

their families in numerous ways. In all instances, families encouraged their family member with AS to pursue higher education. In particular, a community college, was advised as many thought it would be a better place to begin educational pursuits in higher education. Family continued to support the students with AS by assisting with enrollment with disability services.

For a few of the participants, it appeared that the students trusted that their 'mothers' had pertinent knowledge about their disability; therefore, they did not find it necessary to know about it themselves. It is recommended that parents make an effort to share specific disability information so that students with AS have an understanding about not only their disability, but the history of their diagnosis, and the impact of that disability in their lives.

An assumingly unintentional consequence of this support and level of familial involvement is a lack of independence on the part of the student. To combat this result, it is recommended that families encourage their family member with AS to take advantage of opportunities for independence. This can begin prior to entering college. It is recommended that parents participate in transition planning and at the age-appropriate time involve their child with AS in the process. This is particularly important in regard to post-secondary goals. Age appropriate milestones such as driving and work experience should also be encouraged.

High School Educators

The skills required for being successful in college are acquired well before the first day of class on campus. High school teachers and counselors can provide the necessary support and encouragement to prepare students with AS for meeting the demands of higher education. Two participants in this study made references to high school staff that assisted them in some way in their transition to college. Three of participants were referred for vocational assessment which resulted in receiving support from the local vocational rehabilitation agency. Only Olivia, who was not diagnosed with AS until her senior year, did not receive extensive disability support throughout K-12. This ongoing support needs to include more than academic adjustments. Transition planning for students with disabilities must begin at age 16 (IDEA, 2004); however, I recommend earlier intervention when appropriate.

It is recommended that students with AS, as well as students with other disabilities, receive formal transition planning, which would include more than simply naming goals in an IEP. Incorporated within this transition planning should be self-determination programming. It also needs to be recognized that academic achievements are not the only measures of a disability's impact. Social strategies need to be explored to prepare students with AS for the college environment. Finally, the participants in this study were ill-informed about the laws that serve to protect them from discrimination. A component which educates students with

disabilities about their legal rights and responsibilities, needs to be included within transition planning so that they can act as their own self-advocates.

College Faculty

In the college environment, faculty members have the best opportunity to interact with students on a regular basis. Consequently, they have a great impact on the college experience of their students, including those with disabilities. In this study, almost all of the participants reflected positively on their interactions with faculty. Students with AS may need encouragement to advocate for themselves, and approachability of faculty is crucial. It is recommended that faculty provide a welcome environment for students with disabilities. A simple statement in a course syllabus inviting students with disabilities to discuss disability related needs could set the tone for future positive interactions between faculty members and students.

I would also recommend that faculty take advantage of training opportunities that include information about students with disabilities, how to provide accommodations, and why it is necessary. Learning about different disability categories and what types of accommodations are appropriate is imperative to maintaining academic integrity. A faculty member should never feel obligated to provide any unreasonable accommodation. Faculty should work closely with disability services and the student to assist in these determinations. This team approach allows “experts” in each area to contribute. Faculty are the

experts in academic content; disability services is most familiar with legal obligations and appropriate accommodations; and students are the experts in knowing how they learn. Faculty should consider multiple learning styles when developing curriculum and provide options in the ways students can demonstrate mastery of course material. Finally, it is imperative to recognize students with disabilities as individuals and not simply on their disability.

Postsecondary Disability Service Providers

The participants in the study did not express any complaints regarding their involvement with disability services. Based on the literature and data collected from participants, however, it is recommended that postsecondary disability service providers explore the development of a peer mentor program to assist students with AS in the transition into higher education and collegial socialization. This type of support would benefit the students with AS by providing them with a friendly peer knowledgeable about AS who understands the underlying difficulties that the student with AS might be facing. The role of the peer mentor would be to provide social support for the students with AS. This may include discussion about challenges they are facing or any situations that have arisen that they did not understand. The peer mentors could also be helpful in introducing students with AS to other resources and activities on campus.

Higher Education Administrators

College administrators play a vital role in supporting students with disabilities. They determine policy and procedures, allocate funding, and perhaps most importantly are the individuals who establish the culture of the institution. College administrators need to understand that disability goes beyond the context of physical limitations. The success of students with AS and other disabilities involves meeting not only legal mandates on accessibility, but providing a warm and welcoming physical, social, and educational environment conducive to academic development and personal growth. It is recommended that administrators support professional development in the area of disability awareness for faculty and staff. Disability programming on campus would be another way administrators could show their acceptance and support of a diverse college community.

Limitations of the Study

In reflecting on the previously stated recommendations, the reader needs to consider several limitations inherent in this study. The goal of the study was to provide “perspective, rather than truth” (Merriam, 1998, p. 209); therefore the results are not generalizable to the population as a whole. Instead, the value of the findings in this qualitative study will be determined in terms of relevance and use to interested parties. Limitations of the study were related primarily to sample size, diagnosis and characteristics of AS, and researcher bias.

Several factors influenced the sample size of this investigation. First, the sample size was limited by the choice of selection methods. Due to the nature of confidential disability information, this study took place at one community college in the Southeast where I had access to the participants via my connection to the disability services office. To be a part of the study, participants needed to be registered with disability services with a confirmed diagnosis of AS. This need for self-identification and medical confirmation limited the potential number of participants by excluding those who had been diagnosed, but chose not to utilize disability services, as well as those students who may not have known they had AS. Those students eliminated as participants may have had varying levels of self-determination and different college experiences from the participants interviewed.

Several more students than were interviewed were informed of the study by their disability advisors. These students had to confirm their interest with their advisors in order to be contacted. Due to the nature of the social and communication impairment associated with a diagnosis of AS, a few of these students were very hesitant to sit down and talk about themselves with a stranger. One potential participant offered to permit me to speak with his mother about him; however, he did not want to participate. Another potential participant was greatly encouraged by his mother to participate, as she thought it would be a good experience for him, but he was not interested. A couple of potential participants said they would think about it, but they never followed up with their

advisors. Because the communication about the study was coming from the disability advisors, I was mindful of perceived pressure to participate, so I did not request that the advisors reach out more than once to any potential participant.

Another limitation of the study was found in the quality of reciprocal communication expressed by the participants. The participants involved in this study exhibited many of the characteristics of AS outlined in the diagnostic criteria (Appendixes A-E). These characteristics often made it difficult to collect data in the course of the interviews. Participants' perceptions about their interactions with others needed to be considered in the context of being an individual with AS. The data collected, therefore, was somewhat limited by the ability of participants to express themselves in a reflective and informative way.

Finally, researcher bias needs to be considered when measuring the findings of this study. Much of the data collection and reporting had an inherent element of subjectivity. As the researcher in a qualitative study, I played a key role in the research process; thus it was important for me to make every effort to eliminate the possibility of researcher bias. I disclosed information about myself as an individual and my experiences so that readers would be informed when reviewing my personal impressions, observations, and interpretation of the findings. To combat any unintended misrepresentation of the data, I also regularly discussed challenges, concerns, and my overall thought processes with my chair, other committee members, and colleagues not involved with the study.

Implications for Practice

This study was designed to contribute to practice by identifying how the study participants with AS at one community college utilized self-determination. Regardless of the fact that this study was specific to a single group at one institution, the results of this investigation may have meaning to young adults with AS and their families, students with other disabilities, disability service professionals, faculty who instruct students with disabilities, or any other practitioner who is concerned with the improvement of self-determination outcomes and college experiences of students with disabilities.

An important implication for transition-age youth with AS and their family members is that college is possible. Although the participants in this study faced challenges, these students proved that they were able to negotiate the college environment and enjoy overall academic success. Families with young adults who have AS should consider higher education as a viable option when discussing postsecondary plans. Agencies that support individuals with disabilities should recognize this capable population and direct them to support services that will positively impact their transition.

The implications for students with other disabilities are significant. This research highlighted the importance of self-determination in the college experience. Students with other disabilities should engage in the positive self-determination behaviors modeled by the participants and learn from areas where they seemed to struggle.

Four of the five participants in this study had a long history of disability services throughout their K-12 schooling; however, their self-determination was weak in some areas. It would seem advisable for K-12 disability service professionals to include the promotion of self-determination programming in their services. Disability practitioners should provide students with disabilities opportunities to make choices and work on strategies for dealing with failures and successes. Additionally, an effort should be made to frame disability in a more positive light.

College disability service professionals, should encourage the continued development of self-determination by assisting students with AS, and other disabilities, in identifying reasonable accommodations and other support systems that are needed to meet their academic and social needs. For example, coaching students through challenges by role playing, rather than fixing problems without involving the students, would be one way to address self-advocacy and self-efficacy.

The population of students with disabilities within postsecondary education has been increasing (Horn & Berkold, 1999; Horn et al., 2002; Horn & Neville, 2006). That trend has been accompanied by an increased likelihood that college faculty have had, or will have, students with disabilities in their classes in the near future. Faculty should not consider two students with the same disability to be identical cases. Students with disabilities have individual physical, academic, and social needs. Implications for college faculty would be to learn more about

the needs of students with disabilities and to be prepared to address diverse needs in their delivery of curriculum so that every student has an opportunity to learn and show course mastery.

Recommendations for Future Research

Additional research in the area of students with AS attending college is still very necessary. The review of the literature, the research procedures, and the findings impacted the selection of areas that need to be explored further through research.

1. Sparse data exist as to the actual numbers of students with AS attending colleges, and the data available are largely anecdotal in nature (Dutton, 2008; Farrell, 2004; Moore, 2006; Trachtenberg, 2008). Therefore, further studies need to be conducted to determine the true population of students with AS attending college. Additionally, data should be collected on the numbers of these students who do or do not take advantage of disability services. Smith (2007) attempted to gather some of this information, but because of the low response rate and the differing ranges of tracking and categorical determinations from each institution, overall data were lacking. However, Smith's study could be used as a model in future research.
2. A similar study related to self-determination and college students with AS should be conducted at the four-year college or university level to

compare findings. Students who attend four-year colleges and universities may encounter a variety of circumstances not explored in this study due to the individuals' college attendance being at a community college. For example, the literature suggested that living on campus presented many challenges for students with AS (Dutton, 2008; Glennon, 2001; Graetz & Spampinato, 2008; Welkowitz & Baker, 2005). The present study was not able to provide any perspective about living on campus with AS because each participant still lived at home.

3. Studies on adults with AS have indicated these individuals have adjustment issues and general difficulties in adulthood (Howlin, 2000; Müller et al., 2008; Tantam, 2000). Studies are needed to explore the experience of individuals with AS post-college. These data may be able to inform college faculty and staff about what challenges are faced post-college and how better to prepare college students with AS to meet these challenges. In particular, the outcomes of college graduates with AS should be compared with those college graduates who do not have AS.
4. The characteristics of AS may have impacted the participants' perspective on their experiences, their self-analysis, and their interactions with others. Therefore, additional research should attempt to gather information about college students with AS from additional

sources. Parents, professors, disability advisors, and even peers could provide their own perceptions about the self-determination behaviors of college students with AS.

5. Future research studies may want to explore different means of gaining access to potential participants and collecting data. The internet might be utilized for such solicitation. Additionally, a virtual mode of collecting data utilizing email or a chat room style interview may present a more comfortable environment for potential participants to reveal information about themselves. Participants in this study all appeared comfortable online, responding to emails promptly and providing useful feedback. Email communication style could be examined to provide data similar to tone and body language.
6. It is suggested that researchers explore the self-determination of college students with AS using quantitative research strategies. A quantitative study would elicit a different type of data, which could be used for comparison and analysis. Students with AS may respond differently to questions asked using a survey instrument, with forced choice options.
7. The participants in this study were not able to explain their rights and responsibilities in reference to the laws that protect them against discrimination. It is recommended that self-advocacy groups, in and outside the educational system, work with the transition-age students

with disabilities to inform them about these rights and responsibilities and the importance of advocating for oneself. Workshops and age-appropriate materials might be ways to get the word out to this group about what laws apply to them and how to use that knowledge.

8. It is recommended that future research pertaining to students with Asperger's syndrome explore Theory of Mind (Baron-Cohen, 1995) as the conceptual framework of the study in order to investigate how this theory informs the research findings related to the topic.

It is important to mention that during the defense of this dissertation one committee member brought up the possible conflict of my roles between being a doctoral student and a director of disability services. She felt that although my recommendations were solid, they seemed restrained and she wondered if I was holding back based on my professional position. I believe that I was not consciously holding back on my recommendations; however my professional position may have influenced the practicality of my recommendations. My experience in disability services in higher education has made me aware of the fact that financial restrictions, legal parameters, and institutional climate will play a significant role in the overall accessibility and level of support provided to students with disabilities. Therefore, it was difficult to make grandiose recommendations that I did not feel would have a realistic chance of implementation. Rather, I based my recommendations on actions and research I believe could be reasonably carried out.

Summary

This chapter revisited the conceptual framework of this study. The results have been discussed in the context of the literature review, and the limitations of the study have been presented. Recommendations have been outlined for students, family members, high school staff, faculty, disability services staff, and administrators based on the findings. Implications for practice and suggestions for future research have been presented. Finally, a personal perspective on the recommendations from the study was offered.

CASE STUDY CONCLUSION

After lecturing a bit about the assignment topics and successful group dynamics, Jonathon's professor has the class count off to determine the composition of the groups and Jonathon breathes a sigh of relief, as he is usually picked last in these types of situations. Chaos briefly ensues as the class organizes itself according to the new groups but then settles down as each of the groups finds their own corner of the room to work. Jonathon is in a group with one other male classmate and three female classmates, none of who he has had any prior interactions with. His fellow groupmates begin talking immediately about the project topic and how best to highlight their presentation. Jonathon is not really interested in the topic his group was assigned and feels out of place. He considers talking to his professor about not wanting to participate in the group project, but he does not want to draw attention to himself. Then, one of the female members notices that Jonathan isn't talking and quiets down the group for belated introductions. When asked his name, Jonathan quietly mumbles it but doesn't add anything else.

The other group members continue on with their conversation and start to discuss how to divvy up the work. Just when Jonathon decides he will talk to his advisor after class about the situation after all, the same group member who asked his name asked the group if any of them was good with PowerPoint. Jonathan glances up, and when no one else says anything, pipes in that he is "quite proficient" at working with PowerPoint. He explains that he is not only good at organizing the slides, but can add animation and sound effects if necessary. Jonathon goes on to share that he has been working on computers for years and has mastered several software programs on his personal computer. Just when he is about to go into detail about another program, the group leader, as he thinks of her, told him that all sounded great and asked if he will be responsible for the PowerPoint portion of presentation. Jonathon agrees, knowing it will be easy for him. He begins to calm down realizing that if he just has to do the PowerPoint for the group he should be okay.

APPENDIX A
DSM-IV-TR DIAGNOSTIC CRITERIA

DSM-IV-TR Diagnostic Criteria 299.80 Asperger's Disorder (APA, 2000, p. 84)

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1. marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - 2. failure to develop peer relationships appropriate to developmental level
 - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - 4. lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
 - 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
 - 2. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - 4. persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

APPENDIX B
ICD-10 CLINICAL DESCRIPTIONS AND DIAGNOSTIC GUIDELINES

ICD-10 Clinical Descriptions and Diagnostic Guidelines F84.5 Asperger's Syndrome (WHO, 1992, pp. 258-259)

Clinical Descriptions

A disorder of uncertain nosological validity, characterized by the same kind of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. The disorder differs from autism primarily in that there is no general delay or retardation in language or in cognitive development. Most individuals are of normal general intelligence but it is common for them to be markedly clumsy; the condition occurs predominately in boys (in a ratio of about eight boys to one girl). It seems highly likely that at least some cases represent mild varieties of autism, but it is uncertain whether or not that is so for all. There is a strong tendency for the abnormalities to persist into adolescence and adult life and it seems that they represent individual characteristics that are not greatly affected by environmental influences. Psychotic episodes occasionally occur in early adult life.

Diagnostic Guidelines

Diagnosis is based on the combination of a lack of any clinically significant general delay in language or cognitive development plus, as with autism, the presence of qualitative deficiencies in reciprocal social interaction and restricted, repetitive, stereotyped patterns of behaviour, interests, and activities. There may or may not be problems in communication similar to those associated with autism, but significant language retardation would rule out the diagnosis.

Includes:

- autistic psychopathy
- schizoid disorder of childhood

Excludes:

- anaxastic personality disorder (F60.5)
- attachment disorders of childhood (F94.1, F94.2)
- obsessive-compulsive disorder (F42.-)
- schizotypal disorder (F21)
- simple schizophrenia (F20.6)

APPENDIX C
ICD-10 DIAGNOSTIC CRITERIA FOR RESEARCH

ICD-10 Diagnostic Criteria for Research F84.5 Asperger's Syndrome
(WHO, 1993, p. 153-154)

- A. Lack of any clinically significant general delay in spoken or receptive language or cognitive development. Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases be used by three years of age or earlier. Self-help skills, adaptive behaviour and curiosity about the environment during the first three years should be at a level consistent with intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary diagnostic feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.
- B. Qualitative abnormalities in reciprocal social interaction (criteria as for autism).
- C. An unusually intense circumscribed interest or restrictive, repetitive, and stereotyped patterns of behaviour, interests and activities (criteria as for autism; however, it would be less usual for these to include either motor mannerisms or preoccupations with part-objects or non-functional elements of play materials).
- D. The disorder is not attributable to other varieties of pervasive developmental disorder; schizotypal disorder (F21); simple schizophrenia (F20.6); reactive and disinhibited attachment disorder of childhood (F94.1 and .2); obsessional personality disorder (F60.5); obsessive-compulsive disorder (F42).

APPENDIX D
GILLBERG DIAGNOSTIC CRITERIA

Diagnostic Criteria for Asperger's Syndrome according to Gillberg
(Gillberg, 2002, p. 6, Gillberg & Gillberg, 1989)

1. Social impairment (extreme egocentricity) (at least two of the following):
 - a) difficulties interacting with peers
 - b) indifference to peer contacts
 - c) difficulties interpreting social cues
 - d) socially and emotionally inappropriate behavior
2. Narrow interest (at least one of the following):
 - a) exclusion of other activities
 - b) repetitive adherence
 - c) more rote than meaning
3. Compulsive need for introducing routines and interests (at least one of the following):
 - a) which affect the individual's every aspect of everyday life
 - b) which affect others
4. Speech and language peculiarities (at least three of the following):
 - a) delayed speech development
 - b) superficially perfect expressive language
 - c) formal pedantic language
 - d) odd prosody, peculiar voice characteristics
 - e) impairment of comprehension including misinterpretations of literal/implied meanings
5. Non-verbal communication problems (at least one of the following):
 - a) limited use of gestures
 - b) clumsy/gauche body language
 - c) limited facial expression
 - d) inappropriate facial expression
 - e) peculiar, stiff gaze
6. Motor clumsiness
poor performance in neurodevelopmental test

APPENDIX E
SZATMARI, BREMNER, & NAGY DIAGNOSTIC CRITERIA

Diagnostic Criteria for Asperger's Syndrome from Szatmari, Bremner, and Nagy (Szatmari, Bremner & Nagy, 1989, p. 558)

A. Solitary, as manifested by at least two of the following four:

1. No close friends.
2. Avoids others.
3. No interest in making friends.
4. A loner.

B. Impaired social interaction, as manifested by at least one of the following five:

1. Approaches others only to have own needs met.
2. A clumsy social approach.
3. One-sided reactions to peers.
4. Difficulty sensing feelings of others.
5. Detached from feelings of others.

C. Impaired non-verbal communication, as manifested by at least one of the following seven:

1. Limited facial expression.
2. Unable to read emotion from facial expressions of child.
3. Unable to give messages with eyes.
4. Does not look at others.
5. Does not use hands to express oneself.
6. Gestures are large and clumsy.
7. Comes too close to others.

D. Odd speech, as manifested by at least two of the following six:

1. Abnormalities in inflection.
2. Talks too much.
3. Talks too little.
4. Lack of cohesion to conversation.
5. Idiosyncratic use of words.
6. Repetitive patterns of speech.

E. Does not meet criteria for Autistic Disorder.

APPENDIX F
AUTISTIC DISORDER DIAGNOSTIC CRITERIA

DSM-IV-TR Diagnostic Criteria 299.0 Autistic Disorder (APA, 2000, p. 75)

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 2. Qualitative impairments in communication as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - d. persistent preoccupation with parts of objects

- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rhetts Disorder or Childhood Disintegrative Disorder.

APPENDIX G
PARTICIPANT INFORMED CONSENT FORM

Date

Dear Student:

Hello, my name is Jill Szentmiklosi. I am a doctoral student at the University of Central Florida. As part of my dissertation I am conducting a research study of self-determination among community college students diagnosed with Asperger's syndrome. The purpose of this research is to discover what self-determined behaviors are expressed by community college students with Asperger's syndrome in relation to the college experience.

I would like to interview you about being a community college student with Asperger's syndrome. The interview should last about 60 to 90 minutes and will take place in the Office for Students with Disabilities at Valencia Community College. During this interview, I will ask you questions about attending college and your experiences as an individual with Asperger's syndrome. Your insights will help me determine how colleges might assist students with Asperger's syndrome to be successful in college. I plan to interview 4-6 students and use their responses, and yours, and write about the themes revealed in my dissertation. In the future there is a possibility that I might write an article or make a presentation about this research; however you will not be identified by name or linked directly to any specific comments. Your participation in this study will remain confidential.

During the interviews, I will use a digital recorder to capture all your ideas accurately. Afterward, I will have a professional captionist transcribe the recording to help me remember all that was said. The captionist will sign a confidentiality form and return all materials to me after the transcription is completed. I will keep the recordings and transcripts secure and at the completion of this research project they will be destroyed. The only other people who will see the transcripts will be my four dissertation committee members.

I want to assure you that your participation in this research is completely voluntary. If you do not want to be interviewed, you won't be. Any services you're receiving through the student disability office will not be affected by your decision. If there are certain questions that are asked that you do not feel comfortable answering, you can just let me know and we will move on. Also, if during the interview you change your mind about participating, you can stop at any time without consequence.

As part of this study, I will review your academic records to: verify disability diagnosis, collect demographic information, review your academic history and

current academic standing, and assess your advisor contact and utilization of accommodations.

There are not any anticipated risks to you as a participant in the study and if you do decide to participate you will be contributing to a growing body of knowledge on college students with Asperger's syndrome.

If you have any questions about this research project, please contact me at (407) 582-2236. You may also contact my faculty chair, Dr. Rosa Cintrón at (407) 823-1248 or by email at rcintron@mail.ucf.edu. Research at the University of Central Florida involving human participants must be approved by the Institutional Review Board (IRB). This research has been approved by IRB. If you have any questions or concerns about your rights as a research participant please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901. You may also talk to them for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You want to get information or provide input about this research.

Please sign and return this copy of the letter in the enclosed envelope. A second copy is provided for your records. By signing this letter, you give permission to report your responses anonymously in the final manuscript to be submitted to my faculty chair as part of my dissertation research.

Name

_____ I am 18 years of age or older

_____ I have read and understand the interview procedures described above.

_____ I voluntarily agree to participate in the interview.

_____ I agree to have my academic record reviewed for this research study.

_____/_____
Participant

Date

_____/_____
Principal Investigator

Date

APPENDIX H
CONFIDENTIALITY STATEMENT

Statement of Confidentiality

I, _____, transcriptionist, agree to maintain full confidentiality in regards to any and all audio recordings and documentation received from Jillian Szentmiklosi related to her doctoral study on Self-Determination Among Community College Students Diagnosed with Asperger's Syndrome. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-recorded interviews, or in any associated documents;
2. To not make copies of any audio recordings or computerized files of the transcribed interview texts, unless specifically requested to do so by Jillian Szentmiklosi.
3. To store all study-related audio recordings and materials in a safe, secure location as long as they are in my possession;
4. To return all audio recordings and study-related documents to Jillian Szentmiklosi in a complete and timely manner.
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

_____/_____
Transcriptionist / Date

_____/_____
Principal Investigator / Date

APPENDIX I
INTERVIEW PROTOCOL

Interview Protocol

1. What are your long term goals, personally and/or professionally?
 - a. *In what time frame to you expect to accomplish these goals?*
2. What is your primary purpose for attending Valencia Community College?
 - a. *When did you know you wanted to attend college?*
 - b. *Who, if anyone, influenced your decision?*
 - c. *What influenced your decision to attend a community college?*
3. What is your major area of study?
 - a. *Why did you choose that major?*
4. Describe your experiences with faculty, inside and outside the classroom.
5. Describe your experiences managing your course work.
 - a. *Assignments? Study time? Work/School balance?*
 - b. *What strategies have you used to keep up?*
6. Describe your experience with your own peers?
 - a. *Communication with classmates?*
 - b. *Group work?*
 - c. *Socializing in and out of school?*
7. Describe how and why you became involved with disability services.
8. When were you formally identified as an individual with AS?
 - a. *Describe this process.*
 - b. *What is your understanding about your disability?*
9. Describe how having AS impacts your learning?
 - a. *What, if any, accommodations are helpful?*
10. What laws, if any, are you familiar with that apply to students with AS in college?
 - a. *To your knowledge have you made use of these laws? How?*
11. What have been your greatest barriers and challenges during your time so far in college?
 - a. *How have you overcome those barriers and challenges?*
12. What have been your greatest successes so far in college?
 - a. *What, or who, do you feel has contributed to your successes?*
13. What, if any, are the benefits associated with having AS?
14. Is there any other information that you would like to share concerning your experiences as a community college student with AS?

APPENDIX J
INSTITUTIONAL REVIEW BOARD APPROVAL



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901, 407-882-2012 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Notice of Exempt Review Status

From: UCF Institutional Review Board
FWA00000351, Exp. 10/8/11, IRB00001138

To: Jillian M. Szentmiklosi

Date: August 12, 2009

IRB Number: SBE-09-06383

Study Title: Self-Determination Among Community College Students Diagnosed with Asperger's Syndrome: A Qualitative Study

Dear Researcher:

Your research protocol was reviewed by the IRB Vice-chair on 8/12/2009. Per federal regulations, 45 CFR 46.101, your study has been determined to be minimal risk for human subjects and exempt from 45 CFR 46 federal regulations and further IRB review or renewal unless you later wish to add the use of identifiers or change the protocol procedures in a way that might increase risk to participants. Before making any changes to your study, call the IRB office to discuss the changes. A change which incorporates the use of identifiers may mean the study is no longer exempt, thus requiring the submission of a new application to change the classification to expedited if the risk is still minimal. Please submit the Termination/Final Report form when the study has been completed. All forms may be completed and submitted online at <https://iris.research.ucf.edu>.

The category for which exempt status has been determined for this protocol is as follows:

2. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey or interview procedures, or the observation of public behavior, so long as confidentiality is maintained.
 - (i) Information obtained is recorded in such a manner that the subject cannot be identified, directly or through identifiers linked to the subject, and/or
 - (ii) Subject's responses, if known outside the research would not reasonably place the subject at risk of criminal or civil liability or be damaging to the subject's financial standing or employability or reputation.

The IRB has approved a consent procedure which requires participants to sign consent forms. Use of the approved, stamped consent document(s) is required. Only approved investigators (or other approved key study personnel) may solicit consent for research participation. Subjects or their representatives must receive a copy of the consent form(s).

All data, which may include signed consent form documents, must be retained in a locked file cabinet for a minimum of three years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained on a password-protected computer if electronic information is used. Additional requirements may be imposed by your funding agency, your department, or other entities. Access to data is limited to authorized individuals listed as key study personnel.

On behalf of Joseph Bielitzki, M.S., DVM, UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 08/12/2009 11:54:49 AM EDT

IRB Coordinator

VALENCIA COMMUNITY COLLEGE
Human Research Protection (HRP) Institutional Review Board (IRB)

IRB Determination Form

Title of Research Protocol: Self-Determination Among Community College Students Diagnosed With Asperger's syndrome: A Qualitative Study

Principal Investigator (PI): Jillian Szentmiklosi

Date Received by IRB Chair: 07/21/09

IRB Number: 10-002

Based on the IRB Protocol Initial Submission Form (or, as appropriate, the IRB Continuing Review/Termination Form or the IRB Addendum/Modification Form) submitted by the Principal Investigator and for the project identified above, the following determination has been made by the Valencia IRB:

- The research is exempt from IRB review. Exemption category: 2
- The research is eligible for expedited review and has been approved.
- The research is eligible for expedited review but requires modifications and re-submission before approval can be given.
- The research is subject to full review and will be discussed at the next IRB meeting, currently scheduled for _____ (date).
- The research has been subjected to full review and has been approved.
- The research has been subjected to full review and has been disapproved.

Period of Approval: 07/31/09 to 11/20/09
(cannot be retroactive)

Exemption from Valencia IRB review does not exempt the PI or Co-PI from compliance with all applicable institutional, Federal, State, and local rules, regulations, policies, and procedures.

Although the IRB has determined that this application is exempt from IRB review, the Principal Investigator is encouraged to read, understand, and apply the attached Investigator Responsibilities document, which is required of Principal Investigators whose research protocols are approved under the Valencia IRB full or expedited review process.

If you have any remaining questions about Valencia's IRB process, contact the IRB Chair at irb@valenciacc.edu.

Elizabeth I. Gombash
Signature of IRB Chair or Designated Representative

07/31/09
Date

C: IRB File, IRB Members, PI Supervisor/Administrator

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