UNDERSTANDING STUDENTS WITH AUTISM SPECTRUM DISORDERS IN HIGHER EDUCATION

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Abstract

The research study sought to describe the experience of students with autism spectrum disorders (ASD) in higher education. There may not be sufficient support within institutions of higher education for those students with ASD who wish to pursue advanced education; thus this study explored the experience of students with ASD attending an institution of higher education. A key element of the study focused on understanding the experience of students with ASD as they accessed support services. This issue continues to be relevant and significant in that it speaks to a growing population of students new to the higher education experience. Utilizing the methodology of qualitative design, a phenomenological study of a small group of students with ASD in the university setting was conducted. The following research questions were the focus of this study: *What is the experience of students with autism spectrum disorders attending an institution of higher education? What is their experience as it relates to available support systems at Northern University? How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?* Analysis through the lens of disability theory and the achievement ideology enabled a deeper understanding of the students’ overall experience of being a college student, yet one with the unique perspective of having ASD. The data analysis revealed much about the participants’ experience in higher education, and this deep understanding highlighted critical aspects of support for students with ASD. Overall conclusions drawn indicated that the study participants felt very supported and encouraged by staff and peers. These students, in turn, were able to self-advocate in their efforts to achieve academic success.

The number of students with ASD will continue to increase within institutions of higher
education based on the growing student population in postsecondary education and the increasing resources available to these students. Implications for future study addressed this growth and the critical need for continued support and accommodations for these students. The recommendations both specific to this study and on a broader scale include: 1. Continued, clear communication about services available to students with ASD and other disabilities, 2. Accessibility of appropriate support, 3. Provision of volunteer peer tutors or academic peer support, 4. Disability awareness and training for university staff, and 5. Connections with specialists at universities to strengthen resources.

Key words: autism spectrum disorders, higher education, self-advocacy, accommodations, faculty and staff awareness
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Dedication

For my smart, funny, sweet nephew Andrew - I love you and all of our endless baseball conversations.
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Chapter One
Increasing numbers of students with learning disabilities such as autism spectrum disorders (ASD) are now attending colleges and universities worldwide. According to the National Center for Education Statistics, 11 percent of students at the undergraduate level in the United States were said to have disclosed a disability to their postsecondary institution for the academic year of 2007-2008 (U.S. Department of Education, National Center for Education Statistics, 2011). According to the United States Department of Education, “Post-secondary enrollments among individuals with disabilities receiving IDEA services have [also] sharply increased. For example, the percentage of college freshmen reporting disabilities has more than tripled since 1978” (U.S. Department of Education Website, 2011). According to the National Longitudinal Transition Study conducted, Newman et al. (2011) summarized, “Of young adults with disabilities, 60 percent were reported to have continued on to postsecondary education within 8 years of leaving high school” (p. 16). This percentage was comprised of students enrolled in some form of postsecondary education at any point within the 8-year time span after high school completion.

Due to accommodations available through the Individuals with Disabilities Education Improvement Act (IDEA, 1990/2004), students with ASD have demonstrated achievement at the secondary school level, and they now have aspirations to advance to higher education. However, not all students reveal their disability nor do they request academic support services, thus it would be difficult to estimate the exact percentage of students with ASD currently in institutions of higher education. Colleges and universities have more recently begun to provide support services for the needs of these unique students (Camarena & Sarigiani, 2009).
At the study site, Northern University¹, consistent electronic data collection was limited to the past three years, from the 2009-2010 year to present. For the academic year of 2011-2012, slightly higher than 5 percent of the day student population (of 2470 students) had filed with the Office of Disability Services diagnosed with some form of disability. As with the difficulty in ascertaining more precise nationwide statistics, it was not possible to clarify the exact percentage or number of students with ASD as their disability. At Northern University, students identified were only those individuals who had completed the entire registration process with the Office of Disability Services. If students were not planning to seek accommodations from the Office of Disability Services, they may not necessarily have completed the entire registration process (and thus would not be considered in the total count). In addition, if students identified themselves with two disabilities, yet only one was fully documented such as that of learning disabilities in general, the student would be coded in the system as LD. Even if the student identified with having ASD as well, yet lacked the full documentation, the student would be coded solely as LD. The numbers are not as accurate as they could be due to this incomplete documentation as well as to students’ lack of full disclosure. Based on the day student population only, it was reported by the Office of Disability Services that there were two students diagnosed with ASD in 2009-2010. For the year 2010-2011, this number increased to five students total, and for the academic year 2011-2012, thus far, the number had increased to eight students diagnosed with ASD (Office of Disability Services Staff, personal communication, March 30, 2012).

¹ The study took place at a large not-for-profit university in New Hampshire. To protect the anonymity of the school and its participants, the site will be referred to as Northern University and the students will be assigned pseudonyms. Much like the national statistic, this small group is comprised of less than 1% of the student population, yet increasing slowly as more students are diagnosed with ASD.
Problem of Practice

Little research has been done to identify additional learning opportunities for students with autism spectrum disorders (ASD) beyond high school. This research sought to understand the experience of students with autism spectrum disorders in higher education. There may not be sufficient support within higher education institutions for those students with ASD who wish to pursue advanced education. If the support is available, there is little data demonstrating that, in effect, these supplementary support systems are enhancing the academic success of students with ASD. For this particular study, whether or not students with ASD were advocating for assistance and seeking the help provided was a key element.

There is limited research to date that explores students with ASD beyond their primary and secondary school years. Autism was initially diagnosed in the early 1940s as a medical condition, as was a similar condition, Asperger’s syndrome. However, with more increased research and better diagnosis of this neurological disability, a great number of children have been identified on the autism spectrum in more recent years (Kanner, 1943; and Taylor, 2005). The National Center for Educational Statistics reported 13.2 percent of individuals, ages 3-21, receiving disabilities services in the nation’s public school system for the 2008-2009 year. Of this total, approximately 1 percent categorized students diagnosed with autism, a number that had been steadily increasing over the previous 6 years (U.S. Department of Education Website, 2011). Albeit a small population, many of these students will want to pursue postsecondary education opportunities like their peers. The research study at Northern University was of utmost
importance in that it spoke to this emerging student population that was in need of further research and advocacy.

Autism spectrum disorders are behavioral disorders that affect one’s learning and development (both academic and social) in differing levels of severity. The earlier the disorder is detected the better it is in order to provide for service and support for the child or young adult. As noted by the National Autism Association Website, “Since autism was first diagnosed in the U.S. the occurrence has climbed to an alarming one in 150 people across the country” (2009). Autism spectrum disorders “…are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotype patterns of behavior’ (Department of Health and Human Services, 2010, p.3). Children are diagnosed with ASD as early as one year of age, as these individuals will develop cognitively at a slower rate than other children. Autism manifests itself in varying levels of severity and will affect an individual child or adolescent in unique ways. According to the Department of Health and Human Services (2010), “Some early indicators of autism spectrum disorders include the following: does not speak one word by 16 months, does not combine two words by 2 years, does not respond to name, loses language or social skills” (p.8). Individuals are generally assessed by a team of doctors - likely including a neurologist, a psychologist, an occupational therapist, among others - to ascertain the child’s basic intelligence level, language ability, and behavioral social tendencies. Specific measures developed expressly for diagnosing ASD are the Autism Diagnosis Interview-Revised (ADI-R) and the Autism Diagnosis Observation Schedule (ADOS-G).
As individuals with ASD move into adolescence, they continue to struggle with basic social interaction, and they may have difficulty making eye contact with others. Autism spectrum disorders are not “curable”; however, with behavior modification and significant support, an individual with ASD can, to a certain extent, succeed in school and work. It is imperative to investigate available accommodations for students with ASD at institutions of higher education to see how academic and social support contributes to their success. With this investigation, the study intended to better understand the overall experience of students with ASD within the higher education setting.

**Practical and Intellectual Goals**

The practical goals identified the need to explore the field in order to better understand the experience of students with ASD in higher education, as well as to be of assistance to them and to students in the future. At the time of the study, the researcher had no responsibility for services for students with ASD at Northern University – where she was employed - beyond an advising role for some of the graduate students. The extensive research and study will serve to enlighten both professionals and students regarding the services available to students with ASD and other learning disabilities, as well as the importance of self-advocacy of the students. The researcher envisioned better communication between service providers and academic advisers of students with ASD as well as more accessibility to services and accommodations for these students as a result of understanding their experiences. Ideally, students with ASD would be able to better self-advocate for what they need in the higher education setting in the future if communication improves.
The intellectual goals sought to understand the experience and the environment of a student with ASD in higher education. This research identified and explored an important need worthy of addressing, of gaining more knowledge and seeking new insights in the field, and of opening up doors to students with ASD. It is essential to understand this information in order to better serve the growing population of students with ASD in today’s colleges and universities. Regardless of how an individual learns, every student deserves an opportunity to achieve success in higher education, and educators need to make this an attainable and viable option.

**Research Questions**

The research questions proposed are aligned directly with the practical and intellectual goals as noted.

1. What is the experience of students with autism spectrum disorders attending an institution of higher education?
   
   a. What is their experience as it relates to available support systems at Northern University?
   
   b. How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?

**Significance of the Problem**

There is much that educators do not yet know with respect to understanding the obstacles faced by a student with ASD in higher education. This research study opened both “academic” and “social” doors within higher education to students with ASD by gaining insight into that which current students with ASD experience. Investigating the research brought deeper insight
into ways for students with ASD to self-advocate and to enable their academic success, as well as to help them with social adaptation at institutions of higher education. For a student with ASD, often the social adaptation piece - which is particularly important on a university campus - is directly linked to aspects of classroom success or failure.

Little has been reported thus far concerning the accomplishments of students with ASD in higher education. Many colleges and universities have programs in place to serve students with special needs, such as students with ASD. As of yet, there is little to no data to prove that such services are enabling students with ASD to have success in higher education. Resources are available to students with ASD and other learning disabilities at Northern University, where the study took place; however, no studies had been done thus far with respect to the students’ experience. In addition, whether or not all students with ASD were advocating for assistance and seeking the help provided was unknown. A key issue was that students may have been hesitant to advocate for themselves and to take advantage of the opportunities available. Students may have felt embarrassed or “stigmatized” about needing support, or perhaps there were unique personal reasons known only by the student. Gaining insight into and meaning from what students with ASD experience while in higher education informed the research.

Another issue to consider related to the research study is that not all higher education faculty members are trained in ways in which to serve students with ASD. Many professors are masters of their subject matter yet may not be the best at relaying the information through various means in order to meet the learning styles of the diverse student population. Professional development for faculty is necessary in that all students need to feel comfortable and welcome in higher education classrooms. This should be considered an essential part of the work of each
faculty member. The individual college or university program will determine to what extent the student with ASD has a supportive, helpful academic adviser. Disclosure (including necessary and required testing from high school years) on behalf of the student and his or her family enables the support staff and the student’s academic adviser to understand more clearly the student’s learning disability and needs. Most professors truly want to assist their students, but what is often lacking is knowledge, on the part of both the instructor and the student. Instructors are often unaware that a student has a disability due to the fact that the individual is often hesitant to share his or her diagnosis. It is at the discretion of the students as to whether or not they disclose their disability to the Office of Disability Services, and thus seek support from their instructors. There is a crucial need for communication between the key people involved, the individual students and staff.

**Summary of Paper and Organization**

The paper begins with an introduction and a statement of the problem of practice – students with ASD in higher education – and is then followed by the researcher’s practical and intellectual goals and the research questions guiding the study. The significance of the problem and the theoretical framework section (describing disability theory and the achievement ideology) follow. An in-depth literature review is provided, divided into several key areas of focus: preparation/professional development for staff in terms of awareness of ASD, strategies and techniques for accommodations, self-determination and self-advocacy on the part of the student, and academic success versus leaving higher education. The research design is then explained, utilizing the methodology of qualitative design through a phenomenological study. A phenomenological study enabled the researcher to describe the experience and its meaning of
students with ASD in higher education. Data collection methods and analysis follow in the paper. Validity and reliability of the research is addressed next, as well as the crucial section of the protection of human subjects, followed by implications for future study, recommendations, and the conclusion.

**Theoretical Framework**

Disability theory is emerging as a field of value for this research. According to Denhart (2008), “Three foundational ideas form a rudimentary core of disability theory viewing disability as (a) socially constructed, (b) part of normal human variation, and (c) requiring voice to deconstruct it” (p.484). Students with ASD or other learning disabilities are unique and different learners adapting within the social construct that is the university setting. The students then must self-advocate, utilizing their voice to seek the support and accommodations they need to succeed both academically and socially. Enabling students with ASD and LD to speak out and to participate in their own education, instead of solely gleaning input from the faculty and college leaders, gives these individuals “voice” and an active role in their continued education. The phenomenological study in which Denhart (2008) engaged students, enabled the researcher – an individual with LD – to delve very deeply and personally into what the students were experiencing. According to Denhart, “Disability theory demonstrates how social intolerance of human variation creates disability. Such disability is imposed upon these participants where out of fear of stigma they refused to ask for accommodations that would have eased their workload and improved their performance” (2008, p.493). In order to eliminate stigma, students must feel
comfortable to seek assistance from faculty, staff, and peers. These individuals must then strive to be willing and flexible to accommodate a variety of students’ different learning needs.

Supplementary to disability theory, facets of the achievement ideology are applicable to whether or not the student with ASD achieves academic success in higher education. Seibel (1974) affirms,

> In an achieving society, individuals are assigned to work and work-related roles by virtue of their individual merits, competence, talent, etc; insofar as these are relevant to the performance of work roles. To keep such a society running smoothly, its members have to be prepared for the assignment of work roles by individual competence (p.4).

If a student with ASD is supported by his or her adviser and by instructors, and the student maintains the will and has the knowledge in which to self-advocate, competence hopefully will follow. Within an achieving society, it is a common assumption that a learning disabled student, such as one on the autism spectrum, will consistently struggle academically. If this belief persists and nothing is done to alter the situation, inevitably the student will struggle. However, with the appropriate knowledge and support, this student, like many of his peers, has the chance for academic success.

It is important to support and provide key information for all students in order to help them find their unique path. Although developmental theory was not a focus for the theoretical framework related to the research study, Vygotsky’s notion of the Zone of Proximal Development (ZPD) was an area of particular interest and was deemed applicable to the problem of educational practice (in Miller, 2002). In the ZPD, "A more competent person collaborates with a child (or individual) to help him move from where he is now to where he can be with
help. The more skilled adult or peer builds on the competencies the child (or individual) already had and presents activities supporting a level of competence slightly beyond where he is now” (Miller, 2002, p.377). Theorist Rogoff (1990) continued Vygotsky's concept of the ZPD, stressing the fact that individuals learn both through explicit and implicit instruction. Noting that, "Learning is a natural byproduct of involvement in tasks with adults or more competent peers", peers and professors become vital in helping the student, particularly in the case of an ASD student, to continue to develop cognitively (Miller, 2002, p.379).

Vygotsky also would have stressed the need for social interaction for students with ASD, such as through peer tutor work, as collaboration helps students develop cognitively and achieve academically, and better adapt socially. Both collaboration and positive peer work would prove to be an important element that aided in the success of the students with ASD in the study. Vygotsky's views were based on people’s "...interactions with others in social settings and the 'psychological tools' such as language used in these interactions shape children's thinking” (Miller, 2002, p.370). For a student with ASD, this collaboration not only provides cognitive benefits, it is necessary for academic success as well as one’s social acculturation. In addition, behavioral conformity cues are much more difficult to follow (as opposed to explicitly clear and brief directions) for students with ASD. Often these students need to be told or shown, and with significant repetition, before something that might be considered a behavioral, moral, or cultural norm will be understood. Collaborative work with and modeling by one’s peers will support the learning of a student with ASD.

Although studies of the achievement ideology have often been affiliated with research related to race and class struggles, as in MacLeod (2008), the achievement ideology is applicable
to all students, specific to this study, students with ASD in higher education. For students with ASD, there are often some very basic socialization skills lacking which tend to exacerbate their differences and hinder academic success as well. This then magnifies the gap in the achievement ideology for these students. Further, it is what the student chooses to do with this ideology - his or her belief in academic success - that can make a significant difference. With the achievement ideology in mind, all students have the opportunities and abilities to succeed, as long as they are supported in the process.

The theoretical lens of disability theory, as introduced earlier, guided this work to employ a phenomenological study. Understanding the experience of students with ASD in higher education can best be achieved through phenomenology. According to Lester (1999), “Phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore at challenging structural or normative assumptions” (p.1). As students with ASD or LD try to adapt within the social construct of higher education, the students must utilize their voice to seek the support and accommodations they need to succeed both academically and socially. In speaking out – for example, through disclosure of one’s disability - a student with ASD gives his or her learning disability a voice. Once “heard”, this student and other students with ASD will be better understood by peers, faculty, and staff, thus insight can be gleaned into what they experience in higher education. With knowledge for both students with ASD and members of the educational community, the experience within higher education may be better understood and attainable.

The university culture is different from anything most students with ASD have ever encountered and, with assistance from an academic adviser and/or the collegiate study skills
staff, as well as through help from peers, these students can adapt. Vygotsky and his fellow socioculturalists would advocate the following, “In this *culture-as-medium* approach, culture organizes the child’s everyday experiences and, like good soil for plants, nurtures development” (Miller, 2002, p.376). For a student with ASD, the culture and the student’s experience of the higher education environment will play an essential role in his or her academic success.

By participating in the interview process for this phenomenological study, students with ASD were given the opportunity to be heard and to share their unique experience in higher education. How students self-advocated and to what extent they utilized the available accommodations and support available (or chose not to) made up their experience while contributing to their academic success and social adaptation. Students that participated in the study were those who had previously disclosed their disability – that of having ASD - to the Office of Disability Services at the study site, Northern University. At the time of the study, there was a very small population of students that fit these criteria and, based on previous discussions with the Assistant Director of the Office of the Disability Services, 5-7 students would volunteer to participate in the study. Based on the current, small population of students with ASD at the university, no voluntary participants needed to be excluded. The researcher shared her general experiences in higher education with efforts to ensure the comfort level of the students during the interview process. The interview questions (as well as the informal journal writing) aided in gaining understanding into the students’ overall experience of being a college student, yet one with the unique perspective of having ASD.
Chapter Two

Literature Review

At the time of study, there was little research regarding academic success of students with autism spectrum disorders beyond their secondary school years. The questions guiding the literature review were as follows:

1. How are institutions of higher education addressing the needs of students with autism spectrum disorders in order for them to overcome obstacles and achieve academic success?
   a. How are higher education professionals supporting students with ASD to succeed academically?

2. How and to what extent are students accessing the services and accommodations they need?
   a. Are services and accommodations enabling students with ASD and other learning disabilities to be successful both academically and socially in higher education?

The purpose of the literature review was to achieve a better understanding of the overall experience of the student with ASD in the higher education setting. The literature review delved further into the following: the facilities and services available at current institutions of higher education for students with ASD, and the extent to which academic advisers and professors were contributing to support in this area (including whether or not they knew what to do or were aware of the students’ need for assistance). Research also included whether or not students with ASD were accessing the services needed and to what extent. Effort was made to explore research
about the culminating effect of the services available and whether or not services were enabling students with ASD to be more successful academically than they might have been without the support systems. Some research included personal experiences within higher education of individuals with ASD. Themes that emerged from the literature review included focused professional development training for faculty specific to the needs of students with ASD and LD, and problems in the lack of professional preparation (ensuring staff gain better awareness of the presence of students with ASD). Additional themes included specific strategies, tactics, and techniques for staff implementation of accommodations, as well as self-determination and self-advocacy on the part of the student with ASD to aid staff with disability awareness. Research related to accessing services versus discontinuing studies was delved into as well, although limited by what information was available. Aspects and themes that emerged from the research warranted the need for the study at Northern University and its potential contributions to the field.

**Preparation/Professional Development for Staff, Awareness of ASD**

Within the context of higher education - as opposed to secondary schools with structured support systems - there may be support available for students with ASD, but not necessarily to the extent that it is in secondary school. However, as programs come to light (accommodations are made and instructors are trained, among various elements) students with ASD have greater aspirations to experience higher education, knowing that they will be supported in their academic success. The contextual implications generally have to do with staff, professors, and advisers working within the realm or context they have traditionally known, without knowledge of how to support a student with ASD and/or without lack of professional training. As noted by Stodden
and Mruzek (2010), “Strategies such as universal design, person-centered planning, the use of technology, and slight modifications to the culture of the classroom have been effective in facilitating the inclusion of students with ID [intellectual disabilities] in academic settings” (p.132). With proper training and professional development, faculty and staff will be better prepared to work with students with ASD and other intellectual and learning disabilities.

The extent to which academic advisers and professors are contributing to support in this area and whether or not they know what to do, or are aware of the need for assistance is essential to research. There is a wide range of knowledge of ASD and accompanying support from advisers and professors (some of whom are more familiar with ASD than their colleagues), and their training through extensive professional development is crucial to both the academic and social support of students with ASD. There should be consistency in programming in order to ensure that professors are able to support and provide that which students with ASD need, within reason. Leblanc, Richardson, and Burns (2009) and Orr and Hammig (2009) concluded that professional development training should be provided for advisers and professors within higher education settings in order to best serve the learning needs of their students.

LeBlanc, Richardson, and Burns (2009) provide research that demonstrates that, with training, an individual’s perceptions about students with ASD would change, and he or she would become more knowledgeable and prepared to teach individuals with ASD. Their focus was on a lengthy, professional development program for students in a teacher preparation program in order to better prepare the teachers to work with students with ASD. For this study, researchers aligned with the theory that, with clearly designed training sessions, faculty’s perceptions of individuals with ASD would change, their technical knowledge of ASD would
increase, and their teaching strategies for students with ASD would be more effective and appropriate. Researchers expressed the critical need for professionals in the field to increase perceptions, knowledge, and strategies for teaching students with ASD due to an increase of this disability in the student population.

Although their work focused on an educator preparation program (as opposed to those currently in the field), LeBlanc et al.’s (2009) findings “seem to indicate that even a small amount of ‘professional development’ opportunity can have a measurable influence on the lives of both beginning teachers and, by extension, the ‘exceptional’ students they will be required to teach in the fully integrated classroom” (p.177). Particularly useful in the research study were the survey questions implemented and the structure utilized, ideal for future use when considering professional development for those in higher education unaccustomed to students with ASD.

In research by Hart, Grigal, and Weir (2010) emphasis was on the need for instructors to maintain the rigor of college level work and courses, and to not minimize what is expected for students with ASD or LD. They affirm, “Instead, if a student requires modifications, the responsibility falls to the student and to those providing assistance to ensure the course material is accessible and the student will be able to successfully participate” (2010, p.137). The research study brought to light that which was available at the time at the research site, Northern University, and perhaps that which was needed in order to better prepare faculty and staff in teaching students with ASD.

A unique program was revealed in the research of Zager and Alpern (2010) entitled the Campus-Based Inclusion Model (CBIM). This detailed a program or partnership between a public school and a local university that had various benefits for students with disabilities and
opened them up to the college campus experience. Students were technically enrolled in high school still, yet they completed their coursework on a college campus in order to work alongside their peers. The university setting enabled these students to experience that which their peers were, including job training and crucial socialization skills, and transitioned them more smoothly into higher education. Zager and Alpern (2010) noted, “The mission of the CBIM is to educate students with autism and intellectual disabilities alongside their peers to provide a positive, age-appropriate postsecondary option that will prepare them for adult living” (p.153). Although this is not a program currently in existence at the research site, it is one that sheds light on the importance of students with ASD and other learning disabilities working and studying alongside their same age peers in order to enable them to adapt to the higher education setting.

**Strategies and Techniques for Accommodations**

Some of the available literature focuses on specific strategies for students with ASD to achieve academic success in higher education. Stodden and Mruzek (2010) confirm, “Recent reauthorization of the Higher Education Act as the Higher Education Opportunity Act (HEOA) of 2008 (Public Law 110-335) further delineates support for persons with autism and intellectual disabilities to participate in postsecondary education opportunities and thus experience improved employment outcomes as contributing adults within their communities” (p.131). Research delved into that which is currently available at colleges and universities nationwide including disability and academic skills offices (e.g., the Academic Resource Office, Study Skills Office, Disability Services, and/or Academic Support), peer tutoring and writing support centers. Much of the research explored that of accommodations within the classroom setting including extended time
on assessments, recorded and/or scripted lectures, use of laptops and computer aids, access to professors online as well as in-person. Finally, research identified what was known as modified curriculum, or a similarly named variation of one’s curriculum, depending on the institution. The research study sought to identify what students with ASD are utilizing as well as how their overall experience in higher education is enhanced.

The research site, Northern University, has had a fully staffed Office of Disability Services with similar accommodations and support available to students, as noted in Stodden and Mruzek (2010). In order to receive academic accommodations and support, students must provide documentation of their learning disability to the Office of Disability Services at the onset of their studies. Students are then assigned a disability services specialist with whom they will meet and work as their courses progress. At the time of the study, services available from the Office of Disability Services included but were not limited to: ancillary support materials such as copies of lecture notes or a classmate’s notes (volunteer note-takers receive a bookstore stipend), digitally recorded material, extended time on assessments/assignments, alternative assessment environment, altered format of assessments, etc. According to the Office of Disability Services Website, “[Northern University] is committed to and concerned with meeting the needs of students challenged by physical, sensory, psychiatric and/or learning disabilities with regard to the Americans with Disabilities Act (ADA) and Section 504 of the 1973 Rehabilitation Act” (2010).

Information and research gained were shared through the personal experiences and the self-reflective work of Prince-Hughes (2003) and Grandin (2007). Prince-Hughes (2003) reflected on her own experience in the higher education environment, one in which a student
with autism, like herself, has the potential to thrive, “As promising students with special needs, we are often pushed from the one place that can maximize our potential and give our lives meaning” (p.2). Becoming aware of unique learning styles and providing necessary opportunities of support are essential to the success of students with autism. Grandin (2007) stressed the difference in how she, as an individual with autism learns, as compared to a “normal” student, specifically, that she is a visual and associative learner. Grandin affirms, “Pictures are the autistic student’s way of thinking. What teachers can do is work with such thinking patterns and make adjustments that will bring out an autistic student’s strengths” (2007, p.29). Some students with autism learn more readily through numerical or verbal lists of facts. This information is quite useful and theoretically will lead to research affiliated with students’ access of the services as well as provide insight for instructors into the students’ individual needs, strengths, and learning styles.

Through the Open University of Israel, Heiman and Precel (2003) researched current support in place at the university level. Although this study did not focus on ASD specifically, research was done in order to measure academic successes and difficulties and the supports needed by students with learning disabilities (LD) as compared to their non-learning disabled (non-LD) peers. Typical difficulties faced included students lacking certain academic skills, students struggling with social aspects of higher education, and the accommodations and support students needed in order to address these issues. The researchers theorized that the two groups of students coped differently in order to achieve academic success in higher education. Methods utilized were of two different questionnaires/surveys examining qualitative information and quantitative data concerning difficulties and strategies to self-accommodate (and to seek
accommodations from staff). Results demonstrated that students with LD devised specific strategies (usually through more oral and visual means) to help them study and prepare academically in comparison to students without LD who preferred more written explanations. Students with LD had more difficult concentrating during exams and were anxious about time constraints, and they also had difficulty with transitions. Limitations to the study emerged in that all students with LD were considered as one homogenous group regardless of disability. The research study at Northern University focused solely on students with ASD without a comparison group of more traditional students.

Taylor (2005) performed a qualitative research approach involving three students with ASD attending a British university. Taylor (2005) provided significant suggestions for academic accommodations (for class-work and assessments), as well as for training and professional development of the staff. Taylor’s (2005) theoretical framework supported the theory that improvements or adjustments made by the faculty in higher education would better meet the needs of students with ASD. It is imperative that staff and mainstreamed students be aware of and appreciative of the fact that ASD is a disorder. With respect to adjustments to teaching delivery, significant information was gained from students within their “natural” college setting. This included the need for computer-based materials and alternative sources for students with ASD, possible monitoring by professors as to their attendance, and distance-learning materials. The researcher for the study at Northern University anticipated similar responses from the students with ASD during the interview process. Concerning adjustments to assessment practices, students’ needs included modifications to assessments or alternative assessments, separate room accommodations, and extended time. Regarding adjustments to “pastoral care”, it
was noted that assistance was needed in the students’ finding their way around campus, models/maps, and peer support/tutors were all sources that would be well utilized. These elements aided in contributing to the overall experience the students with ASD had in the higher education setting. The research study aligned well with the study at Northern University although the participant group was slightly larger.

Students with ASD generally need support as they struggle with various forms of communication, and these individuals often have difficulty with the more abstract language that would be considered appropriate or standard in a college level class. As Zager and Alpern (2010) affirm, “Understanding and using sarcasm, humor, and non-literal language as well as applying the appropriate social and cultural norms for initiating interactions, exchanging turns, and terminating interactions require a sophisticated level of symbolic behavior”, which would prove quite challenging for a student with ASD (p.152).

The educational initiative of Standards Based Reform (SBR) brought to the forefront the federal mandate of No Child Left Behind (NCLB) and students’ academic success or struggles, as in the case of many students with learning disabilities, such as those with ASD. SBR implores school districts to ensure that all students regardless of ability meet certain standards (expectations of skills) or competencies for their academic courses. Students are then required to demonstrate that they have met all standards through both formal and informal assessments. This often proves to be challenging and overwhelming for students with learning disabilities, as they consistently do not meet the required standards. These prevalent issues correlate well with the work of Simpson (2005) on students with ASD, “In summary, the SBR requirement of NCLB appears to restrict and impede identification of effective practices for students with ASD”
Ways in which to better support and accommodate these students in high school and in higher education are beginning to take shape and to affect student learning and outcomes. According to McDermott (2007), “Standards-based reformers aspire toward an educational system in which students’ educational opportunities and levels of educational attainment will not vary according to where they live, and achievement gaps between advantaged and disadvantaged groups will disappear” (p. 84). However, achievement gaps do exist, and even more so for students with ASD and other learning and intellectual disabilities. To what extent the gaps exist within higher education prompts the need for continued research.

**Self-Determination and Self-Advocacy**

Some of the more recent research done has focused on providing advice for professional staff working with students with ASD in higher education. There is a need for instructors, advisers, and general staff working with students with ASD to encourage and to promote self-advocacy among the students. The support available may be significantly different to that which the student was accustomed in the high school setting. Regardless, the impetus falls on the student to seek support needed. Graetz and Spampinato (2008) affirm the following, “For individuals with Asperger’s syndrome, the academic support such as increased time for test-taking and note-taking may be useful, but other support services, especially those within the societal/relationship domain, may not be addressed” (p.23). Relationship and social skills can be a struggle for most students with ASD, but these often can be supported through peer assistance and/or mentoring groups.
In the area of student self-advocacy, literature was explored to determine how and when students with ASD access needed services. Taylor (2005) and Camarena and Sargiani (2009) researched extensively the concept of self-advocacy for students with ASD or LD. From an early age and more significantly in secondary school, the student with ASD typically follows his or her parent or guardian’s lead in advocating for services and support. Parents generally model this behavior consistently and thoroughly in order to prepare the student with ASD to do this on one’s own in higher education. It is probable that some students with ASD are not accessing the services they need, or likely not to the extent that they should. This may be due to various reasons, such as the student not wanting to disclose information about his or her disability, or perhaps he or she is unable to access the services and support due to lack of communication from the institution. Research related to accessing services versus discontinuing studies was very limited in that there was relatively little information available at the time of the study this was delved into later in the literature review.

Students with ASD and LD often struggle due to long-held stereotypes or perceptions some people maintain on the subject of how they learn. Very often the student feels the stigma of having a disability, and he or she does not want to be perceived as different from his or her peers. Educating college faculty, staff, and community members, as well as supporting these students as they self-advocate for what they need is essential and an important step towards academic success. May and Stone (2010) carried out a study in which students both with and without learning disabilities were surveyed in order to identify their general perceptions about individuals with learning disabilities. The authors confirmed, “As a whole, the study’s findings provide implications for research on the link of stereotypes to self-advocacy and susceptibility to
detrimental effects of stereotypes, including stereotype threat” (May & Stone, 2010, p.490). The researchers’ study revealed that stereotypes about LD in general pervaded. Students needed to be encouraged to advocate for assistance and to be supported in their efforts by a knowledgeable and understanding educational community (by staff, peers, etc.). In this way, the cycle of seemingly negative perception of and stigma identified by students with learning disabilities would lessen in order for them to succeed academically.

Students with ASD in the study by Camarena and Sargiani (2009) demonstrated self-determination, a desire to pursue higher education and, due to significant awareness of their needs, knew that they must self-advocate as they anticipated future difficulties adjusting to a higher education setting. The researchers based their work on the theory that, with significant educational aspirations and support, students with ASD would be successful in higher education. In addition, they theorized that linking support with one’s social skills would positively affect the students’ academic success. Camarena and Sargiani (2009) conducted parallel semi-structured interviews (for both students and parents involved), with both qualitative and quantitative methods incorporated. During the interview process for the study at Northern University, questions posed in relation to both academic and social aspects sought information about the students’ perception of their overall experience.

Results of the Camarena and Sargiani (2009) study demonstrated that both adolescents and parents had significant post-secondary aspirations and goals but were concerned with “readiness” of the academic institution and the social challenges the student would face. The authors demonstrated significant results of the students’ self-awareness as well. Students with ASD and their parents viewed the following supports as necessary as they anticipated higher
education: academic accommodations and support (e.g., assistive technology), transition planning and orientation skills, and social skills support. The study was limited by the small nature of the sample (with limitations in gender and social-class representation due to voluntary participation) but results could be generalized to students with ASD in general. In addition, prior to the study, the nature of the students’ diagnosis in relation to the extent of ASD was not known. It is important to note that there was no comparison study of “typical adolescents” done at this time. Strengths of this type of study were due to the in-depth interview process, and the ability to triangulate responses via multiple familiar perspectives.

With respect to seeking accommodations and self-advocating, students with ASD consistently fear stigma concerning their disability, as noted previously. Denhart (2008) utilized a qualitative research paradigm of a phenomenological study in which the researcher was a participant in the study. The sample strategy was purposeful sampling/criterion-based and consisted of eleven college students diagnosed with LD. Denhart (2008) framed her work from the disability theory perspective, in that barriers to academic success are often caused by external sources rather than because of disability. Denhart (2008) affirmed, “Disability theory demonstrates how social intolerance of human variation creates disability” (p.493). She noted that disability is socially constructed and is a part of human variation; thus, disability requires the individual’s own voice to deconstruct it. Denhart’s results demonstrated the students’ overwhelming reluctance to ask for accommodations for fear of being labeled or stigmatized, as well as the feeling that students with LD had to do significant extra work to keep up with their classes. Results evidenced that students with LD gained confidence from voicing their issues and needs among their peers, and that an LD specialist/adviser is crucial for the students’ success.
The limitations to Denhart’s (2008) study included an inability to generalize the findings (to LD students as a group or to those with ASD) due to fact that the group was self-selected (8:3 females to males, lack of racial diversity). In addition, only students with valid LD documentation were allowed to participate. The study was credible in that similar findings were reflected in the work of different researchers investigating the experiences of students with LD in higher education. This work was researched by Greenbaum, Graham, and Scales (1995); Higgins (1992); and Reis and Neu (1994), as cited in Denhart (2008).

Also in support of the concept that learning disabilities are socially constructed was Dudley-Marling (2004) in stating, “The construction of LD, like any identity, depends on the complex interaction of people, places, and activities. Like other identities, the identity of LD is not only produced in a social context; it is itself part of the context that gives meaning to participants’ actions” (p.485). Within the setting of higher education, a student identified with ASD or LD will make meaning of his or her college experience, ideally seeking accommodations needed and thus succeeding academically with both academic and social support. The research study at Northern University sought to understand the experience of students with ASD by identifying the extent to which these students self-advocated, sought support, and made meaning of their college experience.

Anctil, Ishikawa and Scott (2008) performed a mixed methods study in order to question to what extent a student with LD’s level of self-determination and persistence (self-realization, competence) would enable him or her to have academic success at the university level. Anctil et al. (2008) based their work on a self-determination development framework, identifying the fact that self-determination was what ensured the success of students with LD. Surveys (two self-
determination scales) were administered and interviews were conducted in order to see if the LD students’ self-determination would predict success in transition from secondary school to higher education. Results demonstrated that, in the case of these students, persistence - in seeking the support needed - and hard work enabled one to develop competence, thus self-realization emerged.

Research by Hart, Grigal and Weir (2010) highlighted the importance of student initiative and self-advocacy in regard to receiving necessary accommodations. The authors reminded the reader that parents were not necessarily advocating for their children at this point, “Attendance at college offers a tremendous natural opportunity to practice and refine self-determination and self-advocacy skills” (Hart, Grigal & Weir, 2010, p.143). Students with ASD and or otherwise identified learning disabilities needed to take it upon themselves to ask for the services, accommodations, and support they required. The authors emphasized the following, “Once in college, students need to be supported to speak directly to their college professors to explain learning needs, advocate with disability support offices for needed accommodations, and speak to peers about their disability and how it might affect them” (2010, p.143). In addition, Roberts (2010) stressed the necessity of self-advocacy for students with ASD, “As these individuals enter post-secondary education, they will be required to disclose their disability to staff at the campus disability services office, provide documentation of their disabilities, and express their accommodation needs” (p.160). Adreon and Durocher (2007) confirmed, “Students must discuss their specific learning needs and necessary accommodations with the college to determine which services and supports can be provided in that setting” (p.274). The students with ASD involved in the research study at Northern University were students who had chosen to disclose their
disability to the Office of Disability Services, and they then voluntarily participated in the interview process and study.

Work by Webb, Miller, Pierce, Strawser, and Jones (2004) was appropriate for its focus on the importance of developing young people’s social skills/social competence, skills that would affect both academic success and social adjustment in higher education. If a student is comfortable and feels social acceptance, self-determination and self-advocacy will follow as the student seeks academic success as well as acceptance in the education setting. The researchers theorized that training and support would enable high-functioning students with ASD to gain necessary social skills that would in turn help them fare better academically in higher education. Methods in their study consisted of an intervention employed for a small group of individuals utilizing the SCORE Skills Strategy program (Vernon & Schumaker, 1993; Vernon, 2001, in Webb et al., 2004). The overall goal of the researchers was to test the efficacy of this program in helping the students with ASD gain social skills, thus affecting academic areas as well. Study began with phase I (training of teachers and assistants), phase II (baseline – sessions w/ pre-intervention assessments, games to assess comfort level), phase III (social skills instruction - some components included modeling, coaching, role plays, and games), and phase IV (post-intervention assessments). A multiple probe design was used to measure the students’ skills throughout (specific social skill areas included sharing of ideas, complimenting others, offering help and encouragement, recommending changes nicely, and exercising self-control). The importance of this work was the connection between self-advocacy and confidence a student with ASD or LD might feel to then enable him or her to achieve both academic and social
success. The results of the study were somewhat transferable to the setting of higher education and appropriate for the goals of this researcher.

Through the results, Webb et al. (2004) affirmed that high-functioning students with ASD were able to master the five social skills as instructed in the SCORE Skills Strategy; in addition, these skills could be mastered in a collaborative group environment. The study was limited due to the fact that it would be somewhat challenging to generalize these skills to a different setting or environment. Also, mastery of the assessed skills was not as clear or demonstrable to the parents of these young people. Limitations included the small number of students, a narrow geographic area, and the willingness of families to participate in an evening program.

Hart, Grigal and Weir (2010) stressed the importance of the college environment in preparing students with ASD for the social elements necessary as they transitioned into adulthood, “Being part of campus life, taking college classes with students without disabilities, and learning to navigate a world of high expectations leads to the development of skills needed for successful adult life” (p.134). In addition, advancing in education is becoming more of what is expected of students as they leave high school, and all students should be given this opportunity, if they choose it. College is an important “social” experience and a role in which most young adults want to engage, “Offering opportunities for students with ASD and LD to attend college, in typical ways and with their same-age peers, provides a powerfully positive social experience for those students” (Hart, Grigal, & Weir, 2010, p.136). Of importance as well is that which was noted by Graetz and Spaminato (2009), “For some students considering higher education, college may provide an environment in which they can explore interests without ridicule and experience personal growth” (p.21). With both academic and social support, a
student with ASD or LD can flourish Belch (2004) affirmed, “When a sense of belonging and inclusion are accomplished, a student believes there is a place for him or her” (p.9). For the research study at Northern University, a supportive environment in which a student with ASD feels as if he or she can seek accommodations without stigma, as well as feel comfortable to explore interests and to succeed, were themes that emerged as the students described their experience in higher education.

**Academic Success vs. Leaving Higher Education**

Although this study focused specifically on students with ASD, the literature review was expanded to include studies on students with different learning disabilities as well, and aspects of why students might choose to leave the university setting. Due to the fact that there was little research done on why a student with ASD might discontinue his or her studies, some insight was gained from general research in this area. Referring to his own work on retention within the university, Tinto (1982) noted the following in reference to why students (of all abilities) discontinued their studies, “As to the causes of leaving, evidence continues to mount that students’ decisions to withdraw are significantly affected by the degree of their intellectual and social integration into the life of the institution” (p.697). Although Tinto speaks in general terms of all students, there is much to be said for services and accommodations to support all student ability levels, and even more so those with ASD or LD. The research study at Northern University sought to understand whether or not students with ASD felt that assistance and support affected their experience and their persistence in their degree in higher education.

Although this was not an empirical study, much could be gained from the work being accomplished by the Disability Compliance for Higher Education (2006). This organization
distributes frequent newsletters (paper and electronic) and utilizes various outreach methods, stressing the need for life coaching for self-advocacy of individuals with ASD in order for these students to keep academic issues manageable. In addition, parents are strongly encouraged to take part in the advocacy process. The Disability Compliance for Higher Education (2006) bases its work on the theoretical framework that self-identifying and self-advocating will enhance the academic success of a student with ASD in higher education.

Heiman and Precel (2003) have conducted research on accessing support services in higher education by comparing students with learning disabilities to non-learning disabled students. The decision of whether or not to continue studies in higher education, to withdraw from studies temporarily, or to withdraw completely due to lack of academic success, must be addressed as well as its connection – if one exists – to academic support or lack thereof. Studies have begun in this area as researchers seek a connection between lack of academic support and students with learning disabilities leaving higher education. As stated by Wessel, Jones, Markle, and Westfall (2009), “Many colleges and universities have disability services offices to help facilitate access to higher education and the academic success of students with disabilities, reducing the number of students with disabilities that drop out of college” (p.116). The authors also cited the work of Belch (2004, in Wessel et al., 2009) in considering why students with LD were dropping out and if these students were not only utilizing disability services and accommodations to adapt academically, but socially to the campus life as well. Wessel et al. (2009) noted, “The same reasons for dropping out were provided by both students with and without disabilities (financial problems, personal problems, work); however, the students with disabilities said that stress of school, health, problem with medications, and weather conditions
also impacted their enrollment” (p.117). All of these factors should be taken into account when considering not only academic support for all students, but social and personal support as well, within the university community.

A study conducted by Hill (1994/1995) was unique and rare in that the researcher sought the views and feedback of students with learning disabilities at the time they were enrolled at the college level. This study involved surveying a number of students in several colleges and universities across Canada. Very few studies have been conducted from this perspective, and it is one that cannot be overlooked and further stresses the need for study. The work of Hill (1994/1995) emphasized the critical need for more research (as identified also by the focus of this doctoral work), focusing in on the voice of the students with ASD and LD and learning from their experiences. Recommendations gained from the study included that there be more formal guidelines and structure employed by disability services as to what assistance is provided, “Specifically, each university should develop policies that address the following: nondiscriminatory admission; physical access; modification of academic requirements; provisions of necessary services; provision of necessary equipment; and training of staff” (Hill, 1994/1995, p.18).

In addition, a survey of students with LD conducted by Hill (1996) focused on two key areas of services stemming from the Office of Students with Disabilities (referred to as the OSD in the Canadian universities studied). These areas included what services were available to the students and whether or not faculty and staff were providing necessary accommodations and support. A significant number of students surveyed (twenty-one percent) felt that either a negative perception/stigma towards seeking assistance, or their own lack of knowledge of what
was available to them (through the OSD) did indeed affect their degree program (course or program withdrawal). It should be noted that program or course withdrawal occurred regardless of whether or not services were provided. With universities’ conscious and focused efforts in fully staffing the disability service or academic skills office, as well as communicating thoroughly what is available to all students, better accessibility can be made for those students in need, thus encouraging students to continue their degrees in the future. Veenstra (2009) further emphasizes what must come from the university with respect to student retention, “This includes providing a culture that is student-focused and offering services supportive to the needs of each student. The quality of the student support services can encourage and influence the student’s decision for continuing in the college or university” (p.19). Ascertaining the quality and extent of services available at Northern University and to what extent they affected the students’ persistence in obtaining a degree was a primary goal of the research study.

The literature review was by no means extensive considering the field and, as more students with ASD reach the university level, future studies will need to be done in order to support the academic success of all students. Common themes that resounded in the literature review included suggestions for more thorough professional development training for faculty specific to the unique needs of students with ASD and other learning disabilities, as well as identification of lack of professional preparation (in order to then ensure faculty have a better awareness of students with ASD and how they learn). Through the literature review, some strategies and techniques were gleaned for both staff providing accommodations for students, as well as for students with ASD, to self-advocate for what they need. Research related to student retention in general (not specific to students with ASD or LD) yielded insight into students
discontinuing studies or persevering and continuing their studies yet is limited by little research available.
Chapter Three

Research Design

Research Questions

The research sought to understand the experience of students with autism spectrum disorders in higher education. Whether or not students with ASD were advocating for assistance and seeking the help provided was a key element of the research for this particular study. Both disability theory and achievement ideology provided the lenses through which one could understand the behavior. The study focused on the ways in which students with ASD were supported in their academic efforts. Students were encouraged to self-advocate in their efforts to achieve academic success. In addition, elements of the study were connected to the work of theorist Vygotsky in relation to the importance of one’s surrounding culture and environment. For the study, the surrounding environment was that of the higher education institution in which the individual students were learning, developing and socializing. Students with disabilities found themselves self-advocating, seeking needed accommodations, and overcoming stigma often associated with disability. Available programming and support provided by the university, the students’ perception of what was available, and whether or not these students were seeking the support were key elements contributing to their experience in higher education. The following questions were essential to the study concerning students with autism spectrum disorders attending institutions of higher education.

1. What is the experience of students with autism spectrum disorders attending an institution of higher education?
a. What is their experience as it relates to available support systems at Northern University?

b. How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?

Methodology

For the research, a qualitative design was implemented. According to Creswell (2009), “Qualitative research is a means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem. The process of research involves emerging questions and procedures, data typically collected in the participant’s setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data” (p.4). Qualitative strategies and methods were utilized through implementation of a phenomenological study involving a small group of students.

The choice of a phenomenological study enabled this study to gain deeper insight into students with ASD in higher education. Qualitative research is consistently exploratory and revelatory, delving into fields in which little study has been done, such as that of students with ASD in higher education. Creswell (2009) affirms, “Phenomenological research is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants” (p. 13). Lester (1999) cited the work of Husserl (1970) in stating, “Pure phenomenological research seeks essentially to describe rather than to explain, and to start from a perspective free from hypotheses or preconceptions” (p.1). Phenomenological research
was appropriate for this study in that the researcher was able to examine and describe the shared experience or phenomenon of the participants. Smith, Flowers, and Larkin (2009) also cite the general work of Husserl in noting, “He was particularly interested in finding a means by which someone might come to accurately know their own experience of a given phenomenon, and would do so in depth and rigour which might allow them to identify the essential qualities of that experience” (p.12). For the research study at Northern University, the goal of the researcher was for the participants, students with ASD, to understand and to share their experience in higher education in such a way that the researcher would then be able to understand and to relay their unique experience through description and analysis.

Elements of interpretative phenomenological analysis (IPA) were incorporated in the phenomenological study. According to Smith, Flowers, and Larkin (2009), “IPA is a qualitative research approach committed to the examination of how people make sense of their major life experience. IPA is phenomenological in that it is concerned with exploring experience in its own terms” (p.1). In a phenomenological study, the participants’ experiences and the way in which they relay them will be open to self-interpretation, as well as to interpretation by the researcher. Smith et al. (2009) affirmed, “In IPA research, our attempts to understand other people’s relationship to the world are necessarily interpretative, and will focus upon their attempts to make meanings out of their activities and to the things happening to them” (p.21).

The study of hermeneutics is a theory somewhat overlapping phenomenological study and is in effect when researchers interpret and make meaning from an experience. Moustakas (1994) described hermeneutics as the way in which individuals interpret and gain meaning from an experience, either from one of their own or that of someone else. Every effort was taken to
best interpret the experience of students with ASD at the study site, Northern University. Through interpretive phenomenological analysis, Smith, Flowers, and Larkin (2009) clarify the fact that the researcher identifies “…an interpretation of the meaning for a particular person in a particular context” (p.194). Phenomenological study enabled the researcher to interpret and to describe the meaning for several individuals of their lived experiences of a phenomenon, specific to this study, the experience of individuals with ASD attending an institution of higher education. Clarified in the work of Smith, Flowers, and Larkin (2009), “Meaning-making clearly takes place using certain kinds of resources (narrative, discourse, metaphor, etc.), and with certain sorts of contexts (interactions, such as interviews), and settings” (p.194). For this study, of the experience of students with ASD in higher education, extensive narrative was written, created from the interaction and interviews with the study participants. This enabled deep meaning of the students’ experience to emerge from the phenomenological study.

Site and Participants

The research site was an accredited four-year university in New Hampshire. The anticipated participant group would be a small sample of students (approximately 5-7) enrolled either full-time or part-time in the university, ranging in age from 18-26 years. Each student had voluntarily registered with and sought assistance from the Office of Disability Services at the university. Prior to the study, the individual disability services specialists approached the students privately. The specialists then introduced the students to the project in order to ascertain their interest level for participation in the study. Students could have been either male or female and of any race, nationality and class. These students received an introductory explanation from
the researcher in which the study and its time commitment were outlined. Students were not obligated to participate in the study as it was entirely voluntary.

Students that expressed interest in pursuing the study had read and were asked to sign a thorough Informed Consent Form provided by the researcher. The Informed Consent Form (Appendix B) explained in detail why the student had been chosen for the study and what the study entailed. The students involved were being asked to participate because they had identified themselves as individuals with autism spectrum disorders, and they had sought accommodations and services from the Office of Disability Services. The primary goal of this study was to see how students with autism spectrum disorders were achieving academic success and how they perceived and described what they were experiencing in higher education.

Data Collection

Data collection consisted of the qualitative method of in-depth interviews with participants taking part in two informal one-on-one sessions. The interviews were conducted by the researcher and took place in the Office of Disability Services as well as in a different, more centrally located academic building on campus. An informal interview (of approximately 45 minutes) took place at the beginning of the semester/term. This interview occurred at a mutually convenient time for the participant and the researcher. The researcher used a set list of approximately 25 questions, a list that was modified throughout the session depending on the individual participant and the informal nature of the interview. Each interview began with the researcher ensuring the comfort level of the participant, by asking informal questions about the student and how he was feeling. The full list of interview questions is included in the Appendix.
section (Appendix C) of this work. The interview began with more basic questions asking the student about his interests and hobbies in order to make him feel comfortable. The questions then progressed to areas that delved into academics, accommodations, and support concerning the students’ needs. The researcher relayed to the participant that there were no correct or incorrect answers, and that the student should share only that which he was comfortable. If at any point the student did not want to continue the interview, the researcher would have respected his decision. The interview could then have been continued at a later time at the discretion of the participant. If the participant were to have chosen to discontinue the interview process, the interviewer would have respected the decision.

The researcher generated the interview questions, and they were formulated in consideration of students with ASD or LD within higher education. Prior to the study, the questions to be utilized in the interviews were reviewed by the Assistant Director of Disability Services in order to ensure their appropriateness. Questions included inquiry into personal interests, hobbies, and career aspirations. Questions then became more specific in relation to academic coursework, accommodations and support sought. Some of these questions were modified and adapted from previous work done by Hetherington, Durant-Jones, Johnson, Nolan, Smith, Taylor-Brown, and Tuttle (2010), as well as by Palmer (2006). Particular areas of interest for the interviews were divided into categories with a sample question noted in Table 3.1. For a full list of all possible interview questions, refer to Appendix C.
### Table 3.1 Categories with Sample Questions

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<th>Category/Theme Questions</th>
<th>Sample of Question(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warm-up questions</td>
<td><em>What activities do you enjoy outside of Northern University?</em></td>
</tr>
<tr>
<td>Academic and career aspirations</td>
<td><em>What job/career would you like to do in the future?</em></td>
</tr>
<tr>
<td>Self-awareness</td>
<td><em>Do you know of your weaknesses/areas in which you know you need assistance?</em></td>
</tr>
<tr>
<td>Accommodations/seeking the Office of Disability Services</td>
<td><em>What services does the Office of Disability Services provide that you know about?</em></td>
</tr>
<tr>
<td>Accommodations by professors/classmates</td>
<td><em>What specific ways have professors helped you in class (e.g. extended time on tests or assignments, recorded or scripted lectures, etc.)? What can your friends or family do to help you meet your academic goals?</em></td>
</tr>
<tr>
<td>Self-advocacy</td>
<td><em>Are you comfortable asking for assistance/accommodations from your professors? Please explain.</em></td>
</tr>
</tbody>
</table>

The in-depth interviews included supplementary questions seeking deeper understanding of the students’ experience. During most of the interviews, some open-ended questions were posed as well, depending on how students were responding to the initial questions and based on students’ unique interests. Questions of this nature included a variety of topics as deemed appropriate to the conversation and the students’ previous answers. Some examples included the following:
• Discussing distractions: *Does it help you stay more organized if you are living at home?*
• Reviewing study skills: *How do you approach studying for an exam?*
• Discussing a job search: *How would you tell me that you’re the right candidate for the job/networking?*
• Managing a stressful amount of work: *Let’s look at this on a smaller scale - is it because we are nearing the end of the term?*

More open-ended questions like these tended to reveal even deeper understanding of the students’ experience.

<table>
<thead>
<tr>
<th>Interview Question</th>
<th>Possible Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>What activities do you enjoy outside of Northern University?</em></td>
<td>Hobbies, clubs, volunteer work, work, friends...?</td>
</tr>
<tr>
<td><em>What job/career would you like to do in the future?</em></td>
<td>Academic interests, career, passions, major/minor, favorite class...?</td>
</tr>
<tr>
<td><em>Do you know of your weaknesses/areas in which you know you need assistance?</em></td>
<td>Subjects, classes, interests, comfort level...?</td>
</tr>
<tr>
<td><em>What services does the Office of Disability Services provide that you know about?</em></td>
<td>Accommodations, support, meeting with disability services specialists...?</td>
</tr>
<tr>
<td><em>What specific ways have professors helped you in class (e.g. extended time on tests or assignments, recorded or scripted)</em></td>
<td>Extended time (tests, assignments, recorded or scripted lectures, least distractive environment, alternative assessment, extra-</td>
</tr>
<tr>
<td>lectures, etc.)</td>
<td>help?</td>
</tr>
<tr>
<td>----------------</td>
<td>-------</td>
</tr>
<tr>
<td><em>What can your friends or family do to help you meet your academic goals?</em></td>
<td>Comfort level, in or outside of class, group work, study groups…?</td>
</tr>
<tr>
<td><em>Are you comfortable asking for assistance or accommodations from your professors?</em></td>
<td>Outside of class help, ask questions, hesitancy, self-advocacy…?</td>
</tr>
</tbody>
</table>

*Table 3.2 Additional Prompts Used with Interview Questions*

During the interview process, the researcher took extensive notes, and each interview session was digitally recorded in order to ensure proper transcription of students’ responses. This process and its necessity were carefully and thoughtfully explained to the students at the onset of the interview. The researcher also created field notes from memory and utilized the practice of “memoing” in writing down personal observations and reflections. Field notes and memoing occurred during and immediately following each interview in order to capture accurate notes. A second informal interview (approximately 45 minutes) took place somewhat later on in the term. The researcher then conducted the second interview with the individual participants. This time, however, a more centrally located academic building was chosen in respect of each participant’s personal schedule and class location. The researcher used the original interview questions a second time (with slight modifications depending on each student). By repeating questions, the researcher intended to maintain structure and consistency to the interviews, as well as to provide a repeated measure for comparison. The researcher made certain to ensure the comfort level of the student prior to and throughout the interview process. The participants had the right to decide...
if they wanted to stop and to continue the interview at a later date or to discontinue the process altogether.

Participants were encouraged to maintain an informal journal of their academic and social progress/success, and/or of thoughts, questions, and concerns as they progressed through the semester. Students were asked about their interest in maintaining an informal journal upon receiving the Informed Consent Form at the beginning of the study. This was a voluntary piece of the study, and it served as a means for the researcher to gain further insight into the participants’ college experience. At the mid-point of the semester, the journals (in electronic form) were collected from the students that chose to contribute their reflections. It was hoped that, in having students reflect via a personal journal, they would be motivated by the work of the research project and their own success. In addition, students would then have the opportunity to express concerns and likely would be more self-aware as to their academics and the support needed. It was important to ascertain which, if any, support systems students were utilizing to help them succeed academically. Journal contributions were optional, however, as some students may not have felt comfortable with this aspect of the study.

Data collection also included some general information gained from a meeting with both the Director and the Assistant Director of the Office of Disability Services at Northern University in order to gather information about services and accommodations available for students with ASD and or other disability. Time spent with staff from the Office of Disability Services was minimal and was not considered to be that of an interview. Clarification of this point was deemed necessary, as the focus of the study was the experience of the students themselves and not of how the Office of Disability Services perceived this experience. In
addition, the researcher shared her reflections based on her extensive experience as researcher as well as participant in the interview and research process. Data collection also included personal reflections, to the extent they were provided, by the self-disclosure of the student participants.

The concept of constructivism played an important role in this naturalistic qualitative study and added to the data collection and analysis. According to Golafshani (2003), “An open-ended perspective in constructivism adheres with the notion of data triangulation by allowing participants in a research study to assist the researcher in the research question as well as with the data collection. Engaging multiple methods, such as, observation, interviews and recordings, will lead to more valid, reliable and diverse construction of realities” (p.604). The participants enabled the researcher to go beyond the questions posed in the interviews and all of their contributions added to the depth of data collection gained. The technique of observation (e.g. observing the participants in the classroom setting) was initially considered by the researcher in order to enhance findings, as well as to provide triangulation to the data collection. However, it was suggested by the Office of Disability Services that in-class observations might have created anxiety for the research participants, to which the researcher readily agreed. More subtle observation and reflection took place during the interview process itself in order to enhance the overall findings.

Data collection consisted of consolidation of the information gleaned from both sets of interviews involving the participants. In addition, useful information was gained from the participants’ informal journals, and it was examined along with information/resources initially collected when the researcher met with staff of the Office of Disability Services. During the interview process, the researcher took copious notes and utilized a digital recorder for the
interviews. Various notes from memory were created to supplement the interview notes.

Procedural notes as well as personal reflections/memos were maintained throughout the study.

Transcripts were made from the digitally recorded interviews. The data/text was reviewed beginning with several careful readings of the notes taken during the interviews as well as reading of the digital transcriptions as a matter of initial exploration. After a more extensive review of the materials, the information was divided into labeled segments of related topical themes, which in turn were coded.

<table>
<thead>
<tr>
<th>Sources of Data</th>
<th>Study Sources</th>
<th>Possible Advantages of Source</th>
<th>Possible Limitations of Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td>1st interviews w/ student participants 2nd interviews w/ student participants</td>
<td>First-hand knowledge from the participants in their own words, their voice. Observations can be made by the researcher of the participants (gestures, behavior, etc.).</td>
<td>Possible hesitancy on part of participants to not share all.</td>
</tr>
<tr>
<td>Written documents</td>
<td>Journal contributions</td>
<td>Participants may share more through written word than perhaps in an interview.</td>
<td>Not all participants chose to contribute to the journal entries.</td>
</tr>
<tr>
<td>Audio-visual materials</td>
<td>Notes from Disability Awareness panels</td>
<td>Diverse perspectives in to study (seeing student participants in a different venue).</td>
<td>Not all participants were part of the panels.</td>
</tr>
<tr>
<td>Presentations</td>
<td>Office of Disability Services Presentation Brief meeting with Disability Services</td>
<td>Information provided about services and accommodations.</td>
<td>Factual information only.</td>
</tr>
</tbody>
</table>
Table 3.3 Data Collection Sources - table format adapted from Creswell (2009)

Data Analysis

Qualitative research was deemed appropriate for this study, with the researcher able to delve into the somewhat unknown field of students with ASD in higher education. Qualitative data analysis was conducted in order to reveal deeper meaning into students with ASD and their experience in higher education. As denoted by Creswell in Figure 3.1, the process of qualitative data analysis may be illuminated in the following way (2009, p.185).

Figure 3.1 Creswell Data Analyses in Qualitative Research
A useful method suggested by Creswell (2009) prompted the researcher to code the text in two ways: codes were utilized for the description of the research, and codes were employed for themes or essential categories that emerged for analysis. The descriptive coding included general information about the participants and the research site. The thematic coding focused on autism spectrum disorders in relation to accommodations and support (or lack thereof) as well as on the students’ perspective of their overall experience in higher education revealed during the study.

On the subject of coding itself, lean coding (Creswell, 2009) was employed in order to focus on the most essential themes that emerged. The data was reviewed again to streamline the coding process and to avoid redundancy in codes. The codes were then reduced to primary themes for analysis of the study. An organizational chart was utilized in order to align and correlate the coded material (descriptive or thematic), and several copies of the data were maintained in order to ensure their security and authenticity. Data was organized in a visual way through utilization of tables and graphic organizers in order to represent the themes revealed and the way in which they interconnected. Initially, the researcher had considered utilizing a comparison table as well, that is if the second set of interviews had differed significantly from the first set involving the participants, but this was unnecessary.

In order to analyze the data, the researcher focused on the primary themes that emerged from the interviews and the journal text, for both the description of the study as well as the study’s utility. For description of the research, the one code identified included general information about the participants and the research site. For the research study specific to students with ASD in higher education, codes in relation to the support provided included
“accommodations”, “self-advocacy and willingness to ask for help”, “support from instructors”, “academic strengths”, “positive group work/friends” among varied significant themes/essential categories based on student responses. Key words and phrases for prominent themes included, extended time on assessments and assignments, peer or tutor support, assistive technology including recorded lectures, notes/class lectures on Blackboard (electronic media), and extra help from the instructor. Themes that emerged from the students’ optional, informal journals were coded comparable to that of the sets of interviews. Specific cues and wording appropriate for the prominent themes were used to organize the responses/data. The data was prepared for analysis and MAX QDA software was employed for analysis in addition to analysis “by hand”.

Data analysis consisted of deconstructing what was found, responses to student questions were categorized (as noted earlier based on themes), and findings and conclusions that emerged were summarized. Every effort was made to employ various perspectives for each of the primary themes. The researcher included reflections about the meaning of the findings, as it would have been difficult to remain neutral in a qualitative study such as this. Detail was provided in order to emphasize pertinent student responses. When appropriate, direct quotes were utilized to supplement the work and students’ anonymity was assured as all participants were identified with a random letter. The researcher then made pertinent connections to the existing literature previously reviewed in the study. The researcher’s personal viewpoints emerged in an effort to not only bring forth what the current literature revealed, but also to make comparisons to the work. Suggestions and recommendations were made for future work with students with ASD in higher education based on that which was revealed in the study.
Validity and Reliability

According to Golafshani (2003), “Reliability and validity are conceptualized as trustworthiness, rigor and quality in a qualitative paradigm” (p.604). Distinct from the quantitative paradigm, the terms reliability and validity are generally referred to in a qualitative study as credibility and trustworthiness of the study (Golafshani, 2003). The words transferability and generalizability are also brought forth when discussing the qualitative research study. Reliability and validity in a sense are interrelated and virtually intertwined in qualitative research.

The credibility of the research study was based on the researcher’s work in relaying clear information gleaned from the participants. The small group of student participants was interviewed on two separate occasions with implementation of the same (or similar) questions during both informal interviews. Over the course of the interviews, there were slight variations to the second set of questions based on the informal interview setting and the individual participant. In general terms, each student could be considered unique in his or her learning style and abilities. However, the accommodations and support services that were utilized with success by some students with ASD were reasonably similar accommodations and services that other students with ASD would utilize as well. It is probable, too, that that which was gained from the study – describing the participants’ experience in higher education - would be similar to what other students with ASD might experience. In this way, the study would be considered a reliable one in that the applicability or transferability, as noted by Golafshani (2003), of results would probably be replicated in a similar study as well as useful for all students in the future.

On the subject of credibility, the researcher was concerned with whether or not the
qualitative methods of the phenomenological study employed would yield answers and provide insight into students with ASD and their academic success in higher education. In the true sense of credibility, the study was believable or credible. For the literature review, credible sources of refereed journals were explored. With respect to this qualitative study, the credibility was found in the researcher herself, “Thus it seems when quantitative researchers speak of research validity and reliability, they are usually referring to the research that is credible while the credibility of a qualitative research depends on the ability and effort of the researcher” (Golafshani, 2003, p.600). The ability and the effort of the researcher for this study were understood to be credible.

The study was valid based on the fact that the research questions posed (as to the accommodations and support the participants sought, whether or not the support and services were accessible to these students, and whether or not the students were self-advocating) elicited student responses, which were indicators of validity for this research. Although no tests or measures were administered as in a quantitative study, the validity here employed the terms of generalizability – noted by Locke, Silverman and Spirduso (2010) and Golafshani (2003) - as results that could be generalized - and transferability, based on whether or not information revealed would benefit students with autism spectrum disorders in the future. With emerging themes from the data collection, analysis revealed that the study proved to be valid as well as credible.

Limitations to the study must be noted, and they included the initial way in which students were selected for the study. Within the setting of higher education – specifically to this study - students chose to disclose whether or not they required support from the Office of Disability Services. In turn, students that did so were then asked whether or not they wanted to
participate in the research study. There were limitations due to the fact that not all students with autism spectrum disorders revealed that they were in need of assistance. So too, not all students that had disclosed their ASD would have chosen to participate in such a study. Thus the small population for this particular case study was a voluntary group, a homogenous, purposive sample, in that it included those students with ASD who chose to disclose their disability, to seek assistance, and to willingly participate in the study.

The role of the researcher included that of observer, data collector, and as participant, to the extent that this was possible in the interview situation. Throughout the interview and research process, the researcher attempted to maintain a neutral role in relationship to the participants. The researcher’s beliefs and biases inevitably had a slight influence on the data collection as it would be difficult to avoid this in a qualitative study. The researcher’s beliefs played an important role in how the study progressed, and how the researcher interpreted and analyzed the results throughout. A personal connection – that the researcher has a young nephew with ASD – may have contributed to her bias and work throughout the study.

**Protection of Human Subjects**

In order to protect the human subjects involved in the research study, the proper precautions necessary were taken to protect the students’ privacy. The researcher has completed the “Protecting Human Research Participants” training through the National Institutes of Health (NIH) Office of Extramural Research (Appendix A). The researcher filed an application with both Institutional Review Boards; initially at the university where the study took place, Northern University, as well as through Northeastern University (Appendix D). The risks of this research project were minimal, due to the fact that some students may have had a negative reaction to
being interviewed. The researcher took every necessary precaution to ensure the confidentiality of the participants, and she ensured that the participants were comfortable and were fully aware of the steps and process of the study. Interviews were conducted entirely in private at the comfort level of the student. If students were not comfortable answering any particular question, they did not have to answer. If an interview needed to be rescheduled at a student’s request, this was done quickly. There were no immediate, direct benefits for participation by the students. However, the information learned from this study would be of benefit to future students with ASD in higher education. In addition, information learned would then help professional staff working with students with ASD in the future.

The students’ identity as participants was matched to their responses, but only the researcher for this study was able to see the information. The written summary of this research study would not reveal a participant’s name or identity. The results of the study have been kept completely confidential. No reports or publications used information that could identify the students in any way. In order to protect students’ personal information, each participant was identified by a letter code as information was summarized. Themes that emerged from the interviews (e.g. ways in which the students sought assistance from instructors) were coded/identified for review and analysis. In order to ensure that the responses were accurately and clearly understood, the interviews were digitally recorded. Audiotapes were not identified with a name but were labeled with a letter code. For a study such as this, authorized people may request to see research information about the students in this study in order to ensure that the research was done properly. Permission was granted to individuals authorized by Northeastern
University (through which the researcher was working), or to the Office of Disability Services at
the research site, Northern University, to see this information.

Considering the ethical principles of Mertens (2006) of beneficence, respect and justice, a
researcher must work carefully and considerately to adhere to these principles, regardless of
subject. For this particular case study of students with ASD, ethical challenges might have to do
with the researcher’s sensitivity to the comfort level and respect given to the participants.
Because this particular research problem was a sensitive one, the words of Creswell (2009) were
deemed appropriate, “A core idea of action/participatory research is that the inquirer will not
further marginalize or disempower the study participants” (p.88). The researcher was quite
cognizant of the fact that her role could easily affect what might have been considered an ethical
challenge. Throughout the studies, it was essential to ensure that there was meaningful and
appropriate purpose to the study, that the participants were respected, and that there were
benefits to the research. Participants in this research played an active role in the work and they
had previously given voluntary informed consent in order to do so. Moreover, they were able to
trust in a competent and caring researcher, and were aware that they, as participants, were
involved in work from which future students with ASD and LD would benefit. Similar issues of
which to be concerned included non-biased language and anonymity for the participants in the
data collection and analysis.

Summary

To summarize the key points in Chapter 3 of this work, the researcher stressed the
importance of employing qualitative methods and analysis through the use of a
phenomenological study in order to understand the experience of students with ASD in higher education. Data collection consisted of consolidation of in-depth interviews involving the participants, journal entries, as well as data sources noted earlier. Through extensive transcription and coding (utilizing MAX QDA software and analysis by hand), essential themes emerged about the students’ academic and social experiences. Whether or not students with ASD were self-advocating for assistance and seeking the help provided was a key element of the research for this particular study. The researcher sought to best interpret and describe the students’ experience in higher education. The study was considered both credible and reliable - the researcher worked with great effort to relay clear information gleaned from the participants - and the data gained will inform future study in this area. The significance of this study cannot be underestimated in that the research opened both “academic” and “social” doors within higher education to students with ASD. This was achieved by gaining greater insight into that which current students with ASD perceive and experience.
Chapter Four

Summary of Findings

This phenomenological study was conducted in order to better understand the experience of students with autism spectrum disorders in higher education. A phenomenological study was chosen in order to gain understanding into the experience of students with ASD in terms of academic success within the college setting. A small group of students at Northern University participated in the interview process in order to share their perspective and experiences with the researcher. The students seemed eager to participate in the study, which provided the researcher with a deeper understanding of their experience. Understandably, each student within the university setting is unique, with each having his or her own experience of higher education. However, in understanding the experience of this particular group, one can gain much about understanding what similar students with ASD would also experience in higher education. Students with ASD seemed to be utilizing specific resources and accommodations provided through the Office of Disability Services, and they were able to achieve academic success in different academic areas.

Research Questions

In this chapter, data collection results were reviewed for the study of students with ASD in higher education. The following questions guided this qualitative phenomenological study.
1. What is the experience of students with autism spectrum disorders attending an institution of higher education?

   a. What is their experience as it relates to available support systems at Northern University?

   b. How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?

Data Collection and Results

As the academic year began, students registered with the Office of Disability Services if they were interested in seeking accommodations and support for their particular disability. For this study, students diagnosed with ASD were approached by their disability services specialists and were introduced to the study. After the introduction, the specialists then presented the student with the researcher’s introductory letter explaining the parameters of the study (Appendix D). Once the student expressed interest in the study, the individual disability services specialist relayed the student’s contact information to the researcher. One participant was invited by an academic instructor to volunteer for the study, as opposed to being informed by his services specialist. This was unusual in that the instructor knew of the research study and, due to the fact that the student was very open about his ASD, felt compelled to ask the student if he would like to participate. The researcher was aware of this contact and was appreciative of the participant’s interest and willingness to contribute thoughts about his experience at the university. The researcher followed strict protocol in that the study was thoroughly explained to the student who also read and signed the Informed Consent Form. In addition, the student was
not regularly meeting with his services specialist (to have the study parameters initially relayed through the Office of Disability Services), but he expressed interest in participating in the study. The researcher conducted initial interviews with the student participants at the beginning of the fall term (late September, 2011). Initial interviews took place in rooms provided by the Office of Disability Services, and the appointment times were based on the participants’ academic schedules.

The study took place during the fall semester of 2011 with six total student participants. All student participants were interviewed at the beginning of the term based on their academic schedules. Four of these students, in turn, were interviewed a second time towards the end of the term, November of 2011. Participants understood the details of the study, and they read and signed the Informed Consent Form for the study. Students were randomly assigned letters of the alphabet in order to identify the data without using the participants’ names, and participants were referred to as students U, A, L, I, J. The fifth student (Student A) had scheduling conflicts and a significant course-load, thus opted out of the second set of interviews. The second interviews took place in a different academic building more centrally located on campus. A sixth student (Student M) began the study late and participated in one, longer interview in late October of 2011. The student participants were male, ranging in age from 18-26 years old, and represented each academic level - freshman through senior - at the university. The participants’ grade point average (GPA) ranged from 2.0-3.94 (on a 4.0 scale) although this information was not gained until after the interview and journal data were collected. The participants were domestic, full-time students, and they were commuting to the university from various distances. Two of the students had lived in the dormitories on campus at one or more points during their academic
career thus far, and one other student participant was planning to live on campus the following year.

<table>
<thead>
<tr>
<th>Participant Total</th>
<th>Male/Female</th>
<th>Age</th>
<th>University Year</th>
<th>GPA (4.0 scale)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 students at Northern University</td>
<td>6 male, 0 female</td>
<td>18-26 years</td>
<td>1 freshman, 2 sophomores, 2 juniors, 1 senior</td>
<td>2.0-3.0</td>
</tr>
</tbody>
</table>

Table 4.1 Demographics of the Study Participants

For the data collection, the first (and only) set of interview notes for both Students A and M were used once in the data review, whereas each of the other participants had two sets of interview notes as part of the data. The interview with Student A was included in the collective data of the first interviews. The interview with Student M was included in the collective data of the second interviews. Interviews were informal, ranged from 30-45 minutes per session, and were digitally recorded for accuracy. The data collected included interview notes (both hand-written and transcribed from digitally-recorded sessions), procedural notes, and personal reflections, from both the researcher (through memos) and the participants (through informal journal entries). Four of the student participants chose to contribute electronic journal entries to the study. As mentioned earlier, all notes and recordings from the interviews were kept strictly anonymous and private. The written summary of this research study will not reveal a participant’s name or identity, and the results of the study were kept completely confidential. All digital recordings for the study were to be destroyed following transcription and analysis. Data collected included information gleaned from an initial meeting with the Office of Disability
Services (with the Director and Assistant Director) to ascertain what was provided through their office. In addition, the researcher attended a presentation given by the Director of the Office of Disability Services to the School of Education on campus. The extensive services and accommodations provided by the Office of Disability Services were detailed in the earlier literature review for the study.

**Interview Techniques**

Interview techniques included a familiar, comfortable format as the interviewer consistently began with a welcome and warm-up questions to make the student comfortable as well as to get to know each participant a bit better. Students arrived at a pre-determined location, which had been agreed upon by the researcher and the participant. All of the participants were punctual and seemed reasonably comfortable with the process. The interview environment of a quiet, private, office seemed to support the process as well as to provide comfort level for the students. The interviews, as clarified earlier, were digitally recorded, yet this did not seem to affect the comfort level of the students in any way. Once the interviews began, questions moved from very basic to somewhat more complex in their concern of academic matters, sources of accommodation, student self-advocacy, and other topics. Specific interview questions employed were shared in Chapter 3 of this work, with a complete list in Appendix C of the study. The researcher generally followed the pre-determined and pre-approved questions for the interviews, yet variation was utilized as appropriate, and some questions posed led to deviation into related topics of interest. The researcher followed a pattern akin to that which Smith, Flowers, and Larkin (2009) describe as the rhythm of the interaction of an interview, “At the beginning of the
interview, there will be condensed meanings, narratives, and understandings. As the interview progresses, and the participant warms to the exercise and relaxes into it, there is likely to be a move from the descriptive to the affective, from the general to the specific, from the superficial to the disclosing” (p. 68). Moving into more disclosing or somewhat more probing questions enabled the researcher to go more deeply into what the participants were saying in order to gain even more depth into their experience.

The researcher continually checked with the participants to ensure their comfort level throughout the interview. Participants seemed comfortable, safe, and were enjoying the process, and the researcher did not detect any discomfort or nervousness on the participants’ part. The students understood the questions posed, but at times did not have an answer to a question. This was possibly due to the fact that some of the questions were a bit repetitive, or that the student had previously answered the question connected to an earlier one. Students generally contributed extra information, or simply responded in the same manner to that which they had responded earlier. This particular element was even more prevalent in the second set of interviews, as the students became even more comfortable talking about themselves, their interests, etc. In addition, the second set of interviews seemed to have a more natural flow to them as far as comfort level between the researcher and the participants. Throughout the interviews, open-ended questions were posed as appropriate as necessitated by the students’ responses. Some of the students were more readily responsive and a smaller number needed a bit more clarification or re-wording of a particular question posed. The researcher was able to gain a significant amount of insight into how these students experience the academic and social challenges posed by their disability.
Coding

After transcription of the data was complete, all interview and journal notes were uploaded to MAX QDA software for analysis in order to ascertain which themes were most prevalent. Notes gleaned from several Disability Services panel discussions (provided through the Office of Disability Services) were coded as well. These “panels” were informal discussions in which several students shared with the community information about their unique disabilities, and their experience at the university. Two of the students participating in this study had previously taken part in one or more of the Disability Awareness panel discussions and they agreed to share the data. The panels served as an added forum from which information about ASD and the students themselves could be gleaned and used in the data collection. Data analysis consisted of deconstructing the information gained. Responses to all interview questions and notes were categorized - based on essential categories - and findings and conclusions emerged for summary. In addition, the researcher employed the technique of “memoing” – a common technique in phenomenological studies - during the interview process. Memos consisted of the researcher’s personal reflections and observations, which then added to the themes and sub-categories that emerged. Descriptive coding, which includes general information about the participants and the research site, was employed. Instances of descriptive codes were noted primarily in the introduction or beginning portion of the first interviews. The general descriptive code identified was Description of research, and it was utilized to code moments in which students acknowledged or asked a question about the study or its expectations. There were twelve instances of this descriptive code.
As appropriate for this phenomenological study, analysis was both iterative and inductive. Smith, Larkin, and Flowers (2009) describe the complex process, “It may be an experience which is collaborative, personal, intuitive, difficult, creative, intense, and conceptually-demanding” (p.80). For this particular study, the researcher would agree that the work was both difficult and insightful, but each line of the data collected led to greater interpretation of the participants’ contributions of their experience. After the data sources were transcribed, the researcher followed a similar procedure to the steps aligned by Smith, Larkin, and Flowers (2009) in reviewing the data.

- Step 1: Reading and re-reading
- Step 2: Initial noting
- Step 3: Developing emergent themes
- Step 4: Searching for connections across emergent themes
- Step 5: Moving to the next case
- Step 6: Looking for patterns across cases

In reading and reviewing the notes extensively (data sources were uploaded as separate documents to the MAX QDA software), the researcher labored line-by-line over the work in order to encourage themes to emerge. The researcher followed the process of reviewing each interview question by question to get an overall sense of what the participant was sharing. This acted as somewhat of a “brainstorming” exercise in which significant themes began to consistently repeat within one interview, and then over the span of several interviews, thus connections could be made. This continued as all data sources were reviewed several times in
order to best reveal the perceptions and experiences of the study participants. Certain themes were considered as emergent as they were the most prevalent and appropriate to the study.

The thematic coding focused on autism spectrum disorders in relation to the participants’ overall academic experience at the university including accommodations and support from the Office of Disability Services. The thematic codes determined fell into five essential categories that emerged from the notes: *ASD and self-awareness*, *Academic interests*, *Social interaction (primarily with reference to academics)*, *Support of the Office of Disability Services*, and *Accommodations*. Refer to Table 4.1 in this chapter in which the primary themes and number of occurrences were culled from the data. From within these five essential categories emerged a number of sub-codes appropriate to each theme or “essence”. There were moments in the interviews when themes overlapped in that more than one sub-theme seemed appropriate for a particular segment.

For the theme *ASD and self-awareness*, the following sub-codes emerged: attention to detail/precision, academic strengths, academic weaknesses, workload concerns, self-advocacy and/or willingness to ask for help, and hesitancy to ask for help. For the theme *Academic interests*, the sub-code of careers was identified. For the theme *Social interaction (primarily with reference to academics)*, the following sub-codes emerged: on/off campus activities and/or work, negative group work/interaction, positive group work/friends, living on campus vs. at home, and peer support. For the theme *Support of the Office of Disability Services*, the sub-codes identified were counseling/support provided, and met with services specialist. Finally, for the theme of *Accommodations*, the following secondary themes identified with noted sub-codes emerged: managing without accommodations, tests (on computer), tests (handwritten), electronic
textbooks, recorded or scripted lectures, least distractive environment, support from instructors, and extended time. Initially, the researcher planned to code the data solely based on more general or essential themes. However, it was soon revealed that the sub-codes, in particular those related to *Self-awareness* and *Accommodations*, were most prevalent and proved to be valuable in their distinction.

Various organizational tables generated by the MAX QDA software were utilized in order to align and correlate the coded material (descriptive or thematic) for analysis. These tables were then re-formatted for better visual understanding for the written work of the study. Several copies of the data were maintained in order to ensure security and authenticity of the study. The chart of coded data that follows (Table 4.1) shows the one descriptive code identified as well as the primary thematic codes and occurrences in the data collected. The primary themes were then broken into sub-codes in further detail, all of which was noted in Table 4.2. For clearer identification for the researcher and reader, the codes have been identified by color. Specific cues and wording appropriate for the emerging themes were used to organize the responses/data. A comprehensive total of 454 codes were identified with the most prevalent themes emerging of *ASD and self-awareness* (153 occurrences), *Social interaction* (109 occurrences), and *Accommodations* (103 occurrences).

<table>
<thead>
<tr>
<th>Codes</th>
<th>Total instances of code and sub-codes in review of data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Descriptive</strong> - <em>Description of research</em></td>
<td>12</td>
</tr>
<tr>
<td><strong>Thematic</strong> - <em>ASD and self-awareness</em></td>
<td>153</td>
</tr>
<tr>
<td><em>Academic interests</em></td>
<td>52</td>
</tr>
</tbody>
</table>
Within the primary themes (refer to Table 4.2), more specific sub-codes emerged as the most prevalent from the data. Of the occurrences of *ASD and self-awareness* (153 total), the theme itself was noted 42 times, with its most prominent sub-codes were of academic strengths (32 occurrences) and self-advocacy and willingness to help (24 occurrences). For *Academic interests* (52 total), the theme itself was noted 26 times with the sub-code of careers also noted 26 times. For *Social interaction - primarily in reference to academics* (109 total), the theme itself was noted 23 times, with its most prominent codes that of on/off campus activities and/or work (23 occurrences), and peer support (13 occurrences). Of the occurrences of *Support of the Office of Disability Services* (25 total), the theme itself was noted 4 times, and its most prominent sub-code was that of met with services specialist (13 occurrences). The final theme was that of *Accommodations* (103 total) with the general theme itself noted 23 times. The most frequent sub-codes for *Accommodations* were managing without accommodations (13 occurrences), support from instructors (35 occurrences), and extended time (18 occurrences). The data is noted in Table 4.3.
<table>
<thead>
<tr>
<th>Code System</th>
<th>Total Essential Codes Identified</th>
<th>454</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description of the research (12)</strong></td>
<td></td>
<td>12</td>
</tr>
<tr>
<td><strong>ASD and self-awareness (153)</strong></td>
<td></td>
<td>42</td>
</tr>
<tr>
<td>Academic weaknesses</td>
<td></td>
<td>17</td>
</tr>
<tr>
<td>Academic strengths</td>
<td></td>
<td>32</td>
</tr>
<tr>
<td>Self-advocacy and willingness to ask for help</td>
<td></td>
<td>24</td>
</tr>
<tr>
<td>Hesitancy to ask for help</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Workload concerns</td>
<td></td>
<td>14</td>
</tr>
<tr>
<td>Attention to detail/precision</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td><strong>Academic interests (52)</strong></td>
<td></td>
<td>26</td>
</tr>
<tr>
<td>Career</td>
<td></td>
<td>26</td>
</tr>
<tr>
<td><strong>Social interaction (109)</strong></td>
<td></td>
<td>23</td>
</tr>
<tr>
<td>Negative group work/interaction</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Positive group work/friends</td>
<td></td>
<td>14</td>
</tr>
<tr>
<td>Living on campus vs. at home</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>On and off campus activities/work</td>
<td></td>
<td>23</td>
</tr>
<tr>
<td>Peer support</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Family support</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>Social issues</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Social Skills Group</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td><strong>Support-Office of Disability Services (25)</strong></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Counseling/support provided</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Disabilities Awareness Panel</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>Met w/ service specialist</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td><strong>Accommodations (103)</strong></td>
<td></td>
<td>23</td>
</tr>
<tr>
<td>Tests (on computer)</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Tests (handwritten)</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Managing w/o accommodations</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Electronic textbooks</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Recorded/scripted lectures and notes</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Least distractive environment</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Support from instructors</td>
<td></td>
<td>35</td>
</tr>
<tr>
<td>Extended time</td>
<td></td>
<td>18</td>
</tr>
</tbody>
</table>

| **Table 4.3 Organizational Chart of Essential Category Codes with Corresponding Sub-Codes** |

**Data Analysis**

In reference to the Organizational Chart, Table 4.2, the identified essential categories emerged from the participants’ extensive contributions as well as from the researcher’s perceptions throughout the study. The thematic coding utilized aided in better relaying the students’ perspective of their overall experience in higher education: **ASD and self-awareness**
(for example, in what they see as their strengths and weaknesses), Academic interests (in how they envision their classes and future career), Social interaction (through interaction with peers on campus both in and outside of class), Support of the Office of Disability Services (how students seek the support needed), and Accommodations (which specific accommodations and support are sought for their academic needs). It was also deemed appropriate to create an informational graphic or logic chart (Table 4.4) in order to summarize the findings, thus connecting the themes that emerged with the theoretical frameworks discussed.

<table>
<thead>
<tr>
<th>Student participant/date</th>
<th>Student quote</th>
<th>Theme(s) identified</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Student J, personal communication, September 28, 2011</td>
<td>“Yeah, sometimes a disability can be a strength. It’s just a matter of breaking down the barriers that come with it”.</td>
<td>Self-awareness - academic strengths</td>
<td>Related to disability theory: Students adapt within the social construction that is the university setting (with their disability seen as socially constructed (Denhart, 2008). Student takes on an active role in his education.</td>
</tr>
<tr>
<td>Student M, personal communication, November 4, 2011</td>
<td>“They [my instructors] can usually give me some decent advice on what I am working if I work up the nerve to ask them. I am often hesitant to ask [for help], especially when it comes to larger projects because, when I ask in person, it’s a lot harder to ask in person than in email. Also, the weakness with e-mail is that you can be waiting</td>
<td>Self-awareness - self-advocacy</td>
<td>Connected to disability theory: Students utilize their voice to “deconstruct” the disability and seek support and accommodations.</td>
</tr>
<tr>
<td>Student U, personal communication, October 5, 2011</td>
<td>“I seem to remember always having a slight level of shame involved. Shame is too strong a word, it’s more of just, uh, being embarrassed, although embarrassed isn’t quite an accurate term either, really more hesitant is a good one, perhaps feeling not quite right about asking [for accommodations]. I wonder if I truly need accommodations, or I just need to work harder like everybody else”.</td>
<td>Self-awareness - hesitancy to ask for assistance</td>
<td>Related to the achievement ideology: Knowing a student can succeed if he/she puts forth the effort will aid in success.</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Student U, personal communication, November 15, 2011</td>
<td>“I am working with a group in my native history and culture class which is nice. It’s good, they’re both good people, I like them. We [usually] end up naturally sitting together anyway and we chose each other for the group”.</td>
<td>Social interaction - positive groups work/friends Social interaction - peer support</td>
<td>Connections to the work of Vygotsky: Collaboration with peers/instructors can help a student develop cognitively, achieve academically and adapt socially.</td>
</tr>
<tr>
<td>Student J, personal communication, November 16, 2011</td>
<td>“I did want to mention – a couple of friends of mine came up to me and said they had, uh, some ideas for a game. Yup, they needed an engineer who could provide them with the programming skills and the engine to</td>
<td>Social interaction - peer support Academic interests - career</td>
<td>Related to the achievement ideology and an “achieving society”: With appropriate support (in this case, from peer affirmation), students have the chance for academic</td>
</tr>
</tbody>
</table>

up to 24 hours before they can get back to you. I understand why, but it doesn’t stop the frustration [that instructors are not able to respond immediately]”.
do it. And I said, you know, I think I know just the engine (referring to the Unity engine). My reputation is preceding me!”.

Student I, personal communication, October 19, 2011

“Oh, career, oh yeah, I am thinking about getting a job, starting a career in computer networks, in the field of computer networking”.

Academic interests - career

Connections are made to the achievement ideology: Realization and determination will contribute to the student’s success.

Student M, personal communication, November 5, 2011

“If I was still in high school, maybe [I would seek accommodations] but more recently, it helps that most of my teachers have evolved to the take-home tests on computer, or just the entire test on the computer, where the only barrier is the internet [crashing]”.

Accommodations - support from instructors

Accommodations - managing without accommodations

Related to disability theory: Student can opt to seek support and accommodations as needed (support is met by modifications made by instructors e.g. in the form of take-home tests for all students).

Student A, personal communication, November 18, 2011

“I don’t usually write physically…uhm, I usually use my accommodations when I can. My instructors know the basic procedure, and I think it’s a good thing that I have taken advantage of accommodations (the computer use and the quiet room for tests and extended time) because I think I barely finish on time”.

Accommodations - support from instructors

Connected to disability theory: Student must feel comfortable to overcome and eliminate stigma in order to seek assistance.

Table 4.4 Logic Chart: Summary of Findings with Evidence
As a result of this study, the researcher has uncovered several essential findings:

1. Students with autism spectrum disorders had a realistic and optimistic sense of their abilities to complete a program in higher education with some success. This finding was supported by the achievement ideology framework, in which all students have the capacity to succeed within an achieving society.

2. Students with ASD were able to deconstruct their disability and how it was perceived by using their voice to express their need for accommodations and support. The finding was through the medium of disability theory and the concept of one’s disability being socially constructed. Thus, there was the need for students to self-advocate, thus utilizing their voice to seek the support and accommodations they need to succeed academically.

3. Students with ASD, once comfortable with their peers and instructors, were able to overcome stigma and felt comfortable seeking assistance. Disability theory addresses the uniqueness of each student, each with a variety of learning needs, as students with ASD are able to overcome stigma based on their disability in order to achieve.

4. With support from their instructors and more competent peers, students with ASD continued to gain both academically and socially. These gains were supported by the connections made earlier to Vygotsky’s work on one’s Zone of Proximal Development (ZPD). Within the individual’s realm of capabilities, enhanced learning and success occurred with collaboration and support of peers and instructors.

5. Students with ASD benefited from social interaction both in and outside of class within the setting of higher education. Collaboration and group work helped study participants to
achieve academically and to better adapt socially, and this was supported by Vygotsky’s work on social interaction.

Findings: Themes

The participants in the study at Northern University were a unique group of individuals, but were not much different from typical college students in their eagerness and passion. Through the lens of disability theory and achievement ideology, it became evident that the student participants in the study – and more broadly, students with ASD in higher education – could achieve academic success with significant effort on their part, as well as with support. The students were quite willing to share about themselves and, although the study was focused primarily on academics, they wanted to discuss their families and friendships as well.

Academic Interests and Career

From an academic perspective, each of the participants spoke passionately about his intended major and possible career that included gaming, math and statistics, history, accounting, culinary, marketing, and engineering. Each participant maintained a dedicated interest in a field offered by the university and the student expressed the desire to do well; each participant was able to see the light at the end of the “university tunnel”. Students envisioned themselves completing their degrees - from the participant who was in his first term, to the participant that was in his final year - each had the goal of degree completion in common regardless of the fact that they had ASD. One participant contributed the following about his career and interests for the future, “Oh, career, oh yeah, I am thinking about getting a job, starting a career in computer
networks, in the field of computer networking” (Student I, personal communication, October 19, 2011). This element of the study addressed the achievement ideology in that realization and determination contributed to the students’ success. These young men were a diligent, focused group, were very passionate about doing well, and they knew that they had to work hard to achieve the success they wanted. The theme of Academic interests was quite prevalent in the interviews. The participants stressed their desire to stay organized and to prioritize their work, to succeed in their classes, and to ask for support if needed.

**Self-Advocacy and Accommodations**

At the onset of the study, all participants had basic knowledge of the accommodations available, yet not all had taken advantage of the accommodations they needed for a variety of reasons. These reasons included hesitancy on the student’s part to ask for support, hope that the individual could manage without the accommodations in that they might not be needed, and uncertainty as to the extent of support available. By the second set of interviews (and not coincidentally, as the semester progressed), this had changed somewhat as students were more apt to ask for accommodations and support from their instructors. Not only did the participants have a much clearer idea as to the accommodations and support available to them from the Office of Disability Services but rather, they were also more confident and willing to self-advocate for support. In several of the second interviews, participants were eager and confident to share what accommodations they had accessed and revealed how they benefitted from the support.

The Office of Disability Services seemed to be well utilized by the students primarily in
the form of meetings and counseling with the individual services specialists, and through sponsored activities such as the Social Skills Group, and the Disability Awareness panel discussions. Home life played a very significant role in participants’ academics as well. Students stressed the great importance of family members’ support in keeping them on track. In addition, three students cited the need to be away from the distractions of campus “party” social life. Although the study focused on academics primarily, elements of social life and outside activities did emerge, as the participants shared much of their overall experience on the college campus.

In relation to the theme of *Accommodations*, the support provided by instructors and through the Office of Disability Services most utilized was the following: extended time on tests (and alternative settings for testing), different formatting for tests (whether a student preferred a test on computer or hand-written, as both were mentioned as a concern), and general support from instructors (such as review time before and after class). A unique theme of interest in relation to accommodations was the fact that students frequently wanted to try to succeed academically without seeking accommodations, to either challenge themselves, or to normalize the situation for them. This was of even more interest to the researcher in that it was unanticipated, and the topic led to more discussion into how students worked individually without seeking accommodations or support. One participant reflected, “If I was still in high school, maybe [I would seek accommodations] but more recently, it helps that most of my teachers have evolved to the take-home tests on computer, or just the entire test on the computer, where the only barrier is the internet [crashing]” (Student M, personal communication, November 5, 2011). Although it was of no surprise that the students did not want to appear different from their peers, what was unexpected was the element of “challenge” that a few of the
participants sought when they chose not to seek accommodations. This element spoke to the perspective of the achievement ideology in that all students are able to achieve academically when the effort is put forth. In addition, when students with ASD came to the understanding that their own achievement would occur with support, facets of disability theory were realized. The study participants proved this connection as they put forth significant effort to succeed and were supported in their efforts.

**ASD and Self-Awareness**

The study participants were interested in helping the researcher learn more about ASD and how the students each, in their individual way, worked with their accommodations to have success at the university. The participants were open and seemed to enjoy sharing information about their academic and personal lives and about their diagnosis on the autism spectrum. As the researcher proceeded with the interviews, the students generally became even more comfortable in what they shared. The researcher observed a number of silent cues during the interviews, such as slight smiles and nods, in particular when the participants discussed their favorite subjects and career ideas. A common difficulty for an individual with ASD is that of making eye contact with another in conversation. Interestingly enough, this was not an issue for the student participants who became more comfortable with the interviewer and did make good eye contact throughout their time together.

As the semester progressed, the second set of interviews and the journal entries proved to be revealing as well. Focusing on the prevalent theme of *ASD and self-awareness*, several sub-themes were more frequently mentioned by the student participants. As to self-awareness, one
participant reflected on his disability in the following words, “I have Asperger’s syndrome…yeah it’s a little hard for me to comprehend things so I need things [repeated] a couple times or extra time, stuff like that. I would say [my Asperger’s] is not very severe” (Student L, personal communication, October 18, 2011). Specifically, with respect to students’ strengths, the following were noted as some of their self-described attributes: paying attention, being a good listener, taking good notes, and staying focused. Student A commented, “I take as many notes as I can so I have as much information as I can to try to connect it to different areas” (Personal communication, October 11, 2011). A second participant contributed, “I suppose listening [is a strength] but I get distracted too. Outside of the classroom, hmm, that’s a tough one, I always think of strengths and weaknesses as being relative. Well, believe it or not, contrary to the whole Asperger’s/autism thing, I am very social” (Student U, personal communication, October, 5, 2011). This participant was referring to the fact that many students diagnosed with ASD often have trouble socializing and making friends.

On the subject of students’ weaknesses, one student expressed frustration that manifested in physical terms, in that he struggled with handwriting. This student expressed his difficulties in that he wrote with a lot of pressure, pressing too hard with the writing implement. For this student, frequent computer use was essential. In contrast, however, a different participant expressed technology as a weakness and that he preferred to handwrite his work. Although these two students each were on the autism spectrum, their struggles were unique and their need for accommodations was distinct to the individual. Weaknesses expressed however, did not seem to deviate much from a weakness that another student without ASD might also face. Further struggles included being overwhelmed by workload, such as outlining of research paper
assignments, and the length of reading assignments in particular. When sharing weaknesses, the participants tended to pause during the interviews, not as if they were hesitant to share the information, more so in that they were seeking the correct words to express their difficulties. The researcher was careful to be patient and quiet, yet encouraging during these moments.

One of the students stressed the point that he thought of “his” Asperger’s syndrome (with which he was diagnosed) as more of a benefit than a hindrance to him, because it made him work that much harder than perhaps he might have worked. This student was quoted as saying, “Sometimes a disability can be a strength - it’s just a matter of breaking down the barriers that come with it” (Student J, personal communication, September 28, 2011). What was noteworthy, too, was the fact that the participants, after expressing a weakness they perceived, almost immediately noted the solution or ways in which they had managed to cope to work around the issue, whether it was connected to their ASD or not. The participants spoke of their ability to self-advocate and they were rarely hesitant to ask for assistance, that is, after they had become comfortable enough with the instructor and the class itself. One participant cited his “laziness” as his reason for not consistently asking for assistance (Student U, personal communication, October 5, 2011). This participant gave silent cues of smiling and nodding, thus indicating to the researcher that he knew that this weakness was not a major obstacle and was something that could be easily overcome.

The same participant was particularly insightful when he mentioned hesitancy in asking for assistance, “I seem to remember always having a slight level of shame involved. Shame is too strong a word, it’s more of just being embarrassed, although embarrassed isn’t quite an accurate term either, really more hesitant is a good one, perhaps feeling not quite right about asking [for
accommodations]. I wonder if I truly need accommodations, or I just need to work harder like everybody else” (Student U, personal communication, October 5, 2011). Another participant commented on his hesitancy to ask for help, “They [my instructors] can usually give me some decent advice on what I am working if I work up the nerve to ask them. I am often hesitant to ask [for help], especially when it comes to larger projects because, when I ask in person, it’s a lot harder to ask in person than in email. Also, the weakness with e-mail is that you can be waiting up to 24 hours before they can get back to you. I understand why, but it doesn’t stop the frustration [that instructors are not able to respond immediately]” (Student M, personal communication, November 4, 2011). A third participant reflected on his disability and his own weaknesses in affirming the following, “I have a tendency to learn in a different manner, and have some awkward social tendencies” (Student J, personal communication, September 28, 2011).

Social Interaction

With the theme of *Social interaction* in mind, the participants were generally mixed when discussing friendships and interactions with fellow students. Although this study was focused primarily on the students’ academics, the social elements of friendships, specifically working with partners both in-class and outside of class were prevalent and crucial to the study. For the most part, students felt accepted, welcomed, and supported by their peers. This was clear in not only the students’ words, but also in the non-verbal cues the students gave of smiling, head nodding, and of more focused eye contact. In-class in particular, the participants mentioned positive and productive group and peer work, with very little to say about negative interaction
with peers. Theorist Vygotsky (Miller, 2002) would have stressed the need for social interaction for students with ASD (in a higher education setting, this is exemplified often in group work) as collaboration helps students develop cognitively and achieve academically, as well as better adapt socially. Both collaboration and positive peer work proved to be an important element that aided in the success of the students with ASD in the study. One student participant, however, expressed his difficulty in adjusting to some classroom situations, for example, when working with peers not doing their share of the group work. The student was very open about previous anger control issues, and he relayed recent, significant improvement in controlling his anger and frustration. He was very clear in expressing the fact that working with peers or colleagues was a definite weakness for him.

One participant shared his experience outside of the classroom, one which was related to his strong academic skills in gaming as well as to his personal career interests, “I did want to mention – a couple of friends of mine came up to me and said they had some ideas for a game. Yup, they needed an engineer who could provide them with the programming skills and the engine to do it. And I said, you know, I think I know just the engine [referring to the Unity engine]. My reputation is preceding me!” (Student J, personal communication, November 16, 2011). In this situation, the student shared the support of his peers, given to him in the form of confidence and encouragement, which aided and enhanced his ability to achieve. This moment was one to be viewed through the lens of the achievement ideology within an achieving society.

**Journal Contributions**

Analysis of the journal entry notes, although limited in that not all participants contributed, revealed both academic and social elements of the students’ experience. Student
participants chose to contribute commentary about academics, personal, and social interaction, which generally added to their overall experience on campus. One noted, “My classes have been going well, and communication with my professors and peers has generally been great” (Student J, personal communication, October, 25, 2011). Several journal entries mentioned accommodations that students had utilized in recent days as well as concerns about workload overall. One participant in particular enjoyed the expressive nature of the journal contributions, and he shared much of his social interaction (specifically about his tango lessons!) as well. Analysis into this revealed a higher level of comfort as the semester progressed as well as success with group work and friends. Initially (during the first set of interviews), this student had expressed the desire to make more friends over the course of the semester and, through revealing journal reflection, the student seemed to have done just that. Academic concerns were expressed and seemed typical of what many college students feel, which is overwhelmed by work. One student affirmed, “Far too much work to get done. Why did I procrastinate again? Did I procrastinate? I have never had such an excessive amount of reading in one class, let alone three classes. Thank God there is little in the way of writing” (Student U, personal communication, November 15, 2011).

In general, the participants expressed the need for compromise and cooperation as they understood that there might be challenges involved – as there would be for most students - with class partners or group work and with academic and social issues overall. Outside the classroom, some of the participants emphatically expressed the desire to make more friends. Unfortunately, this was somewhat hampered by that fact that none of the participants were living on campus at the time of study. Support through activities sponsored on campus – through the Office of
Disability Services or different campus organizations – encouraged the students to go slightly beyond their comfort zones and to try new activities. This in turn added to the students’ overall experience within higher education, opening them up to better academic experiences as well as social experiences. This was easily perceived through the participants’ enthusiasm (through verbal language and non-verbal cues) for their current academics, future work, and experience in general at Northern University. The journal writing (in electronic form) had the potential to detail even more of the students’ experience, but it was a voluntary element of the study and not all participants took part. The journal elements revealed similar insight as the students’ interviews, although one participant did share more personal and social interaction through his electronic journal. For example, the student shared the following on the subject of his dance lessons, “Salsa class tonight at the Other Studio. Still hard. Still not used to being beginner level. Still not improving (should be used to that by now.) This style is so different than ballroom salsa. Used to dance here years ago. Instructors are nice enough. Maylena's sweet. Doesn't seem to mind my sense of humor, even though it consists mainly of frustrated profanities” (Student J, personal communication, October, 2011).

Summary

In summary, Chapter 4 highlighted the essential themes that emerged from the data. The students’ experience was relayed in narrative form with direct quotes from the participants noted when appropriate. Sharing firsthand information from the participants was deemed the best way to relay the genuine experience of the students involved. This phenomenological study was chosen in order to gain deeper understanding into the experience of students with ASD in terms
of participation in higher education and academic success at Northern University. In Chapter 5, findings will be discussed in greater detail through analysis of themes and their relation to the initial research questions, connections to the literature review, and the theoretical frameworks employed. Recommendations will be made both at the research study level – specific to the study at Northern University – as well as for all postsecondary institutions.
Chapter 5
Discussion of Findings and Implications for Practice

Introduction

This chapter will continue to enhance the reader’s understanding of what was gained relevant to students with ASD and their experience in higher education. Reiteration of the researcher’s goals and the research questions, the study’s methodology, and theoretical frameworks will be made. The researcher’s findings follow, beginning with the themes or categories that emerged from the data collection and through which integral facet of the study these themes became evident. Recommendations will follow, those specific to the study at Northern University, as well as those also appropriate for any number of institutions of higher education.

For this study, the researcher was motivated by both practical and intellectual goals in order to better understand the experience of students with ASD in higher education. At the beginning of the study, the researcher surmised that there might not have been sufficient support within institutions of higher education for students with ASD. In addition, there were few studies done with clear data demonstrating that, in effect, these expanded support systems are enhancing the academic success of students with ASD. It was anticipated that further research and study would serve to enlighten both professionals and students of the services available to students with ASD and other learning disabilities, as well as stress the importance for self-advocacy of the students. Whether or not students with ASD were advocating for assistance and seeking the help, if provided, was a key element of the research study at Northern University. Practical goals included the hope for better communication between service providers and students with ASD as
well as for more accommodations for these students as a result of better understanding their experiences. The primary research question guiding this study was: What is the experience of students with autism spectrum disorders attending an institution of higher education? The supplementary research questions were: What is their experience as it relates to available support systems at Northern University? and How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?

For the research, the methodology of qualitative design through a phenomenological study was employed. The theoretical framework utilized was through the lens of disability theory and the achievement ideology, both of which proved to be of great value for this research and the study at Northern University.

Findings

The data collected from the interviews with student participants were the most significant sources for the themes that emerged in the study. As the interviews were reviewed line-by-line, certain concepts, words, and ideas were repeatedly expressed by the participants leading to the highlighting of the most prevalent of the themes denoted in Table 5.1. These themes in turn were then categorized into more essential themed groups or super-ordinate themes, terminology used by Smith, Flowers, and Larkin (2009). Organizing and categorizing the themes was aided by the use of MAX QDA software.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Essential/Super-Ordinate Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Academic weaknesses</td>
<td></td>
</tr>
<tr>
<td>and strengths</td>
<td>ASD and Self-Awareness</td>
</tr>
<tr>
<td>---------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>- Self-advocacy</td>
<td></td>
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<tr>
<td>- Hesitancy vs. willingness to ask for help</td>
<td></td>
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<tr>
<td>- Workload concerns</td>
<td></td>
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<tr>
<td>- Attention to detail</td>
<td></td>
</tr>
<tr>
<td>• Academic interests</td>
<td>Academic Interests</td>
</tr>
<tr>
<td>• Career ideas/prospects</td>
<td></td>
</tr>
<tr>
<td>• Positive or negative group work/interaction</td>
<td>Social Interaction</td>
</tr>
<tr>
<td>• Living on campus vs. at home</td>
<td></td>
</tr>
<tr>
<td>• On/off campus activities or work</td>
<td></td>
</tr>
<tr>
<td>• Peer and family support</td>
<td></td>
</tr>
<tr>
<td>• Social issues</td>
<td></td>
</tr>
<tr>
<td>• Social Skills Group</td>
<td></td>
</tr>
<tr>
<td>• Counseling/support provided</td>
<td>Support-Office of Disability Services</td>
</tr>
<tr>
<td>• Disabilities Awareness panels</td>
<td></td>
</tr>
<tr>
<td>• Met with services specialist</td>
<td></td>
</tr>
<tr>
<td>• Tests on computer or hand-written</td>
<td>Accommodations</td>
</tr>
<tr>
<td>• Managing without accommodations</td>
<td></td>
</tr>
<tr>
<td>• Electronic textbooks or materials</td>
<td></td>
</tr>
<tr>
<td>• Recorded/scripted lectures or notes</td>
<td></td>
</tr>
<tr>
<td>• Least distractive environment</td>
<td></td>
</tr>
<tr>
<td>• Support from instructors</td>
<td></td>
</tr>
<tr>
<td>• Extended time</td>
<td></td>
</tr>
</tbody>
</table>

*Table 5.1 Themes Leading to the Essential Categories or Super-Ordinate Themes*
In Table 5.2, the study’s primary and supplementary research questions were correlated with their appropriate essential theme or themes. These essential categories were then identified with the data source or sources from which the themes emerged.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Emerging Themes (Essential Categories)</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the experience of students with autism spectrum disorders attending an institution of higher education?</td>
<td>ASD and Self-Awareness, Academic Interests, Social Interaction</td>
<td>Interviews, Journal contributions</td>
</tr>
<tr>
<td>What is their experience as it relates to available support systems at Northern University?</td>
<td>ASD and Self-Awareness, Academic Interests, Support-Office of Disability Services, Accommodations</td>
<td>Interviews, Journal contributions, Disability Awareness panels, Presentation by Office of Disability Services, Meetings with Disability Services staff</td>
</tr>
<tr>
<td>How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?</td>
<td>ASD and Self-Awareness, Academic Interests, Support-Office of Disability Services, Accommodations</td>
<td>Interviews, Journal contributions, Disability Awareness panels, Presentation by Office of Disability Services, Meetings with Disability Services staff</td>
</tr>
</tbody>
</table>

Table 5.2 Connections: Research Questions-Themes-Data Source

The overarching, essential question guiding the study was the following: *What is the experience of students with autism spectrum disorders attending an institution of higher education?* The experience was best summarized in narrative form for the phenomenological study, and the intent was to make meaning of this experience through analysis and interpretation. The participants’ personal reflections - through the interview and journal communication - reveal
much about their experience. The conscientious choice of a phenomenological study afforded interpretation and description of the meaning for several individuals of their lived experiences of a phenomenon, for this study, students with ASD attending an institution of higher education. Through their voluntary participation in the study, the students had the opportunity to have their “voice” heard and thus were able to share their experience in higher education. Their self-advocacy and to what extent they utilized available accommodations in collaboration with peers and instructors determined both their academic and social experience. This study was of great value and it contributed significantly to educational research in this area. Moreover, the study emphasized the need for further research into the area of students with ASD at the postsecondary level.

Supplementary to the overarching question regarding the students’ experience is the following: What is their experience as it relates to available support systems at Northern University? Based on the interviews and journal contributions, student participants were quite aware of the services and accommodations that were most appropriate to their needs, and they were less aware of services that might not have helped them, which seemed logical. Students with ASD are unique – as are all student learners – and one student may need to seek more accommodations than his peers. When participants were told of an accommodation or service of which they were previously unaware, they seemed confident in that they would seek the accommodation in the future. One example of this was of the note-taking service provided by the Office of Disability Services. This involved the students’ fellow classmates taking extensive notes and receiving a nominal fee for their work. At some point in the future, these notes would be shared with the student in need of the support. One of the participants in the study expressed
interest in this accommodation, but had yet to take advantage of it due to the fact that he was not sure if he needed the support earlier. The student then later realized that this particular accommodation would truly benefit him in the future. Encouraging students with ASD and other disabilities to self-advocate and to seek support should continue to be a priority for all staff within higher education.

Connecting the essential question about the students’ experience and the supplementary question about students’ perceptions of services led the researcher to pose the related supplementary question: *How does an understanding of these experiences contribute to programming for students with autism spectrum disorders in higher education?* Programming for students with ASD at the postsecondary level was deemed important in order to create an environment that supported and nurtured students academically. Students reported services such as counseling and support meetings with their services specialist, as well as the Academic Accommodations form (Appendix E) that the office provided for the students to share with their instructors. This form was to be distributed to the students’ instructors at the beginning of the term indicating what services the student with ASD or different disability needs. Some of the students were aware of the Social Skills Group (meetings held weekly) sponsored by the Office of Disability Services. This type of group served as something from which students with ASD who often struggle with social skills could truly benefit. A number of the services provided by the Office of Disability Services are noted on the Academic Accommodations form (Appendix E). The support and accommodations provided by the Office of Disability Services were extensive and were elaborated upon in Table 5.3 Some of the information was adapted from the Academic Accommodations form (Appendix E). Supplementary to information shared by the
study participants, alternative resources were gained through informal meetings with both the Director and the Assistant Director of the Office of Disability Services as part of this study.

<table>
<thead>
<tr>
<th>Services provided by the Office of Disability Services</th>
<th>Participants used</th>
<th>Participants expressed interest in using this in the future if needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meetings with disability services specialist</td>
<td>Yes – most participants reported weekly meetings</td>
<td>Yes</td>
</tr>
<tr>
<td>Disability Awareness panels</td>
<td>Yes (2 participants)</td>
<td>Yes</td>
</tr>
<tr>
<td>Social Skills Group</td>
<td>Yes (2 participants)</td>
<td>Yes (if schedule allowed)</td>
</tr>
<tr>
<td>In-class technology (audio recorder, laptop, calculator)</td>
<td>Yes- laptops and calculators primarily</td>
<td>Yes</td>
</tr>
<tr>
<td>Computer for tests or for written assignments in class</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Accessible text format</td>
<td>Yes (2 participants – electronic books)</td>
<td>Yes</td>
</tr>
<tr>
<td>Allow student to modify discussion board postings</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Electronic test or hand-written test as preference</td>
<td>Yes, both options preferred by different participants</td>
<td>Yes</td>
</tr>
<tr>
<td>Extended time for tests and/or assignments</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Reduced distraction testing – private</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Note taker</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Provide electronic copies of handouts/materials to student</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Not responsible for spelling without</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>access to spelling tools</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
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<td>---</td>
</tr>
<tr>
<td>Written instructions to accompany oral ones</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Use of screen reader for tests</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Table 5.3 Accommodations/Support of the Office of Disability Services at Northern University

This study revealed that students with ASD were able to benefit from their instructors and peers if they were open and receptive to such support within the environment of higher education. Participants in the study became more comfortable with their classmates and instructors as the semester progressed, and this more “social” comfort level enhanced their academic success as well. Students felt much more comfortable asking questions in and outside of class of their instructors. In addition, students were more receptive to group work as opposed to some hesitancy earlier in the term. These elements were evident in comments the participants made (through the second set of interviews and their journal contributions), as well as were demonstrated in their overall demeanor. When students were encouraged to self-advocate for what they needed, and they felt comfortable in doing so, they were not hindered in their success and achievement followed suit. Truly believing in the potential of the achievement ideology was deemed essential to the academic success of students with ASD in this study. One student contributed the following, “I just hope to succeed and everything, to do well. The feeling I have is that in high school it was a lot easier to get like an A or a B but here it’s a lot harder” (Student L, personal communication, October 11, 2011).
In addition, if one’s comfort level was enhanced, particularly considering students with ASD who often struggled with social interaction, this seemed to benefit the student’s social experience, as observed by Student U, “I am working with a group in my native history and culture class which is nice. It’s good, they’re both good people, I like them. We [usually] end up naturally sitting together anyway and we chose each other for the group” (Student U, personal communication, November 15, 2011). This was but one example of a participant’s reflection on his own social experience affecting academic work in a positive way. A second participant commented,

“I used to be like…hesitant…but I think over the years I have made progress…that’s part of the social part of it [one of the struggles affiliated with ASD], so I am just starting to, you know, it kind of holds you back a little bit, but as far as social goes, I am still having problems with that now. I’d like to improve on that (in all areas). I guess meet with more of these kids more often [meeting with his classmates]. I think over time, with the culinary, I’ll end up with them as a partner so I’ll probably get to know them better, and that will probably work itself out in the end” (Student L, personal communication, October 11, 2011).

Although this student struggled slightly to express what he had hoped, it was clear that he was eager to continue to try to make social connections both in and outside of class. Social interaction for this student stemmed from some group collaborative work in class which was directly intertwined with his career interests, thus positive social interaction would reasonably continue to affect his achievement as well. Denhart (2008) would stress the importance of the social construction that defines higher education. Within this unique environment, both
collaboration and peer work would benefit a student with ASD in both an academic and social manner.

Elements of interpretive phenomenological analysis or IPA (Smith, Flowers, & Larkin, 2009), were reflected in the research gleaned as the researcher interpreted the participants’ experience in higher education. Through the interviews, the participants were able to perceive and relay facets of their experience as the semester progressed (through the interviews, journal contributions, the Disability Awareness panel discussions, etc.). By means of the perspective of Moustakas (1994) and the study of hermeneutics, one could understand how the participants interpreted and gained meaning from their own experience in higher education as they were asked to share their thoughts via the interview and journal process. According to Smith, Flowers, and Larkin (2009), “Although the primary concern of IPA is the lived experience of the participant and the meaning which the participant makes of their lived experience, the end result is always an account of how the analyst [the research] thinks the participant is thinking” (p.80). The informal interviews were conducive to enabling the participants to open up and to feel comfortable enough with the researcher to share their personal successes, strengths, weaknesses, and frustrations, all contributing to their experience on campus.

Researched through the lens of both the achievement ideology and disability theory, it was evident that the participants within the study felt very supported and encouraged by staff and peers. These students were then able to self-advocate in their efforts to achieve academic success. Specifically, the students’ use of their voice to advocate for the support enabled the disability of ASD to be deconstructed - in the eyes of the staff member and the student himself - thus demonstrating disability theory at work. The academic support and/or accommodations
consistently enhanced the individual student’s academic experience, enabling academic achievement. The student’s belief in self and his own abilities to achieve spoke volumes to the achievement ideology. The reality of whether or not one should use one’s voice in seeking accommodations was noted by this participant, “If I was still in high school, maybe [I would seek accommodations] but more recently, it helps that most of my teachers have evolved to the take-home tests on computer, or just the entire test on the computer, where the only barrier is the internet [crashing]” (Student M, personal communication, November 5, 2011). Students with ASD were able to “realize” their own achievement ideology when they were provided opportunities to succeed with support. The importance of recognizing their achievement further prompted the study participants to want to continue their efforts academically. It was quite clear that the participants in this study had certain goals, favorite academic subjects, and even career choices in mind. Truly believing that they would succeed academically and achieve their goals, along with accommodations and support, were what boosted the students’ success within the higher education setting. In an achieving society, Seibel (1974) would stress the need to highlight the students’ strengths – the individual’s competencies - and academic success would result.

Disability theory, as reported by Denhart (2008), reminds the reader that a disability is considered an element of normal human variation, and one must give voice to the disability in order to deconstruct it. Students must feel comfortable enough to overcome and eliminate that stigma they might feel in seeking assistance. In turn, faculty, staff, and peers must be willing and flexible to accommodate a variety of students’ different learning needs. One participant acknowledged, “I don’t usually write physically, I usually use my accommodations when I can. My instructors know the basic procedure, and I think it’s a good thing that I have taken
advantage of accommodations (the computer use and the quiet room for tests and extended time) because I think I barely finish on time” (Student A, personal communication, November 18, 2011).

Credibility and Trustworthiness

The research terms reliability and validity are generally referred to in a qualitative study as credibility and trustworthiness of the study (Golafshani, 2003). The concept of credibility was addressed when the researcher employed a phenomenological study in order to yield answers and provide insight into students with ASD and their academic success in higher education. The study parameters were believable and credible. The trustworthiness of the study was revealed in the researcher’s ability to accurately and clearly transcribe the information gained from the participants and thus was able to describe their experience to the best of her ability. Student participants volunteered to take part in the study in order to have their voice heard – through verbal interviews as well as through written journal notes – to relay their experience at Northern University.

It is probable that what was gained from the study – describing the participants’ experience in higher education - would be similar to that which some other students with ASD would experience. The study would then be considered a reliable one in that the applicability or transferability, as noted by Golafshani (2003), of results would feasibly be replicated in a similar study. In addition, the experience gained would be useful for all students with ASD in the future concerning the aspect of transferability.
Smith, Flowers, and Larkin (2009) review the work of Yardley (2000) and the four principles recommended for addressing the quality of a qualitative study. The principles proved to be appropriate for this study at Northern University and are as follows: *sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance* (Smith, Flowers, & Larkin, 2009, p.180-183).

*Sensitivity to context* began at the onset of the study prompted by the choice of the particular research and the nature of the small population of students with ASD and their experience in higher education. Smith, Flowers, and Larkin (2009) explain, “The researcher may show sensitivity to, for example, the socio-cultural milieu in which the study is situated, the existing literature on the topic, the material obtained from the participants” (p.180). Sensitivity in all aspects was demonstrated in deference to existing literature, to the work done thus far by the Office of Disability Services at Northern University and, most importantly, to all private and confidential information shared by the participants. It was vital to be accurate in relaying what was said throughout the interview process in gleaning the most essential elements about the students’ experience.

*Commitment and rigor* was demonstrated through attention to detail and to protocol from the opening of the study through the analysis and concluding elements of the work. The element of rigor in the study was reflected in how thoroughly the work was carried out, particularly during the interview process itself. As the authors affirm, “Rigour refers to the thoroughness of the study, for example in terms of the appropriateness of the sample to the question in hand, the quality of the interview, and the completeness of the analysis undertaken” (Smith, Flowers, & Larkin, 2009, p.181).
Transparency and coherence were evidenced in the clear way the study process was described throughout this work. From the initial proposal of the research to recommendations made for future work, every effort was made to be transparent in what was being relayed. It was hoped, too, that with transparency inevitably emerged coherence from the research questions posed to the final data analysis.

Impact and importance were manifested in the essence of the study itself. The research – of understanding the experience of students with ASD in higher education – was one of great importance today in that little research has been done thus far. The impact of the results of this study, regardless of the fact that it was of a small population, has the potential to help both students with ASD and future researchers in their quest to better enhance the students’ future experiences at the postsecondary level.

An independent audit (Smith, Flowers, & Larkin, 2009), albeit one that was self-imposed by the researcher, proved to be a vital tool for this work. This was an element of the study that spoke to the researcher’s organizational skills from the study’s inception to its culmination, and it should not be taken for granted. The authors suggest the following, “…If one thinks of an IPA interview project, the trail might consist of: initial notes on the research question, the research proposal, an interview schedule, audio tapes, annotated transcripts, table of themes and other devices, draft reports, and the final report” (Smith, Flowers, & Larkin, 2009, p.183). Each step in the audit process played a key role in performing a “quality check” of the researcher’s commitment and rigor dedicated to the study. Furthermore, steps were taken to assess transparency and coherence throughout the work.
Upon reflection, the researcher became aware that her own personal connection to the research, that of her young nephew with ASD, may have contributed somewhat to her bias and work throughout the study. This could only be seen in a positive light, however, as there was no doubt in the researcher’s mind that, with the attitude, drive, and willingness to self-advocate, the study participants would achieve some modicum of academic success. The researcher was pleased with the study results in that there was significant and extensive support being provided thus far at the university level. At the start of the study, the researcher was optimistic yet realistic in what the participants might or might not reveal about their experience. There was the potential of too few study participants, or that there would be very little revealed through the interview format. One element of reflection to note was that of several of the researcher’s colleagues outside of the study, individuals who seemed doubtful that there would be sufficient support for students with ASD. In informal conversations, several colleagues seemed skeptical upon considering a student with ASD achieving success at the postsecondary level. There was much that was unknown – that which has not been researched or noted to date about students with ASD and their experience in higher education –and that the research would still be considered relatively new. In the researcher’s mind, the most satisfying element of this study was that students with ASD that participated were able to take on the challenge of higher education, and they have demonstrated academic success thus far.

Areas of Vulnerability/Limitations

Some areas of vulnerability became evident as the study took place such as whether or not students would volunteer to participate, as well as how many would follow through with the
process. Fortunately, six students chose to participate with the researcher’s initial goal being that of 5-7 students. The Office of Disability Services at the university provided the initial contact for the student participants. If a student was registered with the Office of Disability Services and diagnosed as having autism spectrum disorders, the student was informed about the study and asked if he or she would like to participate. Although the exact percentage of students diagnosed with ASD was difficult to determine, the students identified by the Office of Disability Services comprised less than 1 percent of the day student population. Those students who expressed interest and volunteered to participate in the study limited the group to six students, which was within the range of the researcher’s original goal. The low number could be considered an area of vulnerability in that the study would not necessarily speak to a larger population. Although it is not possible to generalize the information gleaned, general and significant themes of value emerged to gain information about students with ASD in higher education.

The timing of the study, in that data collection was limited to the university semester could be considered a factor of vulnerability as well. The study was based on the time range of the fall semester and, perhaps, may have had somewhat different results if the study was conducted in the second or spring semester of the school year. One might consider a significant area of vulnerability to be that of privacy, but the researcher kept the privacy and complete anonymity of the students involved in the write-up of the study. The sole individuals on the campus of Northern University that knew of the students’ participation in the study were the three disability services specialists that initially asked the students if they were interested in participating. These individuals were not informed of any of the data collected nor of any connections between each participant and what was contributed. The researcher will share the
final dissertation work with the Office of Disability Services staff at Northern University.

The role of the researcher was of observer, data collector, and as participant to the extent that this was possible in the interview situation. This too may be considered an area of vulnerability. Throughout the interview and research process, the researcher maintained a neutral role in relationship to the participants. It is safe to assume that the researcher’s personal beliefs and biases had a slight influence on the data collection, as it would have been difficult to avoid this in a qualitative study. The researcher’s personal connection (a relative with ASD) was not considered an area of vulnerability but rather one that contributed to the descriptive aspect of phenomenological research. This also added a more personal element to the interviews when student participants heard one of the reasons why the study was of such great interest to the researcher.

**Implications for Future Study**

The exact percentage of students with ASD that were studying at Northern University is unknown as students were not mandated to disclose their disability nor were required to seek services or accommodations. Due to lack of comprehensive testing information, the percentage of the students diagnosed with ASD was information not revealed by the Office of Disability Services. The students that had volunteered for the study had disclosed their information to the Office of Disability Services and were just a few of a very small population of students with ASD on campus, according to the staff with whom the researcher worked. As student growth swells in colleges and universities worldwide, it is clear that this small, undisclosed population of students with ASD is growing, as more students are diagnosed as being on the autism spectrum. This growth indicates the critical need for continued efforts to pursue studies in this area. Future
studies of students with ASD, not necessarily specific to Northern University, would enable the researcher to continue the student interviews at greater length such as over the course of an entire academic year. In like manner, one could gain information through understanding several years of the participants’ experience within higher education to gain an even broader perspective. For the parameters of this particular study, one semester was chosen as the timeframe for the data collection. If permitted, it would prove quite beneficial to prolong the data collection enabling the participants to continue to share their academic experience. Added interviews would shed light on whether or not the participants continued to seek accommodations, or potentially that they sought fewer as they become more accustomed to certain subjects or instructors. The students’ confidence level and ability to self-advocate for support also would be strengthened as the academic year continued, which would be of interest in a study. A future study following the Northern University participants, as they move into work and careers, would be of great interest. One would then gain insight into whether or not the students’ initial goals matched their ultimate work situation with success attained and struggles overcome.

It is recommended that a future researcher use the data collected from this study (use of accommodations, contact with the Office of Disability Services, etc.) and compare it to the support utilized by students with diverse disabilities. This type of study would enable an academic support office such as the one at Northern University to ascertain to what extent certain accommodations/support are needed and whether or not there are accommodations lacking based on student input. A potential future study would enable a researcher to compare a group of students with ASD – their academic needs and the support required – to a group of students not diagnosed with a learning disability. This would be of interest to the researcher seeking
information about the “typical” university student and to what extent he or she might have taken advantage of enhanced support services on campus (e.g. tutoring, writing services, academic support in general). Data gained would enable the researcher to glean more information about what accommodations and support were needed in general by university level students and to see, if possible, how these needs compared to those of students with ASD and learning disabilities in general.

Finally, a similar phenomenological study could be proposed and conducted at a larger university, with the probability of there being a somewhat larger population of students with ASD in a continued effort to research this student population at the postsecondary level.

**Implications for Practice**

In general terms, the researcher’s study at Northern University should have an impact on improved practice in relation to the overall experience of students with ASD in the environment of higher education. Broad implications evidence that continued work must be done originating in the Office of Disability Services (or appropriate office at a particular university). This work must begin even prior to students’ application to a university in that families should be well-aware of what resources will be available. Students must take a pro-active approach in disclosing their disability to the providers in order to be eligible for accommodations. Continued efforts must be made to train faculty and staff in disability awareness and how to implement appropriate accommodations. The study at Northern University documents the good work that has occurred thus far, but also mandates continued efforts to providing communication about services and the necessary follow-through for students in need. All aspects of support should be addressed
beginning with earlier and frequent communication with parents and students, consistent and effective training and awareness for staff as well as for students, and provision of a supportive environment in which students of all abilities have the opportunities and the support to succeed.

**Conclusions Specific to the Study at Northern University**

The study at Northern University addressed and supported the research questions posed concerning the experience of a small group of students with ASD within higher education. In an effort to best describe the students’ experience at the university, a narrative was developed from data collected from student interviews and journal contributions. The overarching essence of the study should be summarized as follows: students with autism spectrum disorders are able to successfully self-advocate and to achieve academically within higher education. At this particular university, the Office of Disability Services, professional staff, and students’ peers are offering significant services to students with ASD and other disabilities in order to help these students overcome the obstacles they face within higher education. During this study, it became quite clear to the researcher that there was clear and frequent communication between services specialists, advisers, instructors, and the students, and that the students had significant access to services and accommodations. Although this study focused solely on students with ASD, the services and accommodations through the Office of Disability Services were available to all students with disabilities, that is, those students who had disclosed their disability to Northern University.

Participants in the ASD study were very self-aware, and they knew of the services and accommodations available and to take advantage of them if needed. One participant noted, “I am
a visual learner, but also an oral learner, for example, for my history class, the professor was mostly oral [in his lecture style], so I take a lot of notes and it really keeps me focused. Some of the professors post their notes on Blackboard, and I sometimes take advantage of that” (Student A, personal communication, October 21, 2011). A participant commented on his academic work, “[My] focus has been pretty good which has enabled me to get work done quicker and with more efficiency. Whatever can be done with most efficiency is usually what I’ll cover first, and then I’ll deal with other problems and ask for help” (Student J, personal communication, September 28, 2011). A third participant summarized his approach to his academic work, “Mainly I focus on just getting what I need to do, done, first, and then I put everything else afterwards. That’s kind of how I go with every class - I set a schedule/list of things due by today and the next day, and then I figure out how to do it” (Student L, personal communication, October 18, 2011).

Recommendations

There are several recommendations that can be made both at the research study level – specific to the study at Northern University – as well as general recommendations for all postsecondary institutions. Categorized in Table 5.4 are the recommendations prompted by the results of the study.

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Connections to the Review of the Literature</th>
<th>Connections to Theoretical Framework</th>
<th>Thematic Codes/ Essential Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continued, clear communication about services available</td>
<td>Strategies and Techniques for Accommodations, Preparation/Professional Development for Staff,</td>
<td>Disability Theory Achievement Ideology</td>
<td>ASD and self-awareness Academic interests Support-Office of</td>
</tr>
<tr>
<td>Accessibility of appropriate support</td>
<td>Strategies and Techniques for Accommodations, Self-Determination &amp; Self-Advocacy, Awareness of ASD</td>
<td>Disability Theory, Achievement, Ideology</td>
<td>ASD and self-awareness, Academic interests, Support-Office of Disability Services, Accommodations</td>
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<td>-------------------------------------</td>
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</tr>
<tr>
<td>Academic peer tutors/per support</td>
<td>Self-Determination &amp; Self-Advocacy</td>
<td>Disability Theory, Achievement, Ideology, Culture &amp; Social Interaction</td>
<td>ASD and self-awareness, Academic interests, Social interaction/collaboration</td>
</tr>
<tr>
<td>Disability awareness training for staff</td>
<td>Preparation/Professional Development for Staff, Awareness of ASD</td>
<td>Disability Theory, Achievement, Ideology</td>
<td>ASD and self-awareness, Support-Office of Disability Services, Accommodations</td>
</tr>
<tr>
<td>Connections with specialists at universities</td>
<td>Preparation/Professional Development for Staff, Awareness of ASD</td>
<td>Disability Theory, Achievement, Ideology</td>
<td>ASD and self-awareness, Support-Office of Disability Services, Accommodations</td>
</tr>
</tbody>
</table>

Table 5.4 Summary of Recommendations

In summary, recommendations were made both specific to this study at Northern University and on a greater scale: 1. Continued, clear communication about services available to students with ASD and other disabilities, 2. Accessibility of support, 3. Provision of volunteer...
peer tutors or academic peer support, 4. Disability awareness and training for university staff, and 5. Connections with specialists at universities to strengthen resources. The Office of Disability Services, as noted, is providing much support and accommodations for students that file with their office and that seek services for a number of disabilities. One means of support provided through the Office of Disability Services is the Social Skills Group, utilized by two of this study’s participants. One recommendation would be that the meeting time (weekly, early evening time) be altered occasionally to enable those students who are commuting to be able to attend. Two study participants noted that they might attend a meeting if the Social Skills Group met earlier in the day, perhaps at lunch. The researcher encourages the Office of Disability Services to continue their good efforts in communicating frequently with the students who have filed with them, reminding them of the services they provide. All participants in the study noted having consistently met with their disability services specialist, and that they planned to continue in the future. It must be noted, however, that not all of the study participants sought accommodations when needed. Reminding the Office of Disability Services to continue to frequently publicize their services would give the students not taking consistent advantage the “push” or encouragement they needed to do so. Furthermore, reminders or notices from the Office of Disability Services might eliminate the “laziness” factor of which some participants admitted kept them from seeking accommodations.

A slightly more difficult theme to address is that of peer support. Participants in this study expressed the general support of their peers at Northern University (primarily through in-class group work). It is essential to note that, even though they expressed interest in socializing, the students consistently noted that academic work was their priority. For the purpose of this
study, the students’ academic success was the general focus of the interviews and data collection. Due to some participants’ lack of certain basic social skills, friendships generally proved to be difficult. In contrast, academics proved to be less of a challenge for these students and actually fun for them. Academics or similar activities were areas in which the study participants could focus, utilizing their strong memorization techniques and good study skills. With academics in mind, the recommendation of peer tutors, or academic peer support of some sort, would bridge the academic need with a much-needed social connection for some of these students.

A recommendation for Northern University, as well as for similar universities, would be for the Office of Disability Services to make connections with specialists at local universities in order to broaden the student community and to strengthen resources. It is hoped that this would provide students with even greater access to facilities, services, and possibly enhanced social outlets as well. Privacy concerns would be of utmost importance, but access to a variety of services would be beneficial in broader terms. In order to reach the greater student population, and to also reach those students with ASD that have hesitated to seek services, the Office of Disability Services should continue their efforts to publicize their good work and services provided. This must be done with students’ comfort level and privacy concerns in mind.

While preparing for this study, the researcher found that all colleges and universities in the area of Northern University had some form of disability services or academic support office, ranging in what they provide as far as accommodations. As a general recommendation, it is clear that all universities could benefit by ensuring that services provided are appropriate to the needs of today’s student population. It is essential to communicate all that which is available, as well as to encourage those with disabilities to not hesitate to file with the service providers. Clear
communication as well as privacy protection is important for all staff and service providers involved.

**Conclusion**

The research sought to enlighten both professionals and students of services available to individuals with ASD, and to address the numerous obstacles a student with ASD faces in his or her quest for higher education. There still may not be sufficient support at some higher education institutions for those students with ASD who wish to pursue advanced education. The research sought better communication between service providers, academic advisers, and instructors of students with ASD, as well as more accessibility to services and accommodations for these students. Under the best of circumstances, students with ASD will be able to better self-advocate for what they need in the higher education setting. Core knowledge in relation to socialization, collaboration among students and staff, change effected by the students themselves, as well as theory on cognitive growth of students with ASD, brought insight into this work. The literature review provided information as to facilities and services available at some current institutions of higher education for students with ASD and the extent to which academic advisers and instructors are contributing to support.

This particular study provided information concerning the reality of whether or not students with ASD were accessing the services needed and to what extent, and the effect of the services available in regards to academic success. It is evident that students with autism spectrum disorders are able to successfully self-advocate and to achieve academically at the postsecondary level. The research study at Northern University shed significant light on the overall experience
of students with ASD in higher education and how they are faring academically and socially. 

Authors Zager and Alpern (2010) reflect on students with disabilities and the progress of IDEA (1990/2004) thus far, “As a result of this legislation and the inclusion movement, increasing numbers of students with significant disabilities, including autism, are participating in programs on college campuses, where they are receiving educational services among their peers” (p.155). Students with ASD or learning disabilities in general are at a disadvantage in that there is a significant gap in their ability to achieve as opposed to their peers’ ability. What students with ASD and other disabilities choose to do with the services and resources available to them either lessens or magnifies this gap and is the achievement ideology at work (MacLeod, 2008). Exactly what the student chooses to do with the achievement ideology - his or her belief in academic success - will make the difference in the student’s experience in higher education.

As the research sought to understand the experience of students with ASD in higher education, results prompted research to move forward in order for educators to better identify what services are currently available to students, and whether or not self-advocacy and access to these services will help students with ASD achieve academic success in higher education. The significance and impact of this study are far reaching and provide greater insight into the world these students with ASD perceive and experience.
References


Appendices

Appendix A

Signed Informed Consent

Signed Informed Consent to Participate in Research Study

Northeastern University, Department of Education
Name of Investigators: Amy E. Tarallo, Graduate Student; Dr. Carol Young, Principal Investigator
Understanding Students with Autism Spectrum Disorders in Higher Education

July 1, 2011

Dear Student of Northern University,

I am inviting you, a student here at the university, to participate in a research project. This form will tell you about the study, but Hyla Jaffe, Liz Henley, and Dennis Green, disability services specialists from the Office of Disability Services, will explain it to you first. Please feel free to ask any questions you have of them, or of me, the researcher. When you are ready to make a decision, you may tell the researcher if you want to participate or not. You do not have to participate if you do not want to do so. If you decide to participate, the researcher will ask you to sign this statement and will give you a copy to keep.

Why am I being asked to take part in this research study? Why is this research study being done?

You are being asked to participate in this study because you have identified yourself as a student with autism spectrum disorders, and you have asked for accommodations from the Office of Disability Services. The purpose of this study is to see how students with autism spectrum disorders are achieving academic success and to describe your experience in higher education.
What will I be asked to do?

If you decide to participate in this study, you will be invited to do the following:

- An informal interview (of approximately 45 minutes) at the beginning of the term (September '11).
- Throughout the study, if you are comfortable, you will be encouraged to keep an informal journal of your thoughts and reactions. At the mid-point of the term, journals will be collected in order to add this informational feedback to the study. This is also a voluntary piece of the study: it is a means for the researcher to gain further insight into your college experience.
- A 2nd informal interview (approximately 45 minutes) near the end of the term December '11.
- During the interview process, the researcher will take extensive notes, and each interview session will be digitally recorded (in order to ensure proper transcription of students’ responses).

Where will this take place and how much of my time will it take?

The interviews will take place with the researcher, Amy Tarallo, in one of the office spaces of the Disability Services suite in Exeter Hall. Amy Tarallo can be reached in Robert Frost Hall (603) 645-9624 ext.3328; please contact her or Liz Henley, Assistant Director, Office of Disability Services, Exeter Hall, (603) 668-2211 ext.2118. The approximate time this will take is noted above.

Will there be any risk or discomfort to me?

The risks of this research project are minimal. As the researcher, I will take every precaution to ensure the confidentiality of the participants, and will ensure that you are comfortable and that you understand each step of the study. Interviews will be conducted entirely in private at the comfort level of the student. If you are not comfortable answering any particular question, you do not have to answer. If an interview needs to be rescheduled at your request, this can be done.

Will I benefit by being in this research?

There are no immediate, direct benefits for participation by the students. However, the information learned from this study may benefit future students with autism spectrum disorders in higher education. In addition, information learned may help professional staff working with students, like you, in the future.

Who will see the information about me?

Your identity as a participant will be matched to your responses, but only the researcher, Amy Tarallo, for this study will see the information about you. However, any written summary of this
research study will not reveal your name or identity. The results of the study will be completely confidential. No reports or publications will use information that can identify you in any way.

In order to protect your personal information, students will be identified by a letter code as information is summarized. Themes that emerge from the interviews (e.g. ways in which you, as a student, seek assistance from your professors) will be coded/identified for review and analysis. Data will be organized in order to learn information about how students like yourself are succeeding in your academic classes. In order to make sure that your responses are accurately and clearly understood, your interview will be audio-taped. Please know that any audiotape will not be identified with your name.

Occasionally, authorized people may request to see research information about you and the other students in this study. This is to ensure that the research is done properly. We would only permit people who are authorized by organizations as Northeastern University (through which the research, Amy Tarallo, is working), or the Office of Disability Services at the university to see this information.

**What will happen if I suffer any harm from this research?**

There should be no reason why you might suffer from a research-related injury. No special arrangements will be made for compensation or for payment for treatment solely because of my participation in this research.

**Can I stop my participation in this study?**

Your participation in this study is completely voluntary. You do not have to participate in this study, and you may quit at any time. If you do not participate or if you decide to quit, you will not lose any rights, benefits, or services that you would otherwise have as a student.

**Who can I contact if I have questions or problems?**

If you have any questions or problems, please do not hesitate to contact the researcher, Amy Tarallo, who can be reached in Robert Frost Hall, 112, (603) 645-9624 ext.3328. Or please contact Liz Henley, Assistant Director, Office of Disability Services, Exeter Hall, (603) 668-2211 ext.2118.

**Who can I contact about my rights as a participant?**

If you have any questions about your rights as a participant, please do not hesitate to contact: Nan C. Regina, Director, Human Subject Research Protection, 960 Renaissance Park, Northeastern University Boston, MA 02115 tel. (617) 373-7570
E-mail: irb@neu.edu
Will I be paid for my participation?

You will not be paid for your participation as it is a voluntary study.

Will it cost me anything to participate?

It will not cost you anything to participate.

Is there anything else I need to know?

You must be at least 18 years old to participate in this study, unless your parent or guardian gives permission.

I agree to [have my child] take part in this research.

____________________________________________ ________________________
Signature of person [or parent] agreeing to take part                      Date

____________________________________________
Printed name of person above

____________________________________________ ________________________
Signature of person who explained the study to the participant above and obtained consent                      Date

____________________________________________
Printed name of person above
Appendix B

Protecting Human Research Participants Certificate of Completion

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Amy Tarallo successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 12/01/2009

Certification Number: 345982
Appendix C

Interview Questions – Understanding Students with Autism Spectrum Disorders in Higher Education

Amy E. Tarallo, Northeastern University Greet the student and make introductions, explaining briefly the role of the researcher and the researcher’s background (Doctoral student at Northeastern University; employed by the university where the study takes place). Explain the researcher’s personal interest in autism spectrum disorders and passion for delving further into educating students with ASD.

Introductory and warm-up questions to make students comfortable:

1. How are you today? What year are you here at the university? What class/classes did you have today?
2. Are you involved in any clubs or activities on campus (if so, what are they)? How often do you participate?
3. What activities do you enjoy outside of school?
4. Do you have work a part-time job or do volunteer work?

Academic and career aspirations:

5. What are your academic goals at the university (major, minor, etc.)?
6. Do you have a favorite class and, if so, why is it your favorite?
7. What job/career would you like to do in the future?
8. If there were any job/career you could do, what would it be?

Self-Awareness:

9. What do you need to help you reach your academic goals?
10. Do you know how your disability affects your learning?
11. What are your strengths in the classroom? Outside of the classroom?

12. Do you know of your weaknesses/areas in which you know you need assistance?

13. To reach your academic goals, are there skills you need that you do not have?

**Accommodations/ seeking the Disability Services Office:**

14. What services does the Disability Services Office provide that you know about?

15. With whom have you met in the Disability Services Office? Approximately how many times have you met with her/him?

16. Do you feel that your visits to the Disability Services Office are helpful?

17. Have you attended any events or used any of the services provided by the Disability Services Office? If yes, please tell me about your experiences.

**Accommodations by professors/classmates:**

18. Have you met with your academic adviser? What can your adviser do to help you meet your academic goals?

19. What can your professors/instructors do to help you meet your academic goals?

20. What specific ways have professors helped you in class (e.g. extended time on tests or assignments, recorded or scripted lectures, etc.)

21. What can your friends or family do to help you meet your academic goals?

22. Have your classmates been helpful to you? If so, please explain.

23. Have there been situations in which your classmates have not been helpful to you?

**Self-advocacy:**

24. Have you asked your professors for accommodations or help in the classroom?

25. If yes, what types of accommodations have you received in the classroom?
26. If you have not asked for accommodations or help, why not?
27. Do you think you will ask for accommodations or help in future classes?
28. Are you comfortable asking for assistance/accommodations from your professors? Please explain.
29. Are you comfortable asking your classmates/friends for help in class? Outside of class?
30. Are you aware of what you need in the classroom to reach your academic goals?
Appendix D

Introductory Letter for Students

August 1, 2011

Dear Student:

Hi, my name is Amy Tarallo, and I am inviting you, a student of Northern University to participate in a research project. I am a doctoral student at Northeastern University studying autism spectrum disorders and this study is being conducted for my dissertation research. Although I work here at the university as the Academic Adviser to the Education students, I want you to know that my position here has nothing to do with the research study.

You are being asked to participate in this study because you have identified yourself to the Office of Disability Services as a student with autism spectrum disorders. The purpose of this study is to explore what it means to be a student with ASD attending an institution of higher education. If you are under 18 years of age, you will need parent/guardian permission to participate.

At our first meeting, I will provide you with a consent form with more detail about my study; however, your assigned disability specialist, from the Office of Disability Services, will briefly explain it to you first. Please feel free to ask any questions you have of them, or of me, the researcher. When you are ready to make a decision, you may tell one of them if you want to participate in the study or not. You do not have to participate if you do not want to do so. If you do not participate or if you decide to quit, you will not lose any rights, benefits, or services that you would otherwise have as a student at the university.

Please let your disability services specialist know how you would like to be contacted by me, through e-mail or by phone, and I will contact you soon after. In addition, it would be great if you let me know what your schedule/availability would be to meet.

If you agree to participate in the study, you will be asked to take part in two interviews which will take place in the Office of Disability Services suite in Exeter Hall. First, you will participate in an informal interview (of approximately 45-60 minutes) at the beginning of the term (September ‘11) with me, Amy Tarallo, the researcher. The intent of the interview is to gather information about your overall experience (both academic and social) here at the university.

You will then participate in a 2nd informal interview (approximately 30 minutes) near the end of the term, December, ‘11. Please know that both of the interviews will be tape-recorded to maintain authenticity of your responses; however, the recorded answers will not be shared with
anyone and will be used solely by the researcher for the purpose of gathering information. After the study, any information you have contributed will be disposed of appropriately.

Throughout the study, if you are comfortable, you will be encouraged to keep an informal journal of your thoughts and reactions. This journal can be in electronic or hand-written form, and can be e-mailed to me, the researcher, or given to me at the mid-point of the term via campus mail. For the sake of keeping all materials private, please do not include your name on the journal. This is a voluntary piece of the study: it is a means for the researcher to gain further insight into your college experience. After the study is complete, the journal will be disposed of as well.

Please contact me if you have any questions at this point.

Amy Tarallo

Northern University
Appendix E

Northern University
Office of Disability Services
ACADEMIC ACCOMMODATIONS FORM (SAMPLE)

TO Northern University instructor/Staff:

FROM Disability Services Specialist:

Staff Telephone: ___________________       Staff E-mail Address: ___________________

Student name: ___________________       Student ID: ___________________

This student has documentation supporting eligibility for accommodations in your class.

**He/she needs to make arrangements with you for the following recommended accommodations.**

Accessible Text Format*
Allow Student to Modify Discussion Board Postings
Computer for Tests
Computer for Written Assignments in Class
Electronic Test Format
Extended Test Time on Timed Tests Only - Time and a Half
In-class Technology - Audio Recorder
In-class Technology - Calculator
In-class Technology - Laptop
Not Responsible for Spelling without Access to Spelling Tools
Note Taker
Provide Electronic Copies of Handouts/Materials to Student
Reduced Distraction Testing - Private
Use of Screen Reader for Tests*
Written Instructions to Accompany Oral Ones

*These items are the responsibility of the Office of Disability Services.
**Accommodations that would fundamentally alter the nature of your course are not deemed reasonable. If there is any dispute between our recommendations and what you provide then the student has been instructed to return to ODS to facilitate a resolution of the dispute.**

*Since it is the student's responsibility to share the form with you, the student must email the Office of Disability Services with confirmation that all necessary arrangements have been made for accommodations in your class. If you have any questions, please contact the Office of Disability Services.*
Appendix F

IRB Application and Approval
NOTIFICATION OF IRB ACTION

Date: August 26, 2011  IRB #: 11-08-12

Principal Investigator(s): Carol Young
Amy E. Tarallo

Department: Doctor of Education Program
            College of Professional Studies

Address: 50 Nightingale Hall
          Northeastern University

Title of Project: Understanding the Experience of Students with Autism
                 Spectrum Disorders in Higher Education

Participating Sites: [Redacted]

DHSS Review Category: Expedited #6, #7

Informed Consents: One (1) signed consent form

Monitoring Interval: 12 months

APPROVAL EXPIRATION DATE: AUGUST 25, 2012

Investigator’s Responsibilities:
1. The informed consent form bearing the IRB approval stamp must be used when
   recruiting participants into the study.
2. The investigator must notify IRB immediately of unexpected adverse reactions, or new
   information that may alter our perception of the benefit-risk ratio.
3. Study procedures and files are subject to audit any time.
4. Any modifications of the protocol or the informed consent as the study progresses must
   be reviewed and approved by this committee prior to being instituted.
5. Continuing Review Approval for the proposal should be requested at least one month
   prior to the expiration date above.
6. This approval applies to the protection of human subjects only. It does not apply to any
   other university approvals that may be necessary.

(Colleen C. Pantalone, Ph.D., Vice Chair
Northeastern University Institutional Review Board)

(Nan C. Regina, Director
Human Subject Research Protection
Northeastern University FWA #4630)
Research Study – Understanding Students with Autism Spectrum Disorders in Higher Education

August 1, 2011

Dear Student:

Hi, my name is Amy Tarallo, and I am inviting you, a student of University, to participate in a research project. I am a doctoral student at Northeastern University studying autism spectrum disorders and this study is being conducted for my dissertation research. Although I work here as the Academic Advisor to the Education students, I want you to know that my position here has nothing to do with the research study.

You are being asked to participate in this study because you have identified yourself to the Office of Disability Services as a student with autism spectrum disorders. The purpose of this study is to explore what it means to be a student with ASD attending an institution of higher education. If you are under 18 years of age, you will need parent/guardian permission to participate.

At our first meeting, I will provide you with a consent form with more detail about my study; however, your assigned disability specialist, from the Office of Disability Services, will briefly explain it to you first. Please feel free to ask any questions you have of them, or of me, the researcher. When you are ready to make a decision, you may tell one of them if you want to participate in the study or not. You do not have to participate if you do not want to do so. If you do not participate or if you decide to quit, you will not lose any rights, benefits, or services that you would otherwise have as a student at University.

Please let your disability services specialist know how you would like to be contacted by me, through e-mail or by phone, and I will contact you soon after. In addition, it would be great if you let me know what your schedule/availability would be to meet.

If you agree to participate in the study, you will be asked to take part in two interviews which will take place in the Office of Disability Services suite in Exeter Hall. First, you will participate in an informal interview (of approximately 45-60 minutes) at the beginning of the term (September ‘11) with me, Amy Tarallo, the researcher. The intent of the interview is to gather information about your overall experience (both academic and social) here at University.

You will then participate in a 2nd informal interview (approximately 30 minutes) near the end of the term, December, ‘11. Please know that both of the interviews will be tape-recorded to maintain authenticity of your responses; however, the recorded answers will not be shared with anyone and will be used solely by the researcher for the purpose of gathering information. After the study, any information you have contributed will be disposed of appropriately.

Throughout the study, if you are comfortable, you will be encouraged to keep an informal journal of your thoughts and reactions. This journal can be in electronic or hand-written form.
and can be e-mailed to me, the researcher, or given to me at the mid-point of the term. For the sake of keeping all materials private, please do not include your name on the journal. This is a voluntary piece of the study; it is a means for the researcher to gain further insight into your college experience. After the study is complete, the journal will be disposed of as well.

Please contact me if you have any questions at this point.

Amy Tarallo
Robert Frost, 112

[Redacted email and phone number]

APPROVED
NU IRB# 11-08-12
VALID: 8/26/14
THROUGH: 1/31/15
Understanding Students with Autism Spectrum Disorders in Higher Education

Amy E. Tarallo, Northeastern University

Text of e-mail to participants (to be sent at the beginning of the term after the students have expressed interest in the study):

Dear Student:

Your Disability Services specialist recently gave me your name as a student who might be interested in participating in my doctoral study: Understanding the experience of students with autism spectrum disorders in higher education. I am looking forward to talking to you about your experience here at [______]. I would like to set-up our first interview, which will last approximately 45 minutes - 1 hour. At this time, I will explain the study in greater detail, and I will have you sign an Informed Consent Form to ensure that you agree to participate in this study (this will take approximately 10-15 minutes). We will then proceed with informal interview questions about your experience here. Interviews will take place during the week, either on a Wednesday morning, during the lunch hour, or after 4:30 pm on most days. This interview will take place in the Office of Disability Services suite in Exeter Hall. Please let me know your availability and the best time for us to meet. You can contact me via this e-mail address [___@northeastern.edu] or call (603) 645-9624 x. 3328.

Amy Tarallo

Text of e-mail to participants (to be sent at the midpoint of the term):

Dear Student:

I hope your semester is going well! If you have chosen to keep an electronic journal for the study, please submit your work to me electronically via the above e-mail address [___@northeastern.edu]. You may submit your electronic journal notes to me all at once, or several times if you are more comfortable doing this. If you have chosen to keep a hand-written journal, you may leave it for me in my mailbox at the Office of Disability Services. Please place your journal in a sealed envelope and mark the envelope clearly for me, Amy Tarallo, with your initials on the outside as well. I will use your journal entry notes to add to the study overall, and then I will dispose of your notes when the study is complete. If you have any questions at all, please do not hesitate to contact me.

Thank you so much,

Amy Tarallo
Text of e-mail to participants (to be sent towards the end of the term):

Dear Student:

I hope you are enjoying your semester. I would like to schedule the 2nd and final interview with you as we near the end of the term. This interview will again take place in the Office of Disability Services suite and will last approximately 30-45 minutes. Please let me know your availability and the best time for us to meet. If you have any questions at all, please do not hesitate to contact me via this e-mail address [redacted] or call (603) 645-9624 x. 3328.

Talk to you soon,

Amy Tarallo
Northeastern University, Department of Education
Name of Investigators: Amy E. Tarallo, Graduate Student; Dr. Carol Young, Principal Investigator
Understanding Students with Autism Spectrum Disorders in Higher Education

August 1, 2011

Dear Student of __________________ University,

I am inviting you, a student of __________________ University, to participate in a research project. This form will tell you about the study, but I will explain it to you first. Please feel free to ask any questions you have of me, the researcher. When you are ready to make a decision, you may tell the researcher if you want to participate or not. You do not have to participate if you do not want to do so. If you decide to participate, the researcher will ask you to sign this statement and will give you a copy to keep.

Why am I being asked to take part in this research study? Why is this research study being done?

You are being asked to participate in this study because you have identified yourself to the Office of Disability Services at __________________ as a student with autism spectrum disorders. The purpose of this study is to explore what it means to be a student with ASD attending an institution of higher education.

What will I be asked to do and how much of my time will it take?

If you decide to participate in this study, you will be invited to do the following:

- An informal interview (of approximately 45 minutes) at the beginning of the term (September '11).

- A 2nd informal interview (approximately 45 minutes) near the end of the term December '11.

  During the interview process, the researcher will take extensive notes, and each interview session will be tape-recorded (in order to ensure proper transcription of participants' responses).

- Throughout the study, if you are comfortable, you will be encouraged to keep an informal journal of your thoughts and reactions. This journal can be in electronic or hand-written form, and can be e-mailed to me, the researcher, or given to me at the mid-point of the term. For the sake of keeping all materials private, please do not include your name on the journal. This is a voluntary piece of the study: it is a means for the researcher to gain further insight into your college experience.
Where will this take place?

The interviews will take place with the researcher, Amy Tarallo, in one of the office spaces in the Office of Disability Services suite in Exeter Hall. Amy Tarallo can be reached in Robert Frost Hall, (603) 645-9624 ext. 3328. The approximate time this will take is noted above.

Will there be any risk or discomfort to me?

The risks of this research project are minimal. As the researcher, I will take every precaution to ensure the confidentiality of the participants, and will ensure that you are comfortable and that you understand each step of the study. Interviews will be conducted entirely in private at the comfort level of the student. If you are not comfortable answering any particular question, you do not have to answer. If an interview needs to be rescheduled at your request, this can be done.

Will I benefit by being in this research?

There are no immediate, direct benefits for participation by the students. However, the information learned from this study may benefit future students with autism spectrum disorders in higher education. In addition, information learned may help professional staff working with students, like you, in the future.

Who will see the information about me?

Your participation in the study will be handled in a confidential manner. Only the researcher, Amy Tarallo, for this study, will see the information about you. Any written summary of this research study will not reveal your name or identity. No reports or publications will use information that can identify you, your school, or any individual, in any way.

In order to protect your personal information, students will be identified by a letter code as information is summarized. Themes that emerge from the interviews (e.g. ways in which you, as a student, seek assistance from your professors) will be coded/identified for review and analysis. Data will be organized in order to learn information about how students like yourself are succeeding in your academic classes. In order to make sure that your responses are accurately and clearly understood, your interview will be audio-taped. Please know that any audiotape will not be identified with your name. All audiotapes will be destroyed following transcription and analysis.

Occasionally, authorized people may request to see general research information about you and the other students in this study. This is to ensure that the research is done properly. We would only permit people who are authorized by the Northeastern University Institutional Review Board (through which the research, Amy Tarallo, is working), to see this information.

Can I stop my participation in this study?

Your participation in this study is completely voluntary. You do not have to participate in this study, and you may quit at any time. If you do not participate or if you decide to quit, you will not lose any rights, benefits, or services that you would otherwise have as a student at .

Who can I contact if I have questions or problems?

If you have any questions or problems, please do not hesitate to contact the researcher, Amy Tarallo, who can be reached in Webster Hall (603) 644-3102 ext. 3328. You can also contact the Professor overseeing my research, Dr. Carol Young, (508) 587-2834.
Who can I contact about my rights as a participant?

If you have any questions about your rights as a participant, please do not hesitate to contact:
Nan C. Regina, Director, Human Subject Research Protection, 960 Renaissance Park, Northeastern University Boston, MA 02115 tel. (617) 373-4588, E-mail: irb@neu.edu. You may call anonymously if you wish.

Will I be paid for my participation?

You will not be paid for your participation.

Will it cost me anything to participate?

It will not cost you anything to participate.

Is there anything else I need to know?

You must be at least 18 years old to participate in this study, unless your parent or guardian gives permission.

I agree to [have my child] take part in this research.

______________________________________________
Signature of person [or parent] agreeing to take part

Date

______________________________________________
Printed name of person above

______________________________________________
Signature of person who explained the study to the participant above and obtained consent

Date

______________________________________________
Printed name of person above

Approved

NU IRB#:

VALID: 11/08/17

THROUGH: 11/24/17