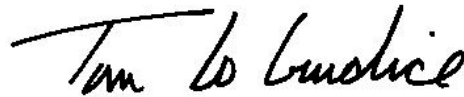


AUTISM:
LIFE AFTER HIGH SCHOOL

Approved:

A handwritten signature in black ink that reads "Tom Lo Giudice". The signature is written in a cursive style with a long horizontal stroke at the beginning.

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AUTISM:
LIFE AFTER HIGH SCHOOL

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by

Callie Jo Gundlach

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Abstract

AUTISM: LIFE AFTER HIGH SCHOOL

Callie Jo Gundlach

Under the Supervision of Tom LoGuidice, PhD

This paper is a report on the life of students with autism after high school, specifically in institutions of higher education or college (U.S. Department of Education, 2003). Autism is a condition that affects a person throughout their life and is usually but not limited to social and behavioral issues. Autism is a spectrum disorder, which means it impacts people's lives differently, from mild to severe (The Centers for Disease Control and Prevention [CDC], 2012). This study focuses on those with mild conditions, otherwise known as high functioning autism (HFA), who are pursuing college opportunities with little experience or help compared to secondary school. High schools are mostly responsible for a student's decision making until the student graduates, then it is almost entirely up to the student to make inexperienced but crucial choices in college that heavily impact their life. The focus of the study was to use a survey and interviews to discover what services are working for students with Autism Spectrum Disorders (ASD) to help guide them in their pursuit of college life and essentially life decisions.

Key terms: autism spectrum disorder, college, higher education, transition programs

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Chapter I: Introduction

Overview

For most high school seniors, graduating is an exciting time in their life. After graduation, some students continue their learning to an institution of higher education or college (U.S. Department of Education, 2003). Anyone attending college for the first time knows there is an adjustment period to multiple things: independent living, classes, homework, new friends and activities, new location, etc. For a person with autism, transitions into college include the above challenges but from a different perspective and experience.

Autism spectrum disorder, according to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, is defined as:

People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items (American Psychiatric Association [APA], 2013, p. 1).

To summarize, autism influences certain communication, social, and behavioral skills. Since autism is a spectrum disorder, it affects people differently and can range from very mild to severe characteristics (CDC, 2012). Autism is also known as a lifespan condition, which means it affects an individual across their entire life, not just during childhood (Kamio, Inada, & Koyama, 2013). An adult with autism interested in going to college has multiple special and new accommodations to adapt to. This dynamic creates a vulnerable and delicate position for the

student. The student with autism has a better chance of success when there are resources and services provided by their school to facilitate their learning and social needs.

Statement of Problem

Students with autism have challenges with communication and social skills that continue past high school. Therefore supports such as social and self-advocacy guidance would be beneficial to them through the transition process in college and make a significant impact to their lives. What types of resources in an institution of higher education works for a high-functioning adult with autism? What types of additional services can a college offer in support of social, emotional, sensory, behavioral, and/or communication proficiency? How can a student with autism better prepare themselves for their role as an independent student in the university setting as whole? These are some of the issues that an ASD learner has to consider when going to college.

Purpose of the Study

The purpose of this educational project is to provide a review of the college information related to adults with autism spectrum disorders; as well as to inform and improve practices in the area of autism and post-secondary education. In order to highlight what is involved with this process additional facts and literature from articles, journals, colleges, and various autism networks nationally, as well as internationally will be presented in this study. Data is also collected from surveying ASD students and interviewing faculty in the disability resource centers at the included colleges.

Significance of the Study

For any individual setting out into college or adulthood, a smooth transition is imperative to their success going forward. This is especially true for an ASD individual who may have significant social and self-advocacy challenges. Due to the social and communication issues

during the process of transitioning into college (and essentially independent living) it is important to examine and evaluate the continuing education system for teachers, family members, as well as other adults with autism seeking information related to best practices.

Definition of Terms

Autism Spectrum Disorder: “persistent deficits in social communication and social interaction across contexts, not accounted for by general development delays; restricted, repetitive patterns of behavior, interests, or activities; symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities); symptoms together may limit and impair everyday functioning” (US Autism & Asperger Association [USAAA], 2013, criteria A, B, C, and D). “Symptoms of people with ASD fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms” (APA, 2013, para. 4).

High functioning Autism: “Asperger syndrome (AS) and high functioning autism (HFA) are often referred to as the same diagnosis. Individuals with AS and HFA have average or above average intelligence but may struggle with issues related to social interaction and communication” (Autism Speaks Inc., 2010, para. 2). The focus of this paper is primarily on students with AS or HFA, because these students are most likely to be permitted and move into an institution of higher education.

Disabled: “physical or mental impairment which substantially limits one or more major life activities; has a record of such impairment; is regarded as having such impairment (National Center for Learning Disabilities” [NCLD], 2013, para. 2).

Handicapped persons: “one who meets the academic and technical standards requisite to admission or participation in the recipients’ education program or activity” (Madaus & Shaw, 2004, p. 82).

Institution of Higher Education: “admits as regular students, only persons having a certificate of graduation from a school providing secondary education or a recognized equivalent; is legally authorized within such State to provide a program of education beyond secondary education; provides an educational program for which the institution awards a bachelor’s degree or provides not less than a 2-year program that is acceptable for full credit toward such a degree; is a public or other nonprofit institution; and is accredited by a nationally recognized accrediting agency or association, or if not so accredited, is an institution that is granted status by such an agency or association that has been recognized by the Secretary for granting of status, [...]” (U.S. Department of Education, 2003, part A). Often referred to as college, postsecondary education, or just higher education; these terms may be used interchangeably.

Action Research: “the systematic collection of information that is designed to bring about social change” (Smith, 1996; 2001, 2007, p. 2)

Transition programs: “to provide students with early awareness of the benefits of continuing their education by enrolling in college; typically providing the following services: academic enrichment, information sharing, mentoring, and social enrichment” (U.S. Department of Education, 2007, p. 1-2).

Delimitations of Research

Data included is collected from national and international resources through the University of Wisconsin System, utilizing the services of Karrmann Library and “Google Scholar” search tools; however the students and faculty surveyed/interviewed are from Wisconsin. Also the students surveyed have high functioning autism or Asperger syndrome, and are attending a technical, 2-year, or 4-year college. Colleges included are public and private institutions, consisting of Southwest Technical College, Madison College or otherwise know as Madison Area Technical College, and the University of Wisconsin-Platteville. Results of the study may not generalize to other groups.

Methods of Approach

The methods of approach used were a descriptive-qualitative study, as well as an exploratory study and action research for a professional study. Data was collected from human subjects through surveys who have high-functioning autism and were attending college. Surveys were administered via SurveyMonkey.com. Interviews only occurred with faculty and staff at the colleges and were documented on an audio recorder and will be archived for three years. In order to validate the results, a discussion with Daniel Leitch, the project advisor, was conducted as well. A brief review of related literature to adults with autism and its impact on life after high school was also conducted. With the focus on valid and reliable instrumentation, the findings will be summarized and synthesized, and recommendations made.

Chapter II: Review of Related Literature

Introduction

It is difficult to describe exactly what autism is and entails, as it differs between each individual who has it (APA, 2013). The similarities of ASD become quite individualistic as children grow up to be adults. As stated so many times during this research process, “students on the spectrum are all different” and “[people] can’t pick characteristics out of each of them and say that all of them have it” (Fayram, 2013 and Garvey, 2013). This chapter will provide an overview of the general characteristics of autism and the experiences that ASD individuals will encounter as they transition into college and elsewhere.

Common Characteristics

A well-known person with autism who is leading a “satisfactory” or meaningful life is Temple Grandin. Grandin is not only known for her advocacy in autism, but she is a well known professor at Colorado State University and best selling author on various topics including her intricate designs in the cattle industry (Grandin, 1995). She was born in the 1940s when both ‘autism’ and/or ‘Asperger’ syndrome were just at their launching stage (National Institute of Neurological Disorders and Stroke [NINDS], 2012) and researchers were just beginning to understand a glimpse of what autism is.

Autism is often associated with certain overt characteristics including social and communication differences and unusual behaviors and interests (CDC, 2012). To give specific examples of such behaviors, in Grandin’s book, some of her early childhood manners are described as: overwhelming sensations of smell and sound and touch; screaming or rocking endlessly; fixed attention for hours on, for example, a few sand grains; a total failure to understand or be understood by other children (Grandin, 1995). In both Grandin’s book (1995)

and other sources, it is explained people with ASD process information in their brain in a different way than other people (CDC, 2012). These different experiences that people with ASD have can create challenging environments to manage, therefore everyone with autism needs to have strong support.

Autism spectrum disorder is touching the lives of more than just those people who have it. Due to it being a life-long developmental disorder it can affect a web of people depending on the individual (Kamio et al., 2013). People involved in the life of a person with autism may include: parents, siblings, family members, friends, teachers, school administration, therapists, doctors, resource specialists, employers, researchers or even other students. Due to the spectrum consisting of a variety of individuals of diverse characteristics, mostly described by social and communication differences and repetitive/stereotyped behaviors, professional help for people with ASD and their families should be well planned for and delivered throughout their lifetime (Kamio et al., 2013). The diversity of results vary as much as the individuals with ASD; some people have been found to lead very pleasing or “satisfactory” lives who have been predicted to do otherwise and vice versa (Kamio et al., 2013).

As Grandin grew up, she learned that the people who were most helpful and supportive to her were the more creative, unconventional types (Grandin, 1995). For instance, one person in particular that especially helped Grandin follow her passions was one of her high school science teachers, Mr. Carlock. He took Grandin’s unique interests and used them to motivate her to study, learn, and essentially manage some of her symptoms of autism. Grandin stated in her book “Mr. Carlock took me to the library and taught me how to do this [searching scientific literature] and take the first step toward becoming a scientist. [...] Mr. Carlock’s training served me well. Later in life, when anxiety attacks were tearing me apart, I was able to research what medication I

needed in the library” (Grandin, 1995, p. 99). Because of the need for support with even the most basics of tasks, the people involved in the life of an ASD person can be critical in shaping their personal interests and general direction in life.

Children Grow Up

First, there are a few more things that a person should know about ASDs. According to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* criteria there are four different types of ASDs: autistic disorder, Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorder—not otherwise specified (APA, 2013). For the purpose of this paper and the diverse literature included, the two main types of ASD are autistic disorder and Asperger syndrome. Although, the DSM-5 criteria have recently changed, in May 2013 these four separate disorders were put into one umbrella term (autism spectrum disorder) with different severity levels (1,2 and 3) depending on the individual (Autism Speaks Inc, 2013).

Although ASDs consist of a range of similar characteristics, there are some common initial signs and symptoms throughout the spectrum (CDC, 2012). For instance, ASDs begin before the age of 3 and last throughout a person’s life, though symptoms may improve (or decline) over time (CDC, 2012). People with ASD might show some of these shared traits: avoid eye contact and want to be alone; have trouble understanding other people’s feelings or talking about their own feelings; repeat words or phrases over and over; give unrelated answers to questions (CDC, 2012). The differences lie in when symptoms begin, how severe the symptoms are, and the exact nature of the symptoms (CDC, 2012). These differences can be compiled into common names such as low-, mild- or high-functioning autism. This paper will mostly be focusing on mild/high-functioning autism spectrum disorder or Asperger syndrome.

If one sample of 50 age 6-17 children is taken, it is estimated that 1 person out of 50 will yield an autism spectrum disorder (CDC, 2013). This is higher than the widely known estimate in 2007 of 1 out of 86 children age 8 currently diagnosed with ASD (CDC, 2013). As already mentioned, ASD is a lifelong disorder; as a result it can be restated from the statistic above that 1 out of 50 *adult people* will have an autism spectrum disorder. In the United States, an estimated 50,000 youth with ASD turn 18 years of age each year (Roux, Shattuck, Cooper, Anderson, Wagner & Narendorf, 2013). What happens to most young adults after graduating from high school? A number of young adults continue their education to college. For many of them, the college experience provides a sense of personal growth and improved self-esteem (Dillon, 2007). Numerous others choose a place of employment instead of college. Employment is a socially acceptable activity and is a major component of passage into adulthood (Roux et al, 2013). There are different types of services that continue after high school to assist people who have ASD with their personal growth into adulthood.

After High School Opportunities

There are a couple of important federal laws to be familiar with as a student with autism or any disability: The Americans with Disabilities Act of 1990 Amendment Act (ADAAA) of 2008 and Section 504 of the Rehabilitation Act of 1973. Both provide special protection and opportunity while attending college (Southwest Tech, 2009). One of the most important definitions to become familiar with is the definition of ‘disabled’, as it is a main area of concern and confusion with these laws. Under ADAAA an individual is defined as disabled if he or she “has a physical or mental impairment which substantially limits one or more major life activities” (NCLD, 2013, para. 2). Examples of major life activities include walking, seeing, hearing, speaking, breathing, caring for oneself, performing manual tasks, earning or working (Southwest

Tech, 2009) and even learning, reading, thinking and concentrating (NCLD, 2013). The individual also needs to have a record of such impairment, for example autism, or regarded as having such impairment, for instance being Deaf (NCLD, 2013).

Another crucial definition to be familiar with, which is quite similar to the meaning of disabled, is ‘qualified handicapped person’. This definition is used more in Section 504, under subpart E or *postsecondary level*, and is defined as “one who meets the academic and technical standards requisite to admission or participation in the recipients’ education program or activity” (Madaus & Shaw, 2004, p. 82). These laws are in effect to provide disabled or qualified handicapped persons with equal opportunities to access program benefits, however they are not required to produce the identical result or level of achievement of a nondisabled student (Madaus & Shaw, 2004). Hence, a student at the college level with disabilities must be able to meet the entries standards set forth by a particular institution or a specific program within the institution. Although, it is reported that in some cases, colleges may be flexible with admission requirements for disabled students (Madaus & Shaw, 2004). Consequently, the role of the disabled student or individual with autism, as well as the school, is much different in college than it is in high school and can cause misunderstandings while in transition.

How Laws are used by Schools and Students

A valuable and understandable chart of information on Section 504 about the specific responsibilities of the student, school, and parent in high school and in comparison to college make it very clear that in college a student with a disability is almost solely responsible for themselves... while the school is mostly responsible for ensuring provision of reasonable accommodations (Madaus & Shaw, 2004, appendix C). Reasonable accommodations comprise of

architectural access, providing essential communication aids and services, and modifying policies, practices, and procedures (Leuchovius, 2003).

In brief, many of the responsibilities are similar to any student, disabled or not, regularly applying to college. For instance, the course selection and program choices are up to the students. Payments, including tuition, housing and food, are all up to the students to arrange (and maybe parents/families) as well. Lastly, monitoring certain things such as student progress and effectiveness of accommodations are held accountable to the students. Most importantly and unlike most students, it is up to the student with a disability to disclose their disability, including the required evaluation from a specific professional in order to guarantee provision of reasonable accommodations (Madaus & Shaw, 2004). As a student with autism transitioning from high school to college, there are a lot of changes to consider and skills to develop in between. Bearing in mind that in high school most areas of responsibilities are the schools' as stated above; in what ways does a student with a disability learn how to navigate these important decisions without specific training?

Extra Support

Since colleges support students with autism and disabilities differently, or are not as easily accessible to help compared to high school, a student with autism may have to search in various places for their specific needs and desires. First and foremost, if a student with autism is seeking assistance through disability acts, then they must *self-identify* or disclose as having a disability to certain faculty at the college. Again, this may include providing the appropriate documentation from the proper professionals, especially for those with learning, psychiatric or chronic health impairments or in other words “hidden” disabilities (Leuchovius, 2003). This may also include informally self-disclosing to professors and peers. Secondly, it is very important for the student

to realize that they need to be *self-advocates* in order to get their specific needs met. If either of these steps are missed, then a school cannot provide any assistance when it is not aware assistance is desired (Leuchovius, 2003). Luckily, a student does not necessarily have to go through this process alone, it can often be advised by the college's Office for Students with Disabilities and other available resources (Leuchovius, 2003).

Most colleges have an Office for Students with Disabilities, or otherwise specified, but they often vary in their assistance to students. Although, these basics are usually covered: testing accommodations (extension of time and/or change in environment), communication help (virtual notes, note-takers, taped lectures, sign language interpreters), physical access to buildings and classes (ramps, automatic doors, front-row seating), tutors (general tutoring center provided to all students, sometimes with an additional fee), and referrals to other resources. For a student with autism, other areas may need more support than just the above basics. This can be a tricky situation, because a college is only obligated to 'reasonable accommodations'. This means the college will adjust such things allowing equal access and equal opportunity to participate, but it will not change the curriculum or essential elements of a program or course (Southwest Tech, 2009). Curriculum changes could very well risk losing a college's accreditation. However, a student with autism may not need changes to the curriculum necessarily, but instead may need certain minor alterations to the regular support system that is offered to students.

Unique Services for Unique Students

From the list above, it may seem like students with autism are well supported by their schools and for some of them the basics may very well be enough. Yet, there are still some areas that may be in need of help... things that are less obvious or behind the scenes, especially in social and behavioral skills (Dillon, 2007). Note: if a college offers more than the minimum level

of services required to the student with a disability, the college may charge extra fees to cover those benefits. For example, pairing a student with an individual learning specialist could cost the student an extra fee (Madaus & Shaw, 2004). Such services as mentors, transition/coach arrangements and/or courses, rehabilitation services, educational group counselors and/or therapy, or tutors are just a few examples of extra assistance that ASD students might benefit from, but unfortunately could possibly be charged extra for.

For instance a mentor/coach could help an ASD student with everyday activities, like dressing and grooming appropriately, as well as encouragement and moral support with friends and college life (Grandin, 1995). An educational group counseling course or education transition course could assist with various things like navigating a college's website and campus, studying for a particular class (tutors too), learning social skills with the chance of role-play in a safe environment, and many other issues such as self-disclosing and socializing with professors and classmates (see appendix E for example teaching methods). A life coach could teach social graces, including using appropriate voice patterns or how to politely confront professors and classmates (Grandin, 1995). A transition coach/mentor could help with the process of changes from high school to college (self-advocacy, independent living, and schedule organization) and college to workplace (interview skills and constructive criticism).

Transitions are a process of change, which should be well planned for throughout an ASD student's life. For a student with autism this shift involves more than a handover from specialist to specialist (McConachie, Hoole, & Le Couteur, 2011). It is these extra services, mentioned above, that are key to success in college for students with autism. As Dillon's article indicated, students who get these essential supports have a higher likelihood of success (2007).

Summary

Autism spectrum disorder is a lifelong condition; therefore support should be well planned for throughout life, to college and beyond. Data did show if the appropriate support is provided, particularly after high school and into college, people with autism could lead a more meaningful and productive quality of life. Support services are legally provided to students with autism through high school, but when students graduate to college these services diminish drastically. Instead of the school's being mostly responsible for a student's educational decisions in college, it is primarily the student's responsibility and with barely any prior experience. With some of the unique services in college, including but not limited to mentors/coaches, group counseling, specialized education transition course and other assistance with specialists/aids, ASD students have a better chance of success. However, the appropriate support varies as much as the autism spectrum; each person requires different services. More research needs to be done on what those services entail in order to better help college students with autism. The survey and interviews involved in this project should help gather information about resources from the students with autism attending college and the faculty involved in assisting those students. The following section goes into more detail of what the survey methodology entails.

Chapter III: Survey Methodology

Overview

In order to understand beneficial resources for students with autism, directly from the students themselves, this researcher developed a survey with Daniel Leitch (see appendix A) for those students attending college to complete. Daniel Leitch is a professor of education at the University of Wisconsin-Platteville, and was involved in planning and implementing this project, specifically with designing and assistance in analyzing the survey and interview data.

Surveys were completed online through SurveyMonkey.com. Interviews were also done with a faculty/staff member one-on-one in each school's office for disabilities, in order to get a better understanding of what resources are offered at their school and suggestions to better resources for students with autism. Afterwards, an observation and discussion of the data was made with the help of Daniel Leitch in order to collect his input as an education professor with a background in special education, and thus making a triangulation of data collection. Again the purpose of this qualitative study is to simply research what is happening in the selected institutions of higher education and decide how to make them better for students with autism or in other words this is an action research study (Smith, 1996; 2001, 2007).

Participants

Adults with autism attending an institution of higher education were recruited with the help of the faculty and staff at the participating institutions. Nothing was known about the students' background (other than they identified as students with ASD) due to the surveys being completely anonymous. The survey was forwarded to students via email by the involved faculty, with the consent form attached. Only two responses total were collected, from an estimate of 88 students total that the survey was sent to.

Instrumentation

This researcher, with the approval of Daniel Leitch to increase the tool's validity, developed the survey used in this project. The survey consisted of 9 ranking questions and 5 short-answer questions. Participants were asked to answer the ranking questions first, and then move on to the short-answer questions if needed. The delivery of the survey was through a free software and questionnaire tool called SurveyMonkey.com. Survey Monkey presents the most acknowledged online trust seals including Norton, TRUSTe, McAfee and the Better Business Bureau. Therefore the data collected is confidential, safe, and secure.

This researcher also developed interview questions used in this project, which also takes on a qualitative approach. The interview responses are used as a branch of the review of literature and in the very last chapter in this paper.

Procedures

The Institutional Review Board (IRB) of the University of Wisconsin-Platteville has approved this project. The final approval letter is included in appendix B and F. Madison Area Technical College has also approved this project, and the final approval letter can be found in appendix C.

Surveys were completed online, via SurveyMonkey.com. See appendix A for questions and chapter 4 for results. The ranking questions fulfilled the results of the survey. The short answer questions were completely optional to answer. The survey took 10-15 minutes to complete. All surveys were completed anonymously. The following was a central part of this survey project:

1. Staff from disability resource offices, were contacted via phone or email to help get student participants for the research survey.

2. Then, research participants were contacted by staff to participate in the online survey.
3. Consent forms were attached to the survey to read before participants took the survey (see appendix D). No signature was needed due to sending anonymous surveys.
4. Surveys were distributed via email and collected via SurveyMonkey.com for a total of **35** days. Some participants responded to short-answer questions.
5. After data collection, all data was processed and analyzed to develop an idea of what resources work for students with autism going to college.

Interviews were done one-on-one, in-person and audio recorded, they will be archived for three years. This researcher came up with some questions to simply guide the interviews, or more appropriately conversations instead of following a rigid agenda. The people interviewed were staff members from the individual school's disability resource center who have present knowledge and experience in college services for ASD students. Below is a brief background on each of the staff members.

The first staff member was a Senior Disability Resource Liaison and worked for Madison College. She was currently working on the revision of the *ASD Guide for Wisconsin Technical College System (WTCS) Staff*. This is a resourceful tool for both professors and students.

Another staff member interviewed, but from South West Technical College, was also working on this guide. She was a Support/Disability Services Specialist and Transition Coordinator. Lastly interviewed was a person who has been recently hired as the Assistant Director for the Services for Students with Disabilities of UW-Platteville. Some of the staff comments can be found in the results, under chapter four.

Below was the basis of our conversation during the interviews:

- Describe your position and responsibilities at your institution of higher education.
- About how many students with autism are attending your institution of higher education?

- Describe the services and resources your school offers to students with autism.
- How are the services offered different for those students who are self-disclosed versus not?
- From your observations, what service/resource is most valuable to students with ASD?
- What ASD service/resource do you think could be improved upon?
- How can professors be educated to better service ASD students?
- Overall, what changes would you like to see in program planning for students with autism?

Triangulation

Triangulation is an action research tool to compensate for the problem of limited validity of an instrument and the lack of reliability associated with new instrumentation. This study used numerous methods to collect data (interviews, surveys, and informal discussion) from multiple sources including ASD students participating in college, staff members from the disability resource centers in the participating colleges, as well as an informal discussion and analysis of the survey data with Daniel Leitch.

Methods of Data Analysis

Due to the limited data from both the survey and interviews, the methods of data analysis were simple. Through basic deductive reasoning this researcher looked for similarities and common ideas from both areas of participation and compared them not only with each other, for instance student-to-student or staff-to-staff, but as well as student's to staff member's responses.

Chapter IV: Results

The purpose of this study was to investigate the disability resources available specifically to students with autism who were attending a few of the local colleges and technical colleges in Wisconsin. Surveys were administered to ASD students, while the staff members were interviewed to collect their experiences and opinion about common trends in autism while attending an institution of higher education. The findings are below under the following questions from the survey and interviews:

Findings

Survey

The first ranking question asked, “Other than the staff of the Disability Resource Center, how understanding are your professors about autism spectrum disorders?” Both students answered, “good.”

The second question asked, “How do your professors help and accommodate your specific needs?” Both students responded, “excellent.”

The third question asked, “How flexible is your schedule? For example, if you need a day off, are you allowed makeup time?” One student answered, “good.” The other student answered, “excellent.”

The fourth question asked, “How helpful is your program counselor in the **beginning** of the semester?” Both students answered, “excellent.”

The fifth question asked, “How helpful is your program counselor **throughout** the entire semester?” One student answered, “good.” The other student answered, “excellent.”

The sixth question asked, “Does your university have a peer mentor program? If yes, how helpful has the peer mentor program been in your adjustment to college? Peer support includes: study skills, campus activity and organization concerns, campus services, and college life.” One student responded, “N/A.” The other student skipped the question. One of the students also commented, “I don’t believe Madison College has one as far as I am aware.”

The seventh question asked, “Does your university have a tutoring center? If yes, how would you rate your tutoring center? [Reading/writing center and math/science center].” One student answered, “good.” The other student answered, “excellent.”

The eighth question asked, “How would you rank your Disability Resource Center’s services?” One student answered, “good.” The other student answered, “excellent.” One of the students commented, “It’s good overall, but improvements can always be made.”

The ninth and last ranking question asked, “Are you satisfied with your education here?” One student answered, “good.” The other student answered, “excellent.” One of the students commented, “The politics of Madison College NEED to improve before I would want to see an increase number of people with ASD here.”

The tenth question consisted of five short answer questions, to get more written comments from the students. All quotes below are direct quotes from the ASD students.

The first short-answer question asked, “What do you **like** about your school?” One student commented, “DRS Services, achievement center.” The other student commented, “I love that my teachers and the staff are extremely helpful and student focused.”

The second question asked, “What do you **not like** about your school?” One student commented, “Congested work out area.” The other student commented, “Administration needs to improve and possibly get new people who approve of keeping and adding exceptionally excellent teachers and staff at Madison College.”

The third question asked, “What additional resources do you think would better your experience?” One student commented, “Having help available for using Civil 3D software. More people helping me with my Civil Engineering Courses.” The other student commented, “Better times for classes. 13 hour school days should not be the only option for certain programs.”

The fourth question asked, “What are your class sizes?” One student answered, “About 20-30 people.” The other student answered, “15-22.”

The last short-answer question asked, “How is your family involved in your college life?” One student responded, “Help me with h/w, job development, helping around the house and expenses.” The other student responded, “Not too much anymore, they will buy school related materials for me that I need from time to time.”

Interviews

Included below are some samples from the interviews and/or quotes from the staff members. The specific question is posted before the responses. The discussions were lengthy, so some of the questions were omitted due to their irrelevance to the research. As mentioned before, the questions were simply a guide to our conversation during the interviews. A full list of the possible questions talked about during interviews was included in chapter three. The following questions or comments were the foundation of our conversation during the interviews:

When staff members were asked, “About how many students with autism are attending your school?” The staff member at one school estimated, “11 students.” The staff member at another school estimated, “70 students.” The staff member at the last school estimated, “7 students.”

When asked to “Describe the services and resources that your school offers to students with autism.” All staff members responded that they have general classroom and testing accommodations, note-taking assistance, along with some form of ebooks. More specifically though, one staff member commented, “Peer-mentoring program.” Another staff member commented, “Department of Vocational Rehabilitation.” The last staff member commented, “24/7 net-tutoring, only for certain courses.”

When asked, “From your observations, what service/resource is most valuable at your school to students with autism?” One staff member responded, “Every student is case by case. Common classroom accommodations, including note-taking, are very crucial and helpful.” Another staff member responded, “Testing accommodations are very common for all students with disabilities, as well as tutoring services in the Student Achievement Center, however students on the spectrum are all different.”

When asked, “What service/resource do you think your school could improve on most?” One staff member commented, “How to support their social and communication and engagements on campus. [These areas are] part of their college education, part of why they are here and in order to gain that access that other students on campus have, we have to figure out a better way to support those kind of needs in addition to classroom accommodations [...] that is as important.” Another staff member suggested, “Nice to have a meeting before [the semester] with ASD student and their professors to make certain plans for the year, including self-

disclosure and certain social, communication, [and/or] sensory issues. For instance sarcasm and jokes, fire drill routine, and rules for appropriate class participation.” The last staff member mentioned, “Students need help with tutoring for specific courses.”

When asked, “How can professors be educated to better service ASD students?” One staff member responded, “Provide more disability specific education or informational sessions for campus as a whole: students, faculty, and staff. I think it’s important to raise the awareness about why students with disabilities often need accommodations and what those accommodations do for a student because a lot of misunderstandings that occur and assumptions are made [when an] instructor may know what the accommodation is but may make some assumptions about the student’s abilities or intellectual capacity based on that. Those assumptions [from teachers] can impact a student tremendously. It’s helpful when professors have a little bit more information and understanding of ASD and how that impacts an individual. Also, understanding sensory issues and how it impacts students behavior with ASD is helpful to frame what instructors are observing.” Another staff member referred to the revision and shortening of the *Autism Spectrum Disorders (ASD) Guide for Wisconsin Technical College System (WTCS) Staff* as being a valuable resource for professors at schools. Pointing to the longer 2009 version, she commented, “Faculty is not going to read all of this.” The last staff member commented, “I don’t think they [teachers] have enough information about autism and [some] don’t have expertise or prior background working with ASD students.” She suggested, “Workshops at the beginning of the year/semester by someone else who specializes in ASD. Strategies for professors on how to deal with ASD students are needed.”

When asked, “What changes would you like to see in program planning for students with autism?” One staff member partially answered this question already when ask about school

improvements that could be made, although she additionally commented, “how to talk to the instructor about normal classroom things or if something [unexpected] happens, is an area that needs more assistance.” Another staff member partially answered this question too when talking about school improvements. She also commented, “There needs to be some sort of education [course] or some sort of training or facilitator for students on the spectrum for when they are in groups, to decipher what people are saying.” Lastly, a staff member commented, “[We] need the other professor’s support with more communication about student’s attendance and progress reports, otherwise it is difficult to hold students accountable. This is the type of help ASD students need sometimes.”

Chapter five continues with a summary of the above findings and possible explanations of findings. Suggestions and recommendations for future directions of research, along with concluding comments are also provided in the next chapter.

Chapter V: Summary, Conclusions and Recommendations

Summary of Findings

Again only two students responded to the surveys, out of a possible 88 total ASD students, from all the involved colleges. Therefore the findings may not be a general representation of all ASD students. Surveys showed that the students are mostly satisfied with their professors, resources, and college overall at their involved institutions of higher education. Both students who participated in the survey study ranked most answers either good or excellent. However, question six from the survey asked about a peer-mentoring program, which helps in study skills, campus activity, organization concerns, campus services and college life. The lack of both students' responses showed that schools might be missing out in these social areas for students with autism.

The interviews from the disability staff members were very resourceful in providing qualitative data. Overall the interviewees provided similar responses; most of the higher institutions involved in this study have the general classroom and testing accommodations, but they vary in specialized accommodations for ASD students. Such accommodations include: socialization and peer-mentoring both in and outside the classroom, as well as preplanning with professors for the school year ahead. Because of the unique nature of the relationship between students with autism and their instructors there seems to be a need for additional support (both for staff and students) in facilitating ASD students into a typical classroom. With the help of raising the awareness about autism, staff members will be able to better provide and support students with ASD (White, Ollendick, & Bray, 2011).

Explanations and Limitations of Study

The main limitation of this study was the limited sample of responses on the survey from ASD students. The survey was not forced upon the students; this researcher wanted them to be comfortable due to the common social barriers involved, hence the convenience of an anonymous online survey. Online surveys are convenient, but they are also easier to dismiss than face-to-face surveys, therefore this is reflected in the low amount of survey responses collected.

Another limitation of the survey was the type of questions (open-ended) asked, which could have deterred students from taking the survey all together. As Sarah Cho, the Survey Pro from Survey Monkey said, “Open-ended questions almost always have a lower response rate” (2014). Although in this researcher’s survey the open-ended questions were set up like closed-ended questions (for instance multiple choice questions with ranking options to click for answers), still a low number of students actually followed through with taking the survey. I also allowed students to add comments if they wanted to after each question and added an additional five short-answer questions at the very end of the survey for other comments. This may have been another factor in discouraging respondents to take the survey. Instead Survey Monkey suggests saving the comments for one general short-answer question, which can include any other comments, questions, or concerns, at the very end of the survey so the respondents have a pleasant experience taking a short survey.

Another limitation was the number of instruments used in this study; including only the survey and interviews. This researcher wanted to interview the students, initially, to get their direct responses and quotes about their school. However, this was much more difficult to obtain

ethically with the students, therefore interviews were taken from the staff members at the disability resource centers and the students surveyed.

Lastly, a pilot study was not administered in this research project due to its' exploratory purposes. This research project simply studied what is happening in our local Wisconsin colleges and deciding how to make them a better place for students with autism. As a result, a needs assessment was conducted on finding out how to better prepare ASD students in social and communication skills, as well as self-advocacy practices for life in college and beyond. From the research, survey, and interview the needs assessment posed true. Therefore, suggested teaching methods are briefly described below and explained in more detail in appendix E.

Conclusions

Despite the limitations, there are some conclusions that can be taken away from this study. Through this process, it is clear that schools are currently performing at a reasonable standard for their students. However, as indicated in the survey and interviews, there are still distinct areas of deficit for the students in adjusting to their college life. These areas include: socialization skills (in order to communicate with professors and students better), self-advocacy (due to the student being mostly responsible for their education needs, unlike before), and raising the awareness of staff members and professors at schools (to better help prevent and manage challenging situations, as well as mentor when needed). Therefore, it is clear that further research would be beneficial for these competency areas for students with autism attending college.

Suggestions: Future Directions for Research

Based on these conclusions, it is recommended that if surveying college students with autism, be careful how the questions are structured; close-ended, short and direct questions might produce better response rates (as suggested by Survey Monkey). However, it would be ideal to actually interview ASD students in order to get their direct, in-depth feedback. Perhaps a group interview, with the help of a familiar face at their school in the background (disability staff specialist), would make it more comfortable for ASD students to participate.

Another suggestion for future research would be looking into the impact of a transition education program to help ASD students better prepare for their college experience. A course focusing on social and self-advocacy skills might be beneficial to assist in the change of responsibilities before college and during college. Currently, transition programs for populations including foreign language, inner-city, and special needs students are popular for providing services that range from academic tutoring, college application assistance, help in accessing student aid (U.S. Department of Education, 2007). For ASD students some additional services to address could be focused on learning strategies for socializing and self-advocacy in the academic setting (U.S. Department of Education, 2013), as well as becoming familiar with their campus life and local community surroundings so they can be prepared for the future.

When students are able to get the additional supports needed from the prominent people in their experiences (on and off campus), they are more able to perform at a their full potential. As Brenda Sunderdance described in our conversation, “For individuals who get supports and are able to become employed and keep employment the autism subsides, not that it goes away, but they develop skills through those employment activities that allow them to be more functional” (2013).

Final Statement

Overall, this research project has been an amazing learning experience through the literature, to the people included and the stories that have been shared with me. One story that came upon me recently was a story about Owen, an adult with autism, attending Riverview School in Cape Cod Massachusetts (CBSNews, 2014). His school is a great example of specialized learning opportunities that an institution of higher education can provide in addition to the general services they already offer. Owen has been able to flourish because of the encouraging support he has received from his family, teachers, and other professionals and friends.

Thinking back to the beginning of this research paper, I talked about Temple Grandin's passion for cattle and how she was able to blossom because of a teacher who noticed this and directed his teachings according to Grandin's interests. Owen is another example of an individual who has been able to take his love for a particular interest and utilize it to express and understand himself, just like Grandin did. He started a club at his school to share his passion for Disney movies with other students. From an early age, Owen found he could more easily relate to others and express himself through the help of characters and stories in the movies. Now as an adult almost graduated from college, Owen runs the Disney Club at Riverview School to stay engaged with the people around him, which has enriched his entire life. As Kevin Pelphrey, who directs the Child Neuroscience Lab at Yale, said, "Individuals with autism have rich experiences, rich feelings, rich emotions -- those can be harnessed to help them learn, to engage with the world" (CBSNews, 2014, para. 30). With the appropriate supports and inspirations, such as those as mentioned throughout this paper, people with autism can continue to grow after high school, to college and life beyond.

APPENDIX A

Survey

Key: 1= Poor 2= Fair 3= Neutral 4= Good 5= Excellent

1. Other than the staff of the Disability Resource Center, how understanding are your professors about Autism Spectrum Disorders? (1-5)
2. Do your professors help and accommodate your specific needs? (1-5)
3. How flexible is your schedule? For example, if you need a day off, are you allowed makeup time? (1-5)
4. How helpful is your program counselor in the **beginning** of the semester? (1-5)
5. How helpful is your program counselor **throughout** the entire semester? (1-5)
6. Does your university have a peer mentor program?
If yes, how helpful has the peer mentor program been in your adjustment to college? Peer support includes: study skills, campus activity and organization concerns, campus services, and college life. (1-5 or N/A)
7. Does your university have a tutoring center?
If yes, how would you rate your tutoring center? [Reading/writing center and math/science center] (1-5 or N/A)
8. How would you rank your Disability Resource Center's services? (1-5)
9. Are you satisfied with your education here? (1-5)
10. Short answer questions:
 - a. What do you like about your school?
 - b. What do you not like about your school?
 - c. What additional resources do you think would better your experience?
 - d. What are your class sizes?
 - e. How is your family involved in your college life?

APPENDIX B



UNIVERSITY OF WISCONSIN
PLATTEVILLE
INSTITUTIONAL REVIEW BOARD

11/20/13

Callie Jo Gundlach
Sponsor: Daniel Leitch
Department of Education
University of Wisconsin-Platteville

RE: IRB Protocol #2013-14-17

Project Title: Autism: Life After High School

Approval Date: 11/20/2013

Expiration Date: 11/19/2014

Your project has been approved by the University of Wisconsin-Platteville IRB via an Expedited Review. This approval is subject to the following conditions, otherwise approval may be suspended:

1. No participants may be involved in the study prior to the IRB approval date listed above or after the expiration date.
2. All unanticipated or serious adverse events must be reported to the IRB.
3. All modifications to procedures, participant selection, and instruments used (surveys, consent forms, etc) must be reported to the IRB chair prior to their use.
4. If the project will continue beyond the expiration date, then the researcher must file for a continuation with the IRB at least 14 days prior to the expiration date. If the IRB approval for this project expires before approval for continuation is given, then a new protocol must be filled out and submitted. Federal guidelines allow for no exceptions to this rule. Any data collected after the expiration date cannot be used in the study.

If you have any questions, please contact the IRB chair at the address below. Include your protocol # on all correspondence.

Sincerely,

A handwritten signature in cursive script that reads "Dr Barb Barnet".

Dr. Barb Barnet
Institutional Review Board Chair
Professor, Mathematics Department
Gardner 451
University of Wisconsin-Platteville
(608) 342-1942
barnetb@uwplatt.edu

APPENDIX C

Madison Area Technical College IRB
 Expedited Review Form
 Page 2

 Date Submitted Madison Area Technical College Institutional Review Board _____
 File Number

Expedited Review of Research Form

Autism: Life After High School
 Title of Research Project

Callie Jo Grundlach, Graduate student: Adult Education, 6084459996, grundlachca@uwplatt.edu
 Principal Investigator/Student Project Director Department Phone Extension Email address

Daniel Leitch, advisor, Education, 6083426046, leitchd@uwplatt.edu
 Co-Investigator/Sponsor Department Phone Extension Email address

 Co-Investigator/Student Investigator Department Phone Extension Email address

Anticipated Funding Source: Not applicable

Projected Duration of Research: 5 months Projected Starting Date: Upon approval

Other organizations and/or agencies, if any, involved in the study: Southwest Technical College

Expedited Review Category (see categories on page 1-check one) 1 2 3 4 5 6 7

SUMMARY ABSTRACT: Please supply the following information below: BRIEF description of the participants, the location(s) of the project, the procedures to be used for data collection, whether data will be confidential or anonymous, disposition of the data, who will have access to the data. Attach copy of the Informed Consent Form and/or the measures (questionnaires) to be used in the project.
 Participants will be adults (18+), with high-functioning autism or Asperger's Syndrome attending an institution of higher education. Surveys with 9 ranking questions will be done anonymously, online via surveymonkey.com, to protect participants safety, rights, and well-being. Five short-answer questions will be attached to survey, in case any student wants to share more of their input; it is not mandatory. Appropriate measures will be taken to protect the confidentiality of participants. Information will be recorded in an anonymous form. No identifying information will be reported. Results of findings will be shared on MINDS@UWP, which is the Karrmann library repository for Master's papers. All surveys will be protected due to confidentiality; no names will be used. A basic statistical analysis (mean, median, mode) will be conducted on answers to survey. Short-answer questions will be sorted and compiled based on similarities, differences, and patterns. The data or summarized results will not be released in a way that could identify any participant. The data will be destroyed after seven years.

The main benefit for participants involved will be an opportunity to get their voice heard about their experiences in college. This will in turn impact families, students, teachers, society and institutions of higher education by informing them of things that are or are not working for students with Autism attending college. This will then contribute to a comprehensive

Expedited Review Form
Page 3

understanding of the past, present, and future of continuing education for those students with Autism who are interested in attending college.

RESPONSIBILITIES OF THE PRINCIPAL INVESTIGATOR:

- Any additions or changes in procedures in the protocol will be submitted to the IRB for written approval prior to these changes being implemented
- Any problems connected with the use of human subjects once the project has begun must be communicated to the IRB Chair
- The principal investigator is responsible for retaining informed consent documents for a period of three years after the project.

Callie J. Gondlach
Investigator/Student Project Director
Signature

12/12/13

Don Rutch, PhD
Co-Investigator/Sponsor Signature (if applicable)

12/11/2013

Signature of IRB Committee Chair: <i>[Signature]</i>	Date: <i>12/11/13</i>
IRB Chair: Check 1 box: <input checked="" type="checkbox"/> Approved <input type="checkbox"/> Approved with Conditions <input type="checkbox"/> Refer to Full Committee Review	

APPENDIX D

CONSENT FORM FOR PARTICIPATION OF HUMAN PARTICIPANTS IN RESEARCH UNIVERSITY OF WISCONSIN-PLATTEVILLE

PLEASE DO NOT PUT YOUR NAME ANYWHERE ON THIS SURVEY. There is no need to identify yourself.

You are being asked to complete this survey to help researchers better understand what works for a student with Autism attending college. Many of the questions ask about the resources provided at your school. Please be as honest as possible and answer all questions to the best of your knowledge. You should be able to complete the survey in approximately 10-15 minutes or less.

Once the study is completed, information will be further analyzed for a seminar paper and posted to MINDS@UW.

Your participation of this survey is entirely VOLUNTARY. By completing this survey you are giving your consent to be involved in the research. If at any point you decide that you do not want to complete the questionnaire, please return it (or exit, if online) and inform the administrator.

Please feel free to ask any questions you may have of the person who is giving you this survey, especially if there is a word or phrase you do not understand. Feel free to write in the margins and/or add any comments at the end of the survey, if you feel you need more space to express or explain an answer.

Thank you for your cooperation and the time you have put into this research project.

If you have concerns about your treatment as a participant of this research, please call or write:

Barb Barnet, IRB chair
(608)342-1743
barnetb@uwplatt.edu

Again, **PLEASE DO NOT PUT YOUR NAME ANYWHERE ON THIS SURVEY.**

Thanks,

Callie Jo Gundlach
(608)445-9996
gundlachca@uwplatt.edu

and

[Daniel Leitch, Sponsor](#)
(608)342-6046
leitchd@uwplatt.edu

APPENDIX E

Suggested Teaching Methods

There are a variety of teaching methods that could be used for this transition course or a similar course, due to the diversity of possible students on the autism spectrum that could be participating. It might be suggested to interview students before this type of course begins in order to get a better idea of the particular needs of the participants at that time, which could change with every different group. Below are ideas for teaching approaches; not all of them may be used at once and some of them may be used together.

- Lecture and class discussion (story telling) by teacher and/or students
 - Use of whiteboard or PowerPoint by instructor as aid in teaching
- Demonstrations by a guest speaker (success story of older student with autism, librarian teaches how to navigate library page, technician to do tutorial on main webpages-D2L, email, etc)
- Reading assignments (in journals, supplementary books, book club, etc.)
- Assignment to outline portions of the readings (have students do an article critique or diary about articles; online discussion board or in class discussion about readings)
- Maps and field trips of campus and community (goes with managing schedule; one activity could be tour of campus, cafes, grocery stores, work, and other common places students will go)
- Role-playing (use of motion pictures, educational films, videotapes or live in-class)
- Problem solving or case studies (resolutions and possible management for meltdowns)
- Tutorial (students assigned to other students for assistance/peer teaching. Buddy system during class: a student is required to get another student's information for various reasons over the course)
- Coaching (special assistance provided for students having difficulty in the course. This will be available through disability specialists)
- Filling out forms ("how to": email professor, self-disclose or announcements, FAFSA, disabilities, etc.... depends per student)

- Compile list of older students or staff members as resource people
- Investigate a life (have students find example of successful person with autism who attended college)
- Join an organization (student organization, club, or volunteer)
- Small group projects (in brainstorming small group, students identify a list of techniques and strategies that best fit their class)
- Surveys (end of class survey to get responses and feedback about course)

APPENDIX F



UNIVERSITY OF WISCONSIN
PLATTEVILLE
INSTITUTIONAL REVIEW BOARD

1/30/2014

Callie Jo Gundlach Sponsor: Daniel Leitch Dept. of Education UW-Platteville

RE: IRB Protocol #2013-14-17

Project Title: Autism: Life After High School Original Approval Date: 11/20/2013

Original Expiration Date: 11/19/2014

A modification to your project has been approved by the University of Wisconsin- Platteville IRB. This modification includes:

Adding UW-Platteville to the relevant affiliations of my survey participants. Also adding Brenda Sunderdand, University Services Associate, to the affiliated personnel involved from UW-P as an interviewee.

This modification does not affect the original expiration date of the project.

If you have any questions, please contact the IRB chair at the address below. Include your protocol # on all correspondence.

Sincerely,

Dr. Barb Barnet

Institutional Review Board Chair Professor, Mathematics Department Gardner 451

University of Wisconsin-Platteville (608) 342-1942

barnetb@uwplatt.edu

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