Postsecondary Transition in Individuals on the Autism Spectrum

by

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A Thesis Presented in Partial Fulfillment
of the Requirements for the Degree
Master of Arts

Approved March 2011 by the
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ARIZONA STATE UNIVERSITY

May 2011

ABSTRACT

Literature reviews, books, and research studies are reviewed in this thesis with the purpose of examining the postsecondary transition of young adults on the autism spectrum (AS). Previous research on the specific social, legislative, victimization, and self-determination issues that young adults on the AS face during their postsecondary transition process is extensively examined as well as research that addresses the viewpoints of postsecondary programs from the perspectives of caregivers and young adults. Research studies and literature reviews that address current postsecondary programs for those on the AS and current adult outcomes for those on the AS are also included in the literature review section. The research aspect of the current thesis involved a postsecondary education transition team at Arizona State University who compared the viewpoints of young adults and parents of young adults on the AS on their experience with the postsecondary transition process and what they believe should be fundamental aspects of the postsecondary transition process. Two forms of a survey were administered (one for the young adult population and another for the parent population). Survey results found a lot of similarities and differences in terms of how caregivers and young adults felt about postsecondary transition. Although both young adults and caregivers expressed a strong interest in postsecondary programs for students with autism, both groups expressed that the likelihood of the young adult attending such a program would be significantly less. Differing viewpoints between the two populations existed on what a postsecondary program should look like. Although the two groups did agree that such programs should consist of an employment and social activities component, young adults felt that programs should have a more diverse set of criteria. Following completion of a secondary program, caregivers saw young adults attending a postsecondary education institution, while young adults perceived themselves as transferring directly into the workforce. On the contrary, caregivers did demonstrate an even variability in choice for opinions. The thesis concludes with the many implications for this study and suggestions for future research.

DEDICATION

This thesis would not have been possible without the dedication, patience, hard work, and support of a wide variety of individuals. First off, my family. My mother being my "main cheerleader" throughout every aspect of the thesis process and beyond. By never giving up on me, she has taught me to always push myself to my limits. Many thanks to my older brother, Bentley, for always being open to critically reading and reviewing many of the several versions that this thesis underwent to get to where it is today. My younger brother, Rockne, always being in the background knowing that I can turn to him for a word of encouragement. Windsor, my youngest brother, for putting up with the side effects of my high stress level throughout the thesis process, and encouraging me to succeed. Also, thank you to the countless number of friends who provided endless words of support and encouragement throughout the thesis process.

AKNOWLEDGEMENTS

I would also like to extend an exorbitant amount of gratitude towards the professionals that made this thesis possible. This thesis would not be where it is today without my advisor and thesis chair, Dr. McCoy, and her support, dedication, and patience. She effectively led me through the thesis process taking the time to read through and provide insightful, constructive feedback on the many versions of this thesis and answered any questions I had. She also took the time out of her busy schedule to serve on the chair of my thesis committee. Many thanks to my committee members: Dr. Cocchiarella and Dr. Radar for taking time out of their busy schedules to take an active role throughout my thesis process. Also, many thanks to Mrs. Kendle who took time out of her very busy schedule to sit in on my thesis committee meetings and provide a unique insight on my thesis. A strong amount of gratitude must be paid to the rest of the Transition Team at Arizona State University. Pattie, Cindy, Garret, Simon, and Dr. McCoy, a significant portion of this thesis has evolved into what it is today due to your hard work and dedication towards the research study. This thesis would not have come to be without the survey participants who took part in the research study. Many thanks for the time and effort you put into filling out the extensive surveys that taught me, and the rest of the transition team a lot. Lastly, thank you to the staff in the Mary Lou Fulton Teachers College Graduate Office and Arizona State University Graduate College Office. You have gone above and beyond the call of duty to ensure the completion of this thesis. Thank you to you all.

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CHAPTER 1

Today, the world of autism is ever changing. Increases in public awareness, research on finding the cause(s) of autism, and development and implementation of effective early interventions surround us. These changes have led to a significant problem that the autism community is realizing. VanBergeijk, Klin, & Volkmar (2008) state that the CDC (Center for Disease Control) estimates that 1 in 166 children in the United States (500,000 Americans) have been diagnosed with ASD (autism spectrum disorder). Hendricks and Wehman (2009) states that an estimated 55,602 to 121,324 adolescents in the United States fall somewhere on the autism spectrum. The education of children who fall on the spectrum is addressed through IDEA 04 that mandates a free an appropriate education between until age 22 or graduation from secondary education. A significant question that must be addressed is What happens to these individuals when they graduate from high school?

Autism spectrum disorders (ASD) have an effect on the areas of social skills, communication skills, and behavior. ASD affects each individual differently and to varying degrees of severity. Several diagnoses can occur on the ASD spectrum. A diagnosis of “classic autism” falls on the lower-functioning end of the spectrum. High-functioning autism (HFA), Asperger Syndrome (AS) and pervasive developmental disorder or not otherwise specified (PDD-NOS) fall on the higher-functioning end of the spectrum (Adreon, & Durocher, 2007).

Throughout the current thesis autism or any related terminology is referring to any disorder on the autism spectrum.

Transition Issues

Preparing students on the spectrum for the secondary postsecondary transition is crucial for success in postsecondary environments (VanBergeijk, et al., 2008, & Hendricks, & Wehman, 2009). A large amount of research exists that demonstrates that the transition from secondary to postsecondary education and/or a vocational environment for students with autism-like disorders is exceptionally difficult (Adreon, & Durocher, 2007; Alspren & Zager, 2007; Prince-Hughes, 2003; & Hendricks & Wehman, 2009)**.** Several reasons exist for this difficulty. First, as VanBergeijk, et al. point out, transitions in general are often difficult and incredibly stressful for those with ASD and their families. For example, some students with ASD may have difficulties with problem solving or self-advocacy skills (Adreon, & Durocher, 2007). Self-determination skills, which individuals on the autism spectrum often struggle with due to being a very abstract concept, are necessary for success in postsecondary life. A basic definition of self-determination skills is a belief that all individuals have the right to direct their own lives, and this right is utilized without any external influences. However, research has shown that with family involvement, adolescents with ASD can develop the self-determination (Field, & Hoffman, 1999). There have been several effective interventions that have been developed to help to improve self-determination skills of students on the autism spectrum (Hendricks, & Wehman, 2009).

Another area in which adolescents on the autism spectrum find difficult are communication skills which are often manifested through inappropriate questions and problems with interpreting and making use of non-verbal communication. Conversations with adolescents with ASD are often fast and abstruse. This lack of communication skills often follows through to adulthood and causes difficulties in vocational settings, which is then manifested in the misunderstanding of idioms, double-meanings, body language, making irrelevant comments to co-workers, and not knowing when to ask a question, thereby resulting in more individuals with ASD being fired due to social or communication difficulties instead of inadequate job performance (Alspren, & Zager, 2007).

Language difficulties have also been shown to cause trouble in developing meaningful friendships in persons that are on the higher functioning end of the ASD spectrum. Primarily, the reason for social obstacles for those with autism is due to the fact that those on the individuals in the autism population are often extremely literal thinkers (Graetz, & Spaminato, 2008). Language is often a lifelong struggle for those with autism. Thus speech-language services are a crucial lifelong intervention (Hendricks, & Wehman, 2009). However, crucial speech-language services, which are necessary for postsecondary success, are eliminated at the age of 21. A portion of the problem is the assessments and interventions that are currently used to assess and treat communication difficulties in individuals with autism-like disorders do not adequately measure or treat the communication difficulties that are often specific to the autism population (Alspren, & Zager, 2007).

Legislative Issues

Research has shown another possible reason for difficulty in the transition from secondary to postsecondary environments for those with autism-like disorders centers around a legislative issue. Currently, colleges are required by ADA (Americans with Disabilities Act) to make accommodations for their disabled population. However, the extent to which accommodation services are offered varies. Also, research suggests that college faculty typically lack in broad understanding of ADA and hold a belief that making appropriate accommodations for students in their classroom on the autism spectrum will hinder the content of their discipline. The ASD population often experiences life skills difficulties, and need accommodations in the life skills area during the transition from a secondary to postsecondary environment. The first semester of college is often most difficult for those with autistic-like disorders because of so many transitions occurring during this stage in their life. For example, students on the spectrum making the transition into postsecondary education settings need to learn self-advocacy, daily living, and study skills. Several accommodations that college students with ASD need may go beyond the scope of what their university currently offers and the services required under ADA which may include oral exams, course selection or substitutions, and flexibility in scheduling of classes (Adreon, & Durocher, 2007).

Researchers have also shown that given the appropriate resources and supports at the postsecondary level, individuals on the autism spectrum can be successful in a college setting (Wahlberg, Rotatori, & Desinger (2003); & Hendricks, & Wehman, 2009). A great deal of recommendations have been made for making the transition from secondary to postsecondary education easier for those on the spectrum. One recommendation is to have students with ASD take one or two community college courses that focus on the student's interests leading to a higher probability of success with college level work. The college selection process for those on the spectrum is crucial in ensuring a successful secondary to postsecondary education transition. Individuals with autism-like disorders must consider whether the college provides appropriate supports that include accommodations/interventions in the areas of social skill groups, psycho-educational groups, directive counseling, vocational training, and life skills coaching. Those on the autism spectrum often have difficulty with organization as well (VanBergeijk, et al., 2008). As a result of smaller class sizes and more individualized attention, community college is an option that has the possibility of leading to a more successful transition for young adults on the autism spectrum. Students with ASD may also consider taking college summer courses during the summer between the student's senior year of high school and freshman year of college in an area in which they are interested (Adreon, & Durocher, 2007).

Postsecondary living arrangements are another fundamental area that must be considered (Volkmar, & Weisner, 2009). Postsecondary living options can fall on a continuum of living at home or in a group home setting to living independently. It has been shown that even if living independently, the majority of individuals even on the higher end of the autism spectrum rely on family for support (Hendricks, & Wehman, 2009).

Social Skills

A few recommendations have been made to help the social skill development of individuals with autistic-like tendencies. One suggestion is to teach the skills being addressed in a community-based or vocational environment. For example, the communication skills that are necessary for success in a vocational environment should be taught in the natural environment where these skills are going to be used. Teaching young adults with autism communication skills in a college-based environment is best done through an inclusion-based setting. Studies have been conducted that show the effectiveness of inclusion-based program at the postsecondary level showing an increase in communication skills that has even transferred over into a successful social life beyond college (Adreon, & Durocher, 2007).

Parent Perspectives

Postsecondary transition is not only difficult for adolescents on the ASD spectrum, but this transition is also extraordinarily stressful for parents and caregivers. Worries about what the future holds for their child with autism often burden parents, who are frequently life-long primary advocates for individuals on the spectrum (Hubert, 2009; & Baskin, 2008). Parents are also often the main financial resource for children with ASD (Volkmar, & Weisner, 2009; & Hendricks, & Wehman, 2009). The perspective of parents of young adults with ASD must be taken into consideration when developing postsecondary transition programs. However, currently minimal research and no literature reviews regarding parents of adolescents with ASD and their perspective on the postsecondary transition process exists.

The researcher searched the following terminology with the goal of obtaining reviews of literature that related to parents of students with ASD and their perspectives on postsecondary transition “autism parent perspectives,” “parent perspectives autism,” “college transition autism,” “autism college transition,” “autism postsecondary transition,” “postsecondary transition autism,” “transition autism,” “autism transition,” “adulthood autism,” “autism adulthood,” “autism parents,” “parents autism,” “autism parents adulthood,” “parents autism adulthood,” “parenting autism,” “autism parenting,” “autism adult,” “adult autism,” autism adult transition,” “adult transition autism,” “autism high school transition,” and “high school transition autism.” The following databases were searched Education: A Sage Full Text Collection, Education Full Text, ERIC (via CSA Illumnia), ERIC (via US Department of Education), and PsycINFO. It was found that parental concerns center around social issues as students on the spectrum approach postsecondary transition (Caruso, & Crawford, 20011; &

Hurbutt, 2008). It was also discovered a main concern for parents of the autistic population is what happens to their children when they are gone? Parents and guardians have expressed the lack of availability of resources available after high school, transportation difficulties, scheduling difficulties, and poor quality of secondary to postsecondary transition services (Hendricks and Wehman, 2009). The researcher was able to obtain a small amount of individual studies that related to the perspectives of parents of individuals with ASD on postsecondary transition. These will be discussed in the following chapter.

Current Adult Outcomes

Howlin (2000) conducted a literature review to explore autism adult outcomes. Her findings found a large amount of studies that showed for the most part, adults with ASD were dependent on parents/caregivers or living in residential care facilities. However, the studies also showed a small percentage of individuals on the spectrum that effectively received a college education, were gainfully employed, and were happily married. Subjects on the spectrum demonstrate social and communication difficulties. Research has shown that most jobs attained by the ASD population have been lower functioning, low-paying jobs not building on the true potential of the autism population. One study has shown that 50% of individuals surveyed with Aspergers Syndrome successfully completed a college degree (Howlin, 2000). Researchers have also proven that adults on the autism spectrum often switch jobs more frequently than their typically developing peers and struggle with this transition (Hendricks, &

Wehman, 2009). Individuals, who are twice exceptional, for example on the ASD spectrum and classified as gifted, have a lot to offer the vocational field in which they are gifted. Today, several programs such as the New Jersey Center for Outreach and Services for the Autism Community (NJ COSAC) provide lifelong services for individuals classified as on the autism spectrum and gifted (Hurbutt, 2008).

The first chapter of this thesis has given an overview of the research that is available on the transition from secondary education to postsecondary education settings or the workforce for individuals with autistic-like disorders. The majority of research has concluded that current transition programs are not sufficient enough to meet the present and future needs of the autistic population. A majority of the adults with ASD are underemployed living at home with family members/caregivers. Effective postsecondary transition programs must identify and address the complex needs of the autism population. A fundamental step in developing appropriate postsecondary transition programs for individuals on the spectrum is to examine what caregivers believe is the fundamental needs of the autistic population. Caregivers, typically parents, often have the means and ethical responsibility for continued support of their adult children on the autism spectrum, and must have a voice in their childrens' transition programs.

Chapter 2

CHAPTER 2

The purpose of the second chapter is to familiarize the reader with the data based studies that have been conducted on the postsecondary transition of individuals on the autism spectrum. The reader should be aware that many of the studies in this chapter have a population of learning disability (LD), behavioral disabilities (BD), and mental retardation (MR). The LD, MR, and BD populations often deal with similar postsecondary issues as individuals on the ASD spectrum. This is the reasoning for including the MR, BD, and LD studies in this chapter. The study's specific population will be clearly noted.

The author of this thesis was unable to find a lot of research that related to specific transition issues that students on the autism spectrum encounter when they face postsecondary transition. The following terms were searched when researching articles that applied to the specific postsecondary transition struggles of individuals on the autism spectrum "autism," "autism spectrum disorder (ASD)," "transition," "transitional," "issues," "difficulties," "disabilities," "postsecondary," "high school," "problems," "college," "vocational," "skills," and "work place." The previous terms were searched electronically in the following databases Education: A Sage Full Text Collection, Education Full Text, ERIC (via CSA Illumnia), ERIC (via US Department of Education), PsycINFO, and Web of Science.

A large amount of factors must be taken into consideration when addressing the postsecondary transition of young adults on the spectrum. Specific transition, social, and self-determination issues, an examination of specific postsecondary programs, parent, sibling, and individuals on the ASD spectrum's perceptions of postsecondary education and the transition process, and the postsecondary outcomes for persons on the autism spectrum are taken into consideration in this chapter.

Transition Issues

Specific Transition Issues

A large amount of the literature on autism has shown that individuals with disabilities with autistic-like traits often have unique, specific postsecondary transition issues. Studies that show this are reviewed in the following section.

When examining the postsecondary transition of adolescents with autism to a postsecondary environment, the quality of the transition process must be looked at. Nuehring and Sitlington (2003) conducted a qualitative based research study to examine the complexity of the postsecondary transition process and the effectiveness of the transition process for adolescents with autism. The population was a high school senior who was currently undergoing the postsecondary transition process and three students who had already graduated from high school and transferred to separate adult vocational service providers. The specific disabilities of participants were not addressed.

Data collection for the Nuehring and Stillington (2003) study was conducted through several taped interviews containing in-depth, open-ended questions, observation of each vocational service provider, and in-depth conversation with the transition coordinator from each program in which participants were enrolled. The researchers also spoke with the work experience coordinator from the high school and the participants' parents as well as observing the classroom of the participant who was still in high school.

Results of the Nuehhring and Stillington (2003) study showed that many successful components of each adult provider program existed including: knowledgeable transitional specialists, variety of choices available to young adults and their families in their local area, and use of proven-effective assessment methods in one of the vocational agencies. Four areas for improvement were: increased education of high school staff, use of effective transition assessment and data throughout the transition process, increased communication between the student and his/her family, the school, and the student's future vocational service provider, and aligned programming between the high school and the student's future environments.

The quality of a student with autism's Individual Transition Plan (ITP) can affect their transition outcome. Everson, Zhang, and Gullory (2001) examined the quality of 329 ITPs throughout Louisiana. The study's population (1% of which fell on the autism spectrum) was high school students with a minimum chronological age of 14 years. The researchers wanted to examine the strengths and weaknesses of the transition component of a select population of students' IEPs.

ITPs for this study were gathered from school districts around the state of Louisiana. Reviewers of the ITPs were trained in ITP review protocol. To ensure reliability, one of the researchers and the reviewers reviewed five ITPs that were not included in the study. The researcher then met with the reviewers and went over the differences in ITP reviews. A researcher also periodically reviewed the reviewers ITPs to ensure that reviewers were following appropriate protocol. Data was then entered into SPSS. Descriptive analysis was used to analyze the demographics portion of the instrument. For the following three sections, frequency procedures were used to analyze this data.

A summary of the results of this study demonstrate that IEP teams in Louisiana generally meet IDEA's requirements for transition planning and services by addressing post school activities such as postsecondary education, vocational training, integrated employment, continuing/adult education, adult service, independent living, and community participation. On the contrary, the current study showed that IEP teams are less likely to address issues such as transportation or medical needs suggested by the state. Everson, et al. (2001) recommends that in order for state recommendations to be more prevalent in IEPs, they should become mandated. The current study also demonstrated that parents and students have been successful in getting their future vision statements expressed in the student's transition discussion and planning activities. Everson, et al. (2001) also showed that the majority of IEPs (88%) identified student post school options and a timeline (56%) to meet these options.

Everson, et al. (2001) expanded on previous research by examining the quality of ITPs for a representative sample of students with disabilities in Louisiana. Prior research had compared the ITPs for those with specific physical disabilities. No one had previously compared the ITPs of students with learning disabilities.

Two major limitations of this study were identified. The first limitation centers on the data collection method used. Reviewers just had the document for data collection, and no way of knowing how the document was developed or whether it accurately reflected the viewpoints of every member of the transition team. The second limitation was that although the researcher did periodically examine reviewers and their reviews, there was no formal procedure for inter-rater reliability.

Everson, et al.'s (2001) study applies to the current thesis. The study measured the effectiveness of IEPs, which are important in the postsecondary transition process. Many of the specific issues such as the importance of transpiration that students on the autism spectrum have issues with in postsecondary transition were measured in the study.

Transition assessment often plays a significant role in the postsecondary transition of students on the autism spectrum. Special educators are key players in the transition assessment process. Thoma, Held, and Saddler (2002) examined the knowledge of special educators on the various types of transition assessment procedures, instruments, and strategies available, and how they applied this knowledge to help students construct a high quality of life after high school. The study built on previous research conducted by Agran and Morgan (1991) who examined what special educators in Nevada knew about vocational assessments, and how special educators applied this knowledge. Thoma, et al. (2002) examined whether any changes in the last ten years on what special educators knew about transition assessments have occurred and how this knowledge was applied. Thoma, et al.'s (2002) population consisted of 84 special educators and transition coordinators in the states of Nevada and Arizona. A minimum of one participant from each school district in the two states took part in the study. 26 participants taught students on the autism spectrum.

Information for this study was gathered through a four-page survey split up into three sections. The first section asked basic demographic information of the special educator completing the survey. The second section consisted of specific questions on the process of conducting transition assessments and the type(s) of transition procedures in which the educator was familiar with. The second section included open-ended and yes/no questions. A portion of this section asked participants to check any of the designated assessment procedures (curriculum-based assessment package, combination of prepared/standardized and informal assessments, student survey of performance and interests, parent survey of student preference and interests, ecological inventories, task analyses, work samples, interviews of students, portfolios, observations, rating scales, person-centered planning processes, standardized assessments, adaptive behavior scales, self-determination assessments, or lack of transition-related assessments) that were used in their schools. The third section of the survey focused on student involvement in the transition process.

Data analysis was quantitative and inputted into SPSS. Results show that the most common transition assessment procedure used by special educators was interview with student. Results also showed that special educators in Nevada and Arizona were generally familiar with and knew how to use transition assessment strategies. Identical results were shown in the Agran and Morgan (1991) study. Over the past ten years, transition services have been expanded to include community living, daily living skills, recreation/leisure, social skills, transportation, and financial skills. Thoma, et al. (2002) also showed that decisions made based around transition assessment are generally made by the transition team. The assessments are conducted on a student-needed basis and are often requested by parents. However, results also indicated that very few special educators were using processes that involved self-determination and/or person-centered assessment/planning processes. These results are exceptionally troubling because self-determination and person centered processes have been shown to lead to more positive adult outcomes

The current study has a few limitations. One of these limitations is Thoma, et al. (2002) was conducted solely in the states of Arizona and Nevada. Therefore, the ability to generalize the results of this study to other portions of the country is limited. There also was a low response rate to the study. 250 surveys were sent out to special educators in the two states and only 84 (33.4%) surveys were returned. Therefore, generalizing these results to special educators in the states of Arizona and Nevada also is limited. Lastly, this study was self-reported data, which questions the study's validity. In order to make a study more valid, other assessment procedures such as observation and review of student files should have also been included

Victimization Issues

Victimization is a challenge for many adolescents on the autism spectrum. Although some research to demonstrate this (for example Roekel, Scholte, & Didden, 2010), studies relating specifically to individuals with disabilities and victimization during the postsecondary transition are even scarcer. Doran, Bulls, and Benz (1996) conducted a study in Oregon and Nevada that examined predictors of victimization for a sample of disabled students in the postsecondary transition process. The authors of the present study did not specify if any of the participants were on the autism spectrum. The study followed 408 students with disabilities for two years. During the first round of data collection, the participants had a minimum age of 17 and took place during the last year of high school. The initial observation took place during the last year of high school and the second observation a year after the student left high school.

The instrument used for this study was phone interviews with parents and students during students' last year of high school and one year after they exited high school. Both parents and students were interviewed. The interview given during the Doran, et al. (1996) study consisted of two types of variables. Predictor variables helped to predict victimization of students and were given during the interview. Victimization outcome variables were determined by parent reports. Parent and student agreement was then calculated. Trained interviewers read each item from a computer screen and immediately entered the data into SPSS. Interviewer agreement was obtained by having interviewers listen to interviews being conducted by interviewers.

Results of the Doran, et al. (1996) study showed that approximately 50% of participants experienced victimization at least once during their educational career. Also shown was a strong correlation between serious emotional disability (SED) status and school personal/ social achievement. Individuals with a SED and low personal/ social achievement were most likely to experience victimization.

The current study was one of the few studies that studied the victimization of adolescents with disabilities in transition. The current article addressed the victimization of students with disabilities. Previous research has also demonstrated that many adolescents with ASD often are victimized.

Social Issues

When examining articles, the author of the current thesis found very few articles that applied to social skills as an issue for individuals on the autism spectrum in postsecondary education transition. The following terms were used as search criteria when looking for articles that related to social skills as an issue for individuals on the autism spectrum in postsecondary education transition "social," "issues," "workplace," "vocational," "postsecondary," "college," "difficulties," "issues," "autism," "Aspergers Syndrome (AS)," "autism spectrum disorder (ASD)," "disability," and "problems." The previous terms were searched electronically in the following databases Education: A Sage Full Text Collection, Education Full Text, ERIC (via CSA Illumnia), ERIC (via US Department of Education), and PsycINFO.

An issue that many students with autistic-like traits struggle with when in postsecondary transition is a lack of appropriate social skills. Research that investigates social skills during postsecondary transition for individuals on the autism spectrum and with autism-like tendencies is reviewed in this section of the current thesis.

One way in which social skills can significantly impact the postsecondary transition of students on the autism spectrum is when students transfer to a vocational environment. Monhan (2003) conducted a study with the goal of examining special education students' ITP- (Individualized Transition Plan) goals related social skills and problem behaviors, general and special education students' self-report on social skills, and the relationship between teacher and employer ratings of problem behavior and social skills in general and special education students. The population of this study was 24 general education students and 24 special education students who were enrolled in high school career and technical education programs and this group of students' general and special education teachers. The authors of the current study did not specify whether any of the participants were on the autism spectrum.

Monhan's (2003) study showed that the ITPs of special education students did not address social skills or problem behaviors. When compared to their general education peers, special education students' ratings for assertion, cooperation, and self-control showed no significant difference. General education students did rate themselves higher in empathy than special education students. Teachers and employers were aligned in their ratings of problem behaviors and social skills of general career and technical education students. In terms of special education career and technical education students, employers rated special education students significantly higher on the cooperation subscale than special educators. Further research is needed to make the connection between better social skills and job success.

The Monhan (2003) study has a lot of connections to the current thesis. One of the main purposes of the present thesis is to measure what students and parents/caregivers believe are the most important aspects in the postsecondary transition process. Monhan (2003) addresses social skills, one of the most crucial areas in which individuals on the autism spectrum experience deficits.

For many with disabilities, a lack of social skills (a common characteristic that accompanies individuals on the autism spectrum) presents a major problem in the workplace. It is essential that social skills be taught during a postsecondary program. Once taught, these skills must be generalized into the natural work environment. The purpose of Clement-Heist, Siegel, and Gaylord-Ross’s (1992) study was to examine the effect of job-related social skills on the generalization of these social skills into the natural workplace for four high school seniors with disabilities. The authors did not specify whether any of the study participants were on the autism spectrum. All baseline and generalization probes were taken at the four participants’ job site at the California State Automobile Association (CSSA). Participants received vocational training and conducted job searches through a Transition School. The three target behaviors that were taught were: ordering job duties, conversational skills, and giving instructions. Generalization training took place at CSSA.

The vocational skills training aspect of this study was comprised of two phases. Phase one consisted of the four participants attending a workshop on employment skills. If after two weeks students did not demonstrate the appropriate skill in their vocational environment, he or she proceeded to phase two of the social skills training. This phase took place in the student’s work environment. The term “in situ” was used to describe this environment because students were learning the work skill within their job environment. Social validity for the study was measured by having one or two of the student’s co-worker(s) fill out a questionnaire, which asked coworkers to rate certain areas of the student’s social vocational skills. A multiple-baseline design was used in this study to measure participants' generalization of social skills to a vocational environment.

The results of the current study indicated that co-workers were consistent in their responses regarding the job-related social skills of the participants of this study. Clement-Heist, et. al (1992) also showed that social behaviors could be taught and generalized to the work environment. It showed that vocational skills training during phase one and phase two were both effective in generalizing social skills training into the workplace. The current study shows a lot of connection to the current thesis. The research in this study demonstrates that social skills, which prove to be a significant area of difficulty for individuals on the autism spectrum, can be effectively taught.

Self Determination Issues

Extensive research has shown that many students with autistic-like tendencies, a lack in self-determination skills often hinders postsecondary transition. However, a select few studies have shown that it is possible for students with autistic-like traits to effectively acquire and act upon self-determination skills during postsecondary transition. Both types of studies are reviewed in this section of the present thesis.

Very few studies have looked into the self-determination skills in students with learning disabilities (LD) and emotional disturbance (ED) in postsecondary transition from various perspectives. Carter, Lane, Pierson, and Glaser (2006) examined the perspectives of parents, educators, and students with LD and ED in regard to self-determination skills. Specifically, the study looked at the self-determination prospects of students with ED, how students with ED and LD compare in their capacity for and opportunities to engage in self-determined behavior, the extent to which educators, parents, and students are similar or vary in their views of adolescents' capacities and opportunities for self-determination, and the relationship between students' capacities to engage in self-determined behavior and the opportunities available to them at school and at home. The participants for this study consisted of 85 secondary education students with ED and 46 secondary students with LD ranging from 14 to 19 years in age. It was not specified whether any of the participants were on the autism spectrum.

In terms of assessment, The AIR-Self-Determination Scale was used to measure participants' capacity for an opportunity to engage in self-determined behavior. Results of Carter, et al.'s (2006) study revealed that the capacity for secondary students with LD to engage in self-determination behavior is often judged by special educators as limited. Parents and special educators also rated self-determination engagement capacity of adolescents with ED significantly lower than students with LD. Viewpoints on the capacity self-determination for students with ED, but not LD, varied from the viewpoints of their teachers. This difference in viewpoints on self-determination capacity is not uncommon for other disabilities that are related to ED. There was a disparity in the evaluations of opportunities available to students with ED and LD. Carter, et al. (2006) also found both LD and ED special education teachers felt that there was minimal opportunities for self-determination at home, while parents felt that there were very little opportunities for special education at school. One explanation for this may be that there is limited communication between parents and teachers in terms of what each are doing to promote self-determination skills in their individual environments.

Prior to the study, no research existed that addressed the association between opportunities and capacities for self-determination. Students with LD and ED often struggle in some of the same areas as students on the autism spectrum. Self-determination is the perfect example. Like those affected with LD and ED, students on the spectrum often lack self-determination skills. Therefore, the results of the Carter, et al. (2006) study do pose some potential applicability to the current thesis.

Effective self-determination is when an individual can make their own choices that align with their unique interests. However, in the case of many individuals with severe intellectual disabilities, caregivers’ decisions on what they believe are the interests of the young adult often led to direct vocational decisions. Martin, Woods, Sylvester, and Gardner (2005) examined whether the vocational decisions made by caregivers were in line with choices made by adolescents and young adults with cognitive disabilities. More specifically, the authors of this study examined what the vocational setting, activity, and characteristic agreements between caregivers and individuals with severe intellectual disabilities. The population for this study was eight individuals with severe cognitive disabilities in school or a community employment setting and their caregivers. One of the participants had autism.

Students used Choose and Take Action Software Program to complete this study and rank various vocational settings, activities, and characteristics. Caregivers then ranked employment settings, activities, and characteristics choices in a setting apart from the individuals with intellectual disabilities. The assessment given to caregivers was like traditional assessment given to families to obtain input.

Results of the Martin, et al. (2005) study show that there was very low agreement (29%) between individuals with cognitive disabilities and their caregivers when ranking the top three vocational settings, activities, and characteristics. Low agreement on the top-ranked choices in the setting, activity, or characteristics categories was also identified. Overall exact agreement for top choices with all three categories combined was 6%.

Despite its limitations, the study does have many benefits and implications for the current thesis. One of the primary benefits is that the Martin, et al. (2005) study showed that students with intellectual disabilities are not acquiring true self-determination. Caregivers are making choices about these students' future that do not align with the student views of their own future. The study has direct implication for the current thesis because one of the participants was on the autism spectrum. Self-determination and choice making is a crucial skill required for success in postsecondary settings for individuals on the autism spectrum.

Postsecondary research has ignored the self-determination of students from culturally diverse backgrounds. Even fewer studies have examined the self-determination practices and their effectiveness for culturally diverse students. Trainor (2005) is an exception. The author specifically looked at the self-determination behaviors of culturally and linguistically diverse (CLD) male adolescents with LD, how CLD male LD students perceive their role in the transition process, and how male CLD students with LDs perceive parents' and teachers' involvement in the transition process. There were 15 participants in this study. All subjects qualified for free or reduced lunch. The study's procedure consisted of document review of participants' ITPs, observations of participants' ITP meetings, and focus group and individual follow-up interviews. The author addressed how she attempted to deteriorate or eliminate her study biases.

Data analysis for the current study was conducted by the researcher who extensively reviewed field notes taken on participants' verbal and non-verbal participation and communication style during interviews and observation sessions. The results of this study showed only minor differences between diverse population's behaviors and perceptions of self-determination. There were five themes that emerged from the research. First, postsecondary goals and the goals aligned in the majority of subjects' IEPs had missing connections and did not align. All participants in the study were minimally involved in their transition process. Subjects said that they rely mainly on their families for transition planning instead of the school. Students did show a high degree of competence and self-determination. Finally, results depicted that study subjects actively acted on their self-determination efforts.

Thus far, the current chapter has shown that self-determination is a vital component of the transition planning process for students with disabilities. However, few studies have examined what self-determination strategies students with disabilities use to meet the vigorous challenges of postsecondary education settings. Getzel and Thoma (2008) conducted a study that looked at the skills that successful self-advocates with disabilities used to ensure that they stay in college and obtain the supports needed for their success and self-determination skills that students with disabilities used to remain and persist in college. The population for this study consisted of 34 students who attended six postsecondary education settings throughout the state of Virginia. The chronological ages of participants ranged from 18 to 48. It is unknown whether any of the participants were on the autism spectrum.

Data collection for the Getzel and Thoma (2008) study consisted of a semi structured interview process within a focus group format. Study results indicate that participants noted that their success in postsecondary education was due in large part to their strong self-advocacy skills. Key specific skills were problem solving, self-awareness, goal setting, and self-management. The majority of subjects also indicated that they felt that their high school experience had not prepared them to understand their disability and how their learning is affected by it. In terms of the advocacy or self-determination skills that participants thought were absolutely essential for staying in college and obtaining the supports they needed, participants noted that seeking support on campus through disability support services and other campus services, developing support systems on campus, and developing self-awareness were vital.

The present study poses a lot of applicability to the current thesis. The most vital connection is that Getzel and Thoma (2008) points out that self-determination and self-advocacy skills are essential for success in a postsecondary education setting. It is important that these essential skills be addressed when dealing with adolescents on the autism spectrum looking to pursue a postsecondary education. Reasoning being that self-determination understanding is often very difficult for students with ASD to grasp, partially because it is a very abstract concept.

Making use of effective methods to teach adolescents on the spectrum self-determination skills is important. Coyne and Fullerton (1999) looked at: the impact that specific instructional methods have on self-determination acquisition for adolescents on the autism spectrum, the challenges that students on the spectrum face when understanding and applying self-determination skills, and the extent to which young adults have applied self-determination skills in their lives. The study took place across two years and involved the development and field-testing of a program to teach self-determination (the program was called Purring Feet on My Dreams) with three classes of students. A total of 23 young adults on the autism spectrum made up the investigation. Visual representation of information and providing information about social situations were implemented strategies to teach program units on self-knowledge, communication, and life planning. Coyne and Fullerton (1999) results indicated that students found it helpful to be able to talk about self-determination acquisition and the struggles they faced with other peers on the spectrum, leading to more of an understanding and acceptance of autism. Also, the majority of students were able to plan steps needed to accomplish life goals, and some were able to engage in self-directed actions towards life goals.

Coyne and Fullerton (1999) adds a lot to the research, including the present thesis. An understanding and acquisition of self-determination skills are fundamental to a positive postsecondary outcome. This study shows that these skills can be taught and even have the potential to be generalized across all aspects of the young adult on the spectrums' life.

Following program implementation, post interviews were conducted on students who participated in the program and their parents. Observation of student behavior during and after program implementation was also used for data collection.

Self-determination can play a big role in transition planning. Wehmeyer, Palmer, Soukup, Gamer, and Lawrence (2007) studied the contribution of self-determination to transition planning knowledge and skills for students with disabilities. The population consisted of 180 postsecondary transition students. 18 of the participants were on the autism spectrum.

Self-determination was measured by the Arc’s Self-Determination Scale, which consists of 72 items. Transition knowledge and skills of study participants was determined through a 20 item questionnaire measuring student knowledge and skills concerning the IEP process, transition planning skills, decision making, self-advocacy, and goal setting. Pre and posttests also included questions on student knowledge of their IEP meetings and transition goals.

Data gathered from the Wehmyer, et al. (2007) was analyzed through: descriptive analyses, regression analyses, and factor analysis. Results indicate that the majority of students with disabilities enrolled in postsecondary programs were not familiar with the positive effects that self-determination and transition planning on their future. Predictors of transition-planning knowledge and skills were self-regulation and self-awareness.

Wehmyer, et al. (2007) has a lot of contributions to the previous research and is connected to the current thesis in many ways. The study demonstrated that student self-determination leads to more student knowledge about the transition process, which is a key component to having students actively involved in the process. The present study applies directly to individuals on the autism spectrum because a portion of the population (10%) was on the spectrum. The remainder of the population’s disabilities demonstrated characteristics similar to those on the autism spectrum. This shows that knowledge about and active involvement in the transition process is a rarity among postsecondary students on the autism spectrum.

Postsecondary Programs and Issues Encountered in Postsecondary Settings

Postsecondary transition is often the most difficult transition that students on the autism spectrum have to make. Adolescents on the spectrum encounter many obstacles in postsecondary settings. Many college programs across the country have implemented effective and ineffective postsecondary strategies to help students with ASD deal with the issues that they encounter in postsecondary education. Studies that address the issues that students on the autism spectrum encounter during postsecondary education and postsecondary programs that attempt to address these issues are reviewed in the next section.

Students with disabilities successfully transitioning to and thriving in postsecondary education settings are becoming more prevalent. Many previous studies have examined specific factors that lead to postsecondary success for students with disabilities. Anctil, Ishikawa, and Tao Scott (2008) studied the cognitive and behavior qualities of successful students with disabilities and how these manifest themselves in successful students' self-determination. The study's specific purposes were to examine how self-determination had affected the participants' successful transition and success in postsecondary education and the researchers examined behavioral manifestations of self-determination. This study was made up of 19 participants who were successfully succeeding in a postsecondary education setting. The authors of the present study did not specify whether any of the study's participants were on the autism spectrum.

Levels of self-determination were measured through two self-determination scales. Interviews were conducted to determine the self-determination factors that made students successful. The following themes assisted students in developing effective self-determination persistence, competence, career decision-making, and self-realization. Effective time management skills, an unstoppable desire to succeed, an understanding ones disability, and his/her strengths and weaknesses also helped to lead to the acquisition of self-determination skills. Many participants said they were not included in the transition planning process.

Anctil, et al.'s (2008) study does have many connections to the current thesis. Research showed that self-determination and the qualities that go along with it can effectively be developed in postsecondary education students with disabilities that often struggle with many of the same issues as individuals on the autism spectrum. Postsecondary programs for adolescents with autism must concentrate on developing the skills and qualities that lead to effective self-determination outcomes.

High levels of self-determination have led to success in postsecondary education for students with disabilities. Russo Jamerson (2007) conducted a two phase qualitative and quantitative research based study to investigate the relationship between successful two-year college students with self-determination, and how students with greater and lesser degrees of self-determination understand and describe the outcomes of their postsecondary experience. No participants in either phase of the present study were autistic. The first quantitative phase of the current study was made up of 48 participants. To gather data in this phase the researchers used the Arc Self-Determination Scale and a researcher developed demographics outcomes survey.

Results of faze one showed that the majority of study participants who had graduated from the program were either full time or part time employed. Participants with a higher degree of self-determination had a higher GPA compared to students with a lower degree of self-determination.

The second faze of the Russo Jamerson (2007) study consisted of qualitative based follow up interviews to examine how college graduates with varying degrees of self-determination described their postsecondary experience. This phase was made up of four participants. Three interviews were conducted. Qualitative results showed that students with higher degrees of self-determination had a more positive postsecondary education experience. The qualitative phase reveals more about the complexity of self-determination and its development.

A common practice among students with disabilities who wish to pursue a postsecondary education is to start their postsecondary education career at a two-year community college. However, many students do not transfer to a four-year institution after completion of an associates degree. Ponticelli and Russ-Eft (2009) examined the effective predictors for transfer from community college to a four-year institution for students with disabilities. Participants in this study consisted of a cohort of students from the years 1995 to 2007 in California 26,751 students attended community colleges during this time frame. 4,741 of the study participants successfully transferred to a four-year postsecondary institution. It is unknown whether any of the participants of the current study were on the autism spectrum.

Data was gathered from the California Community College Chancellor's Office (CCCCO). Data was organized in SPSS. Analysis of data was completed across 12 independent variables. In order to assess whether there was an interaction among independent variables, logistic regression was run.

Independent variables that had a relatively strong correlation with transfer to a four year institution were proportion of transferable courses that the student was enrolled in, number of courses that were taken for credit and could be applied towards a degree, number of courses taken compared to the number of courses completed, and number of courses passed. The top two variables were proportion of transferrable courses in which the student was enrolled and the number of courses that the study participant attempted compared to the number of courses that were successfully completed. On average students with disabilities transferred the same amount of credit classes and took about the same time to complete their associates as their typical peers.

Potecelli and Russ-Eft (2009) added a lot to existing research and has some implications for the present thesis. The main finding was that the study's results demonstrated that California's community colleges generally were very effective in transferring students with disabilities to four-year institutions to further their education. These results apply to the current thesis because it shows that effective transition from community college to a four-year university is possible for students with disabilities, including autism.

Inclusion of students with severe disabilities including autism in postsecondary settings with typical peers is a relatively new concept. As a result, limited research has been conducted on the topic. However, Causton-Theotoris, Ashby, and DeClouette (2009) conducted a qualitative study that examined two postsecondary programs in Central New York that embrace the inclusion of students with severe disabilities. The authors of the current study did not specify whether any of the participants were on the autism spectrum. Specifically, the study looked at the benefits and major accomplishments of these two inclusion-based programs and the obstacles that exist in implementing these programs.

The data source used to explore the study's objectives was an in-depth interview of the major stakeholders of these programs. Interviewees consisted of: parents of program participants, program developers, program staff, and university faculty. Study participants were pre-selected by the researchers. The current study consisted of eight participants. Data collection was conducted by coding themes and looking for and coding themes that occurred throughout the interviews.

There were many benefits and obstacles of inclusive postsecondary programs. Students with significant disabilities and their classmates and benefits to college faculty experienced many benefits from the implementation of the inclusion-based programs. Benefits to students with significant disabilities consisted of individual student growth, first inclusion environment leading to new dreams and possibilities, and opportunities for a normal college experience. Families of students with significant disabilities participating in postsecondary programs centered on inclusion methods improved competence in their children. Benefits for peers of students with significant disabilities were learning to include students with significant disabilities and many natural interactions with students with significant disabilities. College faculty brought about several benefits of inclusion that they saw in their classrooms including making the instructor a more effective teacher and being able to practice the inclusion methods that the professor always emphasized. Institutional or logistic obstacles include limited course selection for the postsecondary inclusion program to mostly lower division, more populated courses making delivery of effective accommodations difficult, the inability for students with disabilities to take classes for credit, parking, transportation, and scheduling difficulties. An attitudinal obstacle that research found was fear of faculty resistance. As a result of being a qualitative study, the results of Causton-Theotoris et. al (2009) cannot be generalized to the current thesis.

Many students with disabilities who enter a postsecondary setting lack the self-advocacy skills required to access accommodations in a postsecondary education setting. Programs in postsecondary settings have been developed to teach self-advocacy skills to ensure success of their disabled population. One such program is examined by Palmer and Rossler (2000). The purpose of the current study was to assess the effects of the Self-Advocacy and Conflict Resolution Training (SACR) program. Study population consisted of two groups of students from two postsecondary institutions. The authors of this study did not specify specific diagnoses of the participants. The control group was made up of 26 students and the experiment group was made up of 24 participants.

SACR is an eight-hour program that addresses communication (self-advocacy) and negotiation (conflict resolution) skills that are essential for students to require the accommodations that are essential for their success in postsecondary programs. After the program had been completed, posttest analysis was conducted on the control and experiment group to measure the effectiveness of the program. The results showed that the program improved the self-advocacy behaviors, conflict resolution behaviors, knowledge acquisition of the student's disability, request of self-efficacy, conflict resolution in terms of self-efficacy, and social competence of the experiment group.

Palmer and Rossler (2000) showed one major contribution to previous research. The study depicted that by implementing the SACR program; students with disabilities can show an increase in self-advocacy, conflict resolution, knowledge of their disability, self-efficacy skills, and social competence. Difficulties with self-advocacy, conflict resolution, and self-efficacy skills are common among students on the autism spectrum. With implementation of a program like SACR, would the same results be demonstrated with students with autism?

It is a well-known fact that postsecondary education leads to overall better vocational outcomes. Limited research has been done to examine whether this is true for the significantly disabled population. Hart, Zafft, and Zimbrich (2004) conducted a qualitative study that examined 40 high school students ages 18 to 22 with severe disabilities including autism (a portion of which had attended postsecondary education and a portion that had not attended postsecondary education) to see if there were any differences in the outcomes of the two groups. The 20 participants who participated in a postsecondary program took part in the College Career Connection (CCC) model concentrating on improving the adult outcomes for secondary students with significant disabilities by improving access to postsecondary education. The data collection procedure used for this study was a matched cohort follow up 21-question survey.

Survey results found five significant relationships. First, participation in postsecondary education led to more students with severe disabilities experiencing competitive employment. Students who participated in postsecondary education worked fewer total hours per week in paid employment than those who did not participate in postsecondary education. In terms of accommodations, survey participants who participated in postsecondary education used more and had a greater repertoire of accommodations in the vocational environment. Participants who participated in postsecondary education had a greater likelihood of receiving a high school diploma. 16 of the 20 subjects who participated in a postsecondary transition program went on to pursue a postsecondary education after graduation.

A common practice for high schools across the country is to encourage students to take advantage of postsecondary education options while still in high school through the local community college. Recently, these options have been made available to students with learning, cognitive, and intellectual disabilities (LCID) Hart, Mele-McCarthy, Pastermack, Parker, and Zimbrich (2004) conducted qualitative study that examined 25 programs across the country that offered secondary students with LCID the opportunity to participate in community college postsecondary settings while still in high school. Services and accommodations offered to LCID students in these programs were examined. Researchers did not note whether any of the programs surveyed in this study served students on the autism spectrum. The method for data collection used in this study was a survey sent to the 25 participating programs.

Results of the Hart, et al. (2004) study indicates that surveyed programs fit into three categories substantially separate, mixed programs, and inclusive, individual support. 13 of the postsecondary programs surveyed were mixed, eight were inclusive, and four were substantially separate programs. The most common barrier that survey results found was the attitude that students with LCID did not belong in college, or their curriculum needed to be adjusted. Other barriers consisted of transportation, entrance standards, and lack of transition planning.

An increasing number of students with Aspergers Syndrome (AS) are entering postsecondary settings. However, prior to Smith's (2007) study, very little research existed to see if whether or not students with AS were receiving the accommodations needed to ensure their success in postsecondary education. Smith (2007) conducted a qualitative and quantitative, exploratory study that examined the needs of students with autism in postsecondary settings and what accommodations are available to students on the spectrum in higher education settings. The research subjects consisted of a staff member of 29 postsecondary institutions' disability support services (DSS). 102 surveys were originally distributed. It is unknown whether any programs served students on the autism spectrum. The instrument for the current study was a survey that looked into the accommodations that each DSS office offered to students with AS. Upon receiving surveys, the researcher coded the dada using SPSS.

Quantitative results of the Smith (2007) study indicated that the majority of students with AS pursuing postsecondary educations are attending universities compared to junior colleges, technical colleges, and other institutions. The most accommodations offered by institutions were time and a half on exams and an alternative testing site. Only 15% of institutions offered a DSS counselor and tutoring for students with AS. No institutions surveyed offered support groups and 56% percent of participating institutions offered counseling services for students with AS. To educate faculty on AS, the most common method used by postsecondary institutions in the present study was a one-to-one discussion with a DSS counselor.

Qualitative data results of the Smith (2007) survey gathered information on specific programs, counseling, and support groups available to students with AS. The results of this study indicate that a lot of students with AS are choosing to pursue a postsecondary education. However, the institutions that this study surveyed were providing services that were directed towards serving the entire disability population, and not specifically their students with AS. As a result of AS being such a diverse disorder, accommodations in postsecondary education need to be individualized to meet these students’ unique needs.

Although the number of students with significant disabilities participating in postsecondary education is increasing at an astronomical rate, very little research has been conducted on students with severe disabilities in postsecondary education. Neubert, Moon, and Grigal (2003) conducted a survey of teachers in postsecondary sites in Maryland serving students with significant disabilities. Educators were asked to provide information regarding their students’ level of inclusive activities on college campuses and in the community. Participants consisted of one teacher in 13 postsecondary settings in Maryland serving students ages 18 to 21. The authors did not indicate whether any of the participating postsecondary programs served students on the autism spectrum.

Results indicated that the majority of students were engaged in vocational training. Access to college courses and extracurricular activities was limited. All sites had a strong linkage between school personnel and adult service providers.

The United Kingdom is seeing an increasing number of students with Aspergers Syndrome pursuing a postsecondary education. Taylor (2005) conducted a qualitative study looking at the type of adjustments to instruction and assessment that would be appropriate for students with Aspergers Syndrome in United Kingdom's higher education system. The population was three subjects with Aspergers Syndrome enrolled in a postsecondary education setting in the United Kingdom.

Results of Taylor (2005) showed that faculty teaching in higher-education settings need to be aware that group work could cause difficulty for students with Aspergers Syndrome in a higher education setting. Carefully selecting group members or offering an independent project option for students with Aspergers can make adjustments. Students with Aspergers Syndrome may require reminders to attend class sessions. Taylor (2005) also indicated that individualized coursework assessments, instead of group assessments, should be considered for students with Aspergers Syndrome in higher education. Extensions on course assignments, taking exams in another room, and keeping university staff educated on AS were among other higher-education accommodations mentioned that may be appropriate for students with Aspergers Syndrome.

It is not uncommon for individuals on the autism spectrum to have sensory issues. What happens when these individuals transfer into postsecondary education settings? Madriaga (2010) wanted to qualitatively examine how the sensory issues experienced by many students on the autism spectrum impacted their ability to socially interact in typical university environments. The study took place in the United Kingdom. The population was eight postsecondary education students on the autism spectrum across the country. Seven participants were in their first year of postsecondary education. One student was in his first year of obtaining his MA. The data collection procedure consisted of the researcher conducting life-histories interviews. Data analysis was completed by transcribing interviews. Analytical analysis was completed by the researchers looking for common themes within the interviews.

Findings of Madriaga (2010) indicated that two study participants could not attend freshman orientation week and four participants could not hang out with friends at local student pubs because of the high level of sensory input present in these environments. As a result of not being able to participate in these social events, loneliness and isolation were commonly experienced. Half of the study participants enjoyed the pub, freshman orientation, and other college social events. Half of the study participants found the library had too much sensory input for them.

Family Perceptions on Postsecondary Transition Issues

Parent Perspectives

A viewpoint that cannot be ignored when addressing postsecondary transition of young adults with autism and related disabilities is the perspectives of parents/caregivers on the postsecondary transition process and its desired outcomes. Parents/caregivers are often the individuals who know their child best. Studies that examine parent perspectives of students with autism and related disabilities on the postsecondary transition process and its outcomes are reviewed in the following section.

As postsecondary education becomes more of a reality for students with intellectual disabilities, families of postsecondary transition aged children and their viewpoints must be taken into consideration. Griffin, McMillan, and Goddapp (2010) conducted a study, which examined families of young adults with intellectual disabilities and their knowledge and perceptions of the postsecondary education (PSE) process. The study had three purposes. First, the researchers wanted to determine the perceptions of families on transition planning and the barriers that study participants encountered in gathering knowledge. Second, study authors wanted to identify any demographic characteristics that might align with varied expectations for students after high school. Third, a determination was made of families of students with intellectual disabilities and their concerns regarding enrolling children with intellectual disabilities in PSE and the PSE program characteristics that families found most vital. Participants were made up of one 108 family members of postsecondary transition-aged students with intellectual disabilities. 35% of participants had children on the autism spectrum. The data collection method use was a survey developed by the Tennessee task force for postsecondary education for students with intellectual disabilities. Electronic and paper versions of the survey were developed. The survey instrument consisted of four sections: information about primary respondents, information about the student with an intellectual disability, perspectives on PSE options, and open-ended questions.

Data analysis for the present study consisted of all survey data being inputted into SPSS. Several ANOVAs were conducted across various sections of the survey. Although parents considered PSE opportunities to be beneficial for their transitioning children with intellectual disabilities, parents did not believe that educators were encouraging PSE options. Minimal access to resources and poor communication between parents and teachers of students with intellectual disabilities were cited as significant barriers that parents saw as holding them and their children back from pursuing PSE options. Research also indicated that caregivers of students with lower reading levels were less likely to consider PSE as a feasible option for their child. Study participants indicated that primary concerns and expectations for PSE programs centered on child safety and preparation for the work force.

The present study does have more implications for the current thesis than any other research study reviewed. The current study's data collection system is almost identical to the one used in the current thesis. The present thesis' data collection system will be further examined in future thesis chapters.

A specific diagnosis on the autism spectrum that is becoming significantly more prevalent on college campuses across the country is students with Aspergers Syndrome (AS). Young adults with AS find it difficult to meet the strong social demands that postsecondary institutions place on them. Minimal research studies have examined parent perspectives of the availability of psychosocial accommodations at the postsecondary level and their young adults' ability to access such services. Morrison, Sanosti, and Handley (2009) conducted a qualitative study that looked at parent perceptions regarding supports that college bound students with AS require at the postsecondary academic level to be successfully adjust to the academic and psycho-social demands of the college experience. Researchers also looked at the self-advocacy skills required for students with AS to obtain the supports to be successful in the college environment. Four mothers with transition-aged youth with AS participated in a focus group that made up this study.

Morison, et al. (2009) results showed that participants expressed a desire for more reasonable and appropriate supports and accommodations for their young adults such as: increased collaboration between the disability support center and professors, the disability support center offering more supports to promote self-advocacy, and scheduling accommodations. Participants in the focus group brought up the point that students with AS often struggle with self-advocacy in postsecondary education settings.

Parental viewpoints on the areas involved in the postsecondary transition of their students with disabilities must be considered. Grigal and Neubert (2004) examined a few of these areas by looking at parents of students with disabilities and their viewpoints on the importance of secondary instructional domains, transition planning areas, and the post school expectations for their child enrolled in secondary education. 234 parents who had students with high or low incidence disabilities participated in the current research. Diagnosis specification was not reported. The instrument researchers used for the present study was a well-developed survey that went through several drafts, revised after feedback from professionals and parents.

Grigal, and Nuebert (2004) results showed that parents with high and low incidence disabilities significantly varied in the values they placed on instructional domains, transition planning areas, desired independent living situations, and post school expectations regarding education and employment.

Some limitations existed in Grigal and Nuebert 2004) study that are worth noting. First, the response rate for the current survey, which was mailed to participants, was low (24%). Research participants came from two school districts in one mid-Atlantic state. Therefore, caution needs to be taken when generalizing results to any other population.

Regardless of limitations, the present study does have a few implications for the current thesis. Just as in the present thesis, extensive parent values were measured in the current study. A large percentage of parents with students with low incidence and high incidence disabilities reported postsecondary education as a feasible option for their child. A lot of the parent values regarding postsecondary education measured in the Grigal and Nuebert (2004) study were also measured in the current thesis.

The importance of self-determination in postsecondary transition for students with autism and related disorders has already been emphasized. However, a comparison between parent and educator viewpoints on self-determination has yet to be addressed. Grigal, Neubert, Moon, and Graham (2003) conducted a study with the purpose of comparing the viewpoints of parents and students with high and low incidence disabilities and their general and special educators on self-determination. Study participants were made up of 234 parents and caregivers who had children with high/low incidence disabilities and 248 teachers who taught students with high/low incidence disabilities. Study authors did not specify whether "high/low incidence disabilities" included autism spectrum disorder. Data for the present study was gathered through one survey for parents/caregivers and one survey for secondary special and general educators. Data analyses on the two self-determination measurements developed were analyzed through several factor analyses.

Girgal, et al. (2003) results indicate that parents of adolescents with disabilities encouraged the teaching of self-determination skills at school. Parents whose child was enrolled in college preparation or career technology courses believed that students should attend, and be very involved in IEP meetings. However, parents who had children who attended solely community-based/life skills courses put less of an emphasis on student involvement in the IEP process. Parents believed that although the school was teaching self-determination skills, their children with disabilities were not acquiring self-determination skills.

A small percentage of educators who responded to the present study believed that they were aware of the concept of self-determination and how to teach it. The majority of teachers who were familiar with self-determination believed that their school was doing an inadequate job of teaching and allowing the practice of essential self-determination skills.

The current study does have a few implications for the current thesis. Grigal, et al. (2003) was the first research study to measure parent and teacher perceptions of self-determination in students with disabilities. Self-determination is a key factor in an effective postsecondary transition for students with disabilities, and the viewpoints of parents and teachers on this subject cannot be ignored when developing and implementing postsecondary programs.

A small amount of research has examined adolescents on the autism spectrum and their parents’ views on the feasibility and outcomes of postsecondary education. Ivey (2004) examined the extent to which parents’ expectations differ from their ratings of expectations on the likelihood and importance of achieving specific outcomes for their children with autism. 25 parents who resided two mid-western states participated in the investigation. Children ages ranged from 4 to 20 years.

Parents' importance and likelihood of obtaining certain outcomes varied significantly in eight areas friend support network, secure financial future, safe from physical harm, highest education possible achieved, has his/her own children, accepted in the community, happy and satisfied, lives independently, and is successful vocationally. Although parents expressed high importance in these areas, the likelihood that they would be achieved for their autistic child was lower.

One connection of this study to the current thesis is it deals specifically with individuals on the autism spectrum. However, it must be noted that the average age of children on the autism spectrum is significantly lower than those measured in the current thesis. Ivey (2004) had participants with who had children with an average age of six to ten, while the present thesis' participants were between the ages of 18 and 24. Ivey (2004) findings indicated a lot of concerns that parents have about future lives of their children on the autism spectrum. The present thesis compares many similar issues.

Many mother-child relationships play a significant role during the transition from adolescence to adulthood. However, very few studies have examined the mother-child relationship during this crucial period. Lounds, Seltzer, Greenberg, and Shattuck (2007) conducted a four and a half year investigation into how the changes that adolescents and young adults were experiencing during this phase of life impacted maternal wellbeing and the quality of the mother-child relationship. 104 mothers of children on the autism spectrum and their children in Wisconsin and Massachusetts participated in this study. Dependent and independent variables were measured. For a complete list of the study's dependent and independent variables, see Lounds, et al. (2007), p.p. 405-407. Each variable was conducted four times throughout the study to measure changes in maternal wellbeing and the mother and child relationship.

Lounds, et al. (2007) found that the majority of mothers adapted to the changes that take place in their child during their son or daughters adolescent and young adult period. Autism symptoms and problem behaviors in subjects on the spectrum declined during the study period. However, when compared to mothers with daughters on the spectrum, mothers of sons with autism experienced higher rates of depression. When adolescents left high school, the mother-child relationship improved. When an increase in medication related to autism symptoms occurred, maternal depression decreased.

Lounds, et al. (2007) adds a lot to the current thesis. The majority of parents participating in the current thesis were mothers of individuals on the spectrum. Although the thesis does not look into maternal wellbeing or the quality of the mother-child relationship, it does give some possible insight into the quality of the relationship between the mothers and children participating in the thesis research.

Mothers of children with severe disabilities often know their children best. Therefore, it is important to consider their perceptions of their young adult's quality of life during postsecondary transition. Mcintire, Kramer, and Simmerman (2004) conducted a qualitative study that looked at the perception of mothers of children with severe disabilities on their child's quality of life. 30 mothers with children with severe disabilities ages 18 to 24 made up the study's population. A portion of the study's participants did have children on the autism spectrum. Researchers recorded and scribed the interviews.

Mothers of children with severe disabilities found: recreation, activities, hobbies, having their son or daughter's basic needs met, the participation of their young adult in a social network, and having their child be happy or content were most important components of young adult's quality of life. Work, communication capabilities, and overall health were found less important.

Sibling Perspectives

The author of this thesis found minimal research relating to siblings of individuals on the autism spectrum and their perceptions on postsecondary education. The researcher used the following terms when looking for articles that addressed the perspectives of siblings of individuals on the autism spectrum on postsecondary transition "sibling," "perspectives," "postsecondary," "transition," "brother," "sister," "high school," "college," "workplace," "vocational," “viewpoint,” “autism,” “autism spectrum disorder,” “Aspergers Syndrome (AS),” and “disability.” The previous terms were searched electronically in the following databases Education: A Sage Full Text Collection, Education Full Text, ERIC (via CSA Illumnia), ERIC (via US Department of Education), and PsycINFO.

A perspective that is often overlooked when considering postsecondary transition is the perspective of siblings of individuals on the spectrum. Siblings of individuals with autism often end up becoming the primary caregivers for their autistic sibling. Studies that analyze the perceptions of siblings of individuals on the autism spectrum are taken into consideration in this section.

Minimal research exists examining the perspectives of siblings of individuals with disabilities on their brother or sister’s future. Chambers, Hughes, and Carter (20004) conducted a study that examined and compared the perceptions of parents and siblings of individuals with severe disabilities regarding the following domains: employment, social, leisure, recreation, residential, daily living skills, and postsecondary education. Eight parents and siblings of high school students with severe disabilities made up the investigation. One of the individuals with a severe disability did have autism.

Both parents and siblings reported having limited knowledge about postsecondary options for family members with significant disabilities. Parents noted that they were more involved in the postsecondary transition process than siblings. Both parents and siblings held the belief that family members with severe disabilities would work in segregated employment (for example a day center) and live with parents. Parents and siblings rarely discussed postsecondary options or opinions with each other or other family members.

Although Chambers, et al. (2004) does not have any immediate applications to the present thesis, one possible connection must be noted. Researchers were the first to examine sibling perspectives of individuals with significant disabilities on post school options. This viewpoint is crucial, because siblings are most likely going to take over care of their brother or sister with significant disability once parents are no longer able to.

Youth and Young Adult Postsecondary Perspectives

Beliefs and Expectations

The beliefs and expectations of young adults on the autism spectrum must be taken into consideration when addressing anything related to postsecondary transition. Studies that examine individuals on the spectrum's viewpoints on postsecondary education are addressed here.

Active student involvement in the IEP process is important for students with disabilities to develop self-determination skills. What about student perceptions on the nature and extent of their involvement in the IEP process? Agran and Hughes (2008) conducted a preliminary study with a population of 17 high school students with moderate to severe disabilities and 56 junior high school students with a variety of disabilities. Disability diagnosis was not specified. A survey was developed for the study instrument. Survey distribution was conducted through a graduate student read the survey and recorded participants’ answers.

Although self-determination skills were taught to study participants, few could self-monitor their behavior. Although study participants indicated a desire to make their own decisions, a small percentage was actively involved in the IEP process. Junior high school participants showed to have more self-determination skills than subjects in the high school sample. The cause for this finding could be students in the high school sample came from a lower socioeconomic area.

Agran and Hughes (2008) did have a few limitations. Although the samples were taken from two states, they were small. As a result, none of the results can be generalized to a population beyond the investigation’s population. However, possible implications for the current thesis do exist and must be noted. Agran and Hughes gave insight into student perceptions of self-determination acquisition and the IEP process. This viewpoint is crucial to consider when addressing the postsecondary transition of students with disabilities such as ASD.

Active student involvement in the entire postsecondary process is important for postsecondary success of students with disabilities. Williams-Diehm and Lynch (2007) conducted a study with the purpose of determining what knowledge students with disabilities possess about transition planning and how students perceive the role of school staff in the transition planning process. 103 participants receiving special education services in a mid-sized high school in

Texas participated in the current study. A portion of the population was on the autism spectrum. A ten-item survey verbally administered for data collection.

The majority of students in this study had no knowledge of the IEP process and minimal knowledge of the purpose of a transition plan. Students' personal, vocational, and academic goals did not align with students' ITP goals. Although the majority of young adults actively participated in their ITP meetings, they did not believe that their opinion was valued by teachers. A large percentage of adolescents were not satisfied with adult service providers and the role that they had in the transition process. Only two participants indicated that their families were consulted prior to the transition meeting, and the family member's opinions were highly valued in the meeting. Students did not believe that the high school staff had helped them meet their transition goals.

Transitioning from school to a postsecondary setting can be a very stressful time for students on the autism spectrum. Browning, Osborne, and Reed (2009) conducted a qualitative investigation with the purpose of examining the school to post school transition stress level of young adults with ASD compared to the stress level of non-disabled peers making the same transition. Ten individuals on the spectrum and seven non-disabled participants enrolled in their last year of secondary school in England made up the study. Data gathering consisted of researchers directly interviewing participants.

There were many differences in the group on the autism spectrum and the group with no known disability. The latter group worried more about their future in terms of education, but coped well with stress. Participants with ASD worried about future physical harm and peer relationships, and did not cope with stress as well.

When going through the postsecondary transition planning process, it is vital to include the educational aspirations for students with high-functioning autism (HFA) and their families. Camarina and Sarigiani (2009) conducted a qualitative based research study that assessed the postsecondary education aspirations of young adults with HFA and their families. Perceived obstacles that prevent students with HFA from succeeding in postsecondary settings were also addressed. 21 adolescents with HFA and their families participated in this study. Data collection was completed through a 63-question interview.

Both parents and young adults with HFA showed a strong interest in postsecondary education options. However, both groups were concerned about the adolescent with HFA socially succeeding in a postsecondary education environment. A strong gap between the hopes of parents and their children and actual resources available to assist them with the postsecondary transition processes existed. The majority of the students interviewed were not educated on their disability and how it affected them. Some students surveyed did not believe that they had a disability.

Young adults and their parents often have some similar, and some differing views in terms of postsecondary transition. In order for the transition process to be most effective, both viewpoints must be taken into consideration.

Powers, Powers, and Greenen (2009) specifically looked at the following four questions. Do youth and parents agree on the important goals that they want youth with disabilities to attain in adulthood? Are parents and youth in agreement on the level of supports that youth require to attain important life goals? Do parents and youth have the same viewpoint on youths' level of preparedness to meet important life goals? Does agreement between parents and adolescents on these topics vary by age? 270 parents and 242 students with disabilities from two western states participated in this study. Independent samples were gathered for the investigation. None of the study participants were on or had children who were on the autism spectrum.

Getting a good doctor, having health insurance, and finishing high school were shown as the three most important immediate goals that both parents and young adults with disabilities felt must be accomplished. Youth and parents also placed a strong emphasis on learning to take care of oneself, safety protection, speaking up for oneself, and the importance of self-determination. Both students and parents noted that family involvement was helpful during student transition into adulthood. Parents did put more emphasis on teacher support during the postsecondary transition process. However, youth reported encountering greater barriers in the transition process. Parents often underestimated the self-esteem of young adults.

Powers, et al. (2009) does have a few limitations. Parents and students were sampled independently leaving no one to one correspondence between parents and youth with disabilities. Like many surveys that are mailed out, there also was a low response rate for this study (22%). The investigation is exploratory in nature.

Postsecondary Outcomes

The author of the current thesis found limited research studies that related specifically to the postsecondary outcomes of students with autistic-like traits. The following terms were searched when researching articles that related to the postsecondary outcomes of individuals with autism-like traits that had gone through a postsecondary preparation program “autism,” “autism spectrum disorder (ASD),” “disability,” “Aspergers Syndrome (AS),” “postsecondary,” “outcomes,” “employment,” “vocational,” and “college.” The previous terms were searched electronically in the following databases: Education A Sage Full Text Collection, Education Full Text, ERIC (via CSA Illumnia), ERIC (via US Department of Education), and PsycINFO.

An examination of the postsecondary outcomes of individuals on the autism spectrum is essential to obtain a full understanding of the strengths and weaknesses of current postsecondary programs. This section reviews studies that examine such outcomes.

Limited research exists examining the post school outcomes of individuals with disabilities, which are crucial to determining the effectiveness of postsecondary preparation programs. Baher, Flexer, Beck, Amsutz, Hoffman, Brothers, Stelzer, and Zechman (2003) consisted of a group of transition coordinators getting together to develop a cost-efficient way of evaluating transition services and post school outcomes for inclusion in their schools' program improvement efforts. 140 students who had a specific disability and were one to three years post high school graduation in the state of Ohio participated in the study. A small percentage of the participants were on the autism spectrum. Data collection was completed through in person and phone interviews. Full time employment and postsecondary education were included as outcome variables in the current investigation. Data analysis was conducted by coding survey results, and then inputting the survey results into SPSS.

68 participants (49%) had full time employment and 53 graduates (38%) were enrolled in a postsecondary education setting. Female participants showed to have significantly negative in-school and postsecondary vocational and postsecondary education outcomes compared to their male counterparts. Transition outcomes did have a correlation with the school setting (urban, suburban, or rural). Participants who attended a rural or suburban high school had much better employment and better postsecondary education outcomes than young adults who attended secondary education in a rural setting. Participants who had a learning disability also showed significantly better employment and postsecondary education outcomes compared to study participants who had other disabilities.

There are many limitations of Baher, et al. (2003) that impact how the study can be applied to the current thesis. The study results can only be applied to the school districts that the participants graduated from in Ohio and was primarily investigative. The researchers also eliminated students who had only received speech services and who had dropped out of high school.

The viewpoint of adults with Aspergers Syndrome (AS) on their postsecondary vocational outcomes has been highly ignored. However, Hurbutt and Chalmers (2004) conducted a qualitative based investigation with the purpose of providing information about adults with AS and their employment experiences and what can be done to prepare individuals with AS for a positive vocational experience. The study was made up of six adults with AS who participated in an initial and follow-up interview regarding their vocational experience.

All participants in the current study noted that they had difficulty finding and maintaining a full-time job that met their specific interests and qualifications. Difficulties centered on lack of appropriate social and communication skills and sensory issues. One recommendation that study participants made in order to enhance the vocational experience for individuals with AS is make use of job coaches and job mentors. Clear indication of job duties, responsibilities, and expectations were factors that lead to vocational success for study participants.

Employment satisfaction is an excellent way to measure the adult outcomes of individuals with learning disabilities. Madus, Ruban, and Zho (2008) conducted a study that examined the employment satisfaction of college graduates with learning disabilities. 500 recent graduates with disabilities from two west coast postsecondary institutions and one east coast postsecondary institution took part in this investigation. Participants' specific disabilities were not specified. Data was collected through a survey that was mailed to participants. Graduates with learning disabilities reported a high rate of employment satisfaction. A high percentage of participants used accommodations directed towards their specific learning disability in the workplace. Many graduates were confident in their ability to effectively perform the many facets of their jobs. Individual salaries were significantly higher than previous studies.

Residential outcomes must be considered when addressing postsecondary outcomes of individuals with disabilities. Heat, Rubin, and Rush (1998) conducted an investigation with the purpose of identifying geo-political, family, personal, circumstance, and school program variables that correlated with the degree of residential independence five years after individuals with disabilities exited high school. 5,462 cases that had exited from the secondary education system between the years of 1987 and 1990 were examined in two urban school districts. Specific disability diagnosis was not indicated in the study. Extensive data collection was done through phone parent surveys, student record examination, and school personnel phone interviews.

More independent postsecondary residential outcomes were associated with individuals who had highly developed daily living and social skills. Prevalence and severity of problem behaviors also played a role in residential independence. Work-study programs may also promote independence. Heat, et al. (1998) has a few implications for the present thesis.

Although individuals on the autism spectrum were not specifically addressed in the study, at the time this study was conducted, ASD did fall under the low-incidence disability category. The Heat et. al study (1998) conducted a very thorough analysis of the residential outcomes of individuals with disabilities. The survey that makes up the current thesis emphasizes parent viewpoints on the importance of residential independence as a factor that leads to independence following secondary education.

Conclusion

In summary, chapter two has provided an extensive literature review on postsecondary transition as it relates to individuals on the autism spectrum. Specifically, issues that young adults on the autism spectrum making the transition into adulthood encounter were addressed including unique obstacles related to postsecondary transition aged youth on the autism spectrum, social, and self-determination issues often encountered by the autism population during postsecondary transition.

Additionally, effective and ineffective postsecondary programs and obstacles that young adults with autism often encounter in postsecondary settings were compared. The author also looked at the perceptions of young adults on the autism spectrum, parents, and siblings of individuals one the spectrum in relation to postsecondary transition. Studies that relate to the transition outcomes of the autism population were also reviewed. Studies have shown that there are many positive areas of the postsecondary transition process, and many areas in need of improvement as well.

The purpose of this thesis is to compare the viewpoints of young adults on the autism spectrum and their parents on secondary and postsecondary education.

The research questions that are going to be addressed are as follows.

1) How do the viewpoints of young adults on the autism spectrum on their secondary education compare to that of their parents?

2) How do the postsecondary expectations of young adults on the autism spectrum and their parents compare?

Chapter 3

CHAPTER 3

Method

Participants

In order to participate in the study, participants had to meet the following requirements a specific diagnosis that fell on the autism spectrum and a chronological age between 18 and 25. Parents participating met the criteria of having a child who was on the spectrum and the child must have been between the chronological ages of 13 to 25 years. Participants were selected from across the greater Phoenix metropolitan area.

Instruments

Two survey instruments; one for parents/caregivers and one for young adults were used for this study. Both surveys were adapted from the survey instrument developed by the Tennessee Task Force for Postsecondary Education for Students with Intellectual Disabilities for a study conducted through Vanderbilt Kennedy Center (Griffin, et al. 2010). Vanderbilt's study was made up of a population with intellectual disabilities with a non-aggregated set of individuals with autism. The population for the current thesis was individuals on the autism spectrum and their caregivers.

Description of the Survey

Parent Survey

The first section (questions 1 through 11) of the parent survey addressed parent demographics. The second section (questions 14 through 18) addressed information regarding young adult characteristics. Section three (questions 24 through 35) measured the secondary experience of individuals on the autism spectrum. Section four of the parent survey (questions 35 to 42) measured parents' perceptions on postsecondary education and what characteristics parents felt were the most vital to consider when a postsecondary option was selected. The last section of the parent survey (questions 43 to 50) consisted of open-ended questions related to postsecondary options. The results of this section were not included in this thesis. See Appendix A for the parent survey.

Young Adult Survey

Section one of the young adult surveys (questions 1 to 11) consisted of parent/caregiver demographics. Section two of the young adult survey (questions 14 through 18) addressed information about the young adult on the autism spectrum's characteristics. The young adult survey's section three (questions 19 through 35) measured the high school experience of individuals on the autism spectrum. Section four of the young adult survey (questions 36 through 42) measured the young adults' perceptions on postsecondary education and what characteristics young adults on the autism spectrum felt were the most vital to consider when selecting a postsecondary education option. The last section of the young adult survey (questions forty three to fifty) was be made up of open-ended questions related to postsecondary options. The results of this section were not going to be included in this thesis. See Appendix B for the young adult survey.

Procedure

First, members of a transition team through Arizona State University modified the Vanderbilt surveys to fit individuals on the autism spectrum through minimal wording changes. The members of the Task Force for Postsecondary Education for Students with Intellectual Disabilities that formed the young adult and caregiver surveys were contacted and gave the Arizona State University transition team permission to use the surveys for the present study. Next, sites around the Phoenix Metropolitan area that serve young adults on the autism spectrum were identified for survey distribution, and permission from survey sites to conduct the survey was obtained. Following site obtainment, a lead researcher from the transition team for each site was selected. The site lead then administered the surveys to young adults on the autism spectrum and caregivers of young adults with ASD.

Survey administration consisted of the site lead giving participants a letter explaining the purpose of the study. A copy of the survey explanation letter administered to participants is included in Appendix C. At that time, the investigator described the study and procedures for maintaining confidentiality (i.e. use of non-identifying labels for participants, destruction of submitted surveys upon project completion). Participants completed the survey and returned the survey to the investigator. Survey participants were given the option of completing the survey in person or through the mail. A coding system was developed and each survey was coded in order to protect survey participant confidentiality. Survey participants sealed their own envelope that included the completed survey.

Data Analysis

The research study design was a descriptive mixed-method design through a collection of qualitative and quantitative data. Data analysis was identical for the young adult and parent surveys. Section one data analysis consisted of descriptive analysis in the form of a frequency count for each question, which described the demographic information of the parent/ primary care giver.

The second section's data analysis was conducted by comparing each question's young adult and caregiver response describing the characteristics of the young adult on the autism spectrum through a T-Test. The transition team came together and looked for trends in the data. The data analysis procedure for sections three and four was identical to section two's data analysis procedures. Section three described the high school experience of the young adult on the autism spectrum. Section four measured the young adults' and their parents' perceptions on postsecondary education and what characteristics young adults on the autism spectrum and their caregivers felt were the most vital to consider when selecting a postsecondary education option.

Results and Discussion

Demographics

22 **(**81%) of parent/ caregiver participants were female. Previous studies have shown similar gender profiles (Griffin et al., (2010); Morrison, et. al (2009); & Mcintire, et. al, et al. (2004)). 11 young adults were male (69%) and 5 young adult participants were female (31%). Mcintire, et al. (2004) and Lounds, et al. (2007) showed similar results. The Center for Disease Control (CDC) estimated that three to four times more males fall on the autism spectrum continuum when compared to females (VanBergeijk, et al. (2008)). 48% (13) of guardians who participated in the current survey were between the ages of 51 to 60 old. The young adult population was much younger with six young adults (38%) being between the ages of 18 and 19 years old. (Lounds, et. al (2007)); Camarina and Sarigiani (2009); & Powers et. al, (2009)) showed similar discrepancies between parent and young adult ages.

Minority ethnic groups were under-represented in the current research (23 caregivers (85%) were Caucasian and four caregivers (15%) classified themselves as “other”, and 14 young adults (88%) were Caucasian, one Asian/Pacific Islander (6%), and one Native American (6%). This underrepresentation of minorities collaborates with previous research in chapters one and two. Parents who participated in the current survey were highly educated (20 (74%) had received a minimum of a college degree, while three (11%) had doctoral degrees). Although minimal studies exist that examine the education levels of parents of young adults on the autism spectrum, Griffin, et al. (2010) did depict similar results. Only two (12%) of the young adults surveyed had obtained a college diploma. A possible factor that may have contributed to the lower education level of young adults is young adults in the survey had a mean age of 21.5 years. However, previous research was in line with these results (Hurbutt, & Chalmers, 2004). For parent survey see Appendix A and for young adult survey see Appendix B.

14 caregivers (52%) were employed full time. Although minimal research supported high caregiver employment rates, Griffin et al. (2010) did depict similar results. High unemployment rates among young adults on the autism spectrum have been shown to be very prevalent in previous research (Hurlbutt & Chambers, 2004). In the current survey, 11 (69%) of young adults were unemployed, consistent with Hurbutt and Chambers (2004) research. However, Hurbutt and Chambers (2004) did show high employment rate among its participants. 14 (55%) of caregivers surveyed were employed in what is classified as middle to upper class occupations. Although minimal research existed on caregivers of young adults on the autism spectrum and their occupations, Griffin, et al. (2010) did show that the majority of caregiver participants that participated in their study were employed in traditionally middle to upper class occupations. Of young adults that were employed in the current survey, only one (6%) was employed full time as an artist. Four young adults (25%) were employed part time. Hurlbutt and Chambers (2004) showed similar findings. 19 (71%) caregiver participants were married, four (14%) were divorced, two (7%) were widowed, one (4%) was never

married, and one (4%) was engaged. Another finding was 15 caregivers (55%) had one to two children at home. All young adult participants were not married and had no children. A factor here could be six young adult participants (38%) were between the ages of eighteen and nineteen years old. The oldest participant was 27 years old. Young adult marital and number of children findings were consistent with past research (Howlin, 2000). In his review of literature, Howlin (2000) did review a few studies that consisted of study participants with a much higher age when compared to the current study.

Comparisons of Young Adult and Parent Response

Survey results found many young adult and caregiver similarities and differences in the rating of the young adult with ASD's ability to perform specific tasks. Surveys also compared caregiver and young adult's viewpoints on postsecondary transition, barriers encountered during postsecondary education transition, and state mandated tests required to pass secondary education.

Ability to perform specific activities

The juxtaposition of the parents' and the young adults' answers to the survey asking their opinion on the ability of the young adult to perform specific activities yielded a spectrum of results. A differentiation existed between activities that can be translated and/or into a broad range of individual tasks (e.g., household chores can encompass doing the laundry, cleaning, or taking out the trash) showed more differentiation between the parent and young adult answers. In terms of activities than could be simply defined (e.g., walking, speaking, and eating), the answers were directly related and yielded similar results. For activities that could be more complexly defined (e.g., leisure, relationships, financial responsibility, etc.) there seemed to be a more inverse relationship in the results with the young adults that scored themselves higher in task ability than the caregivers.

In general, the data suggested that young adults seem to have more confidence in their ability to complete construct-complex tasks such as financial issues, preparing meals, leisure activity, and/or relationships (Powers, et. al, 2009). The majority of the surveyed young adults still lived at home. Therefore, their comprehension of personal independence, financial responsibility and task capability may have skewed the results as they may not have fully encountered the daily responsibilities of independent living and have the safety net of parental supervision when needed (Adreon & Durocher, 2007). The constant presence of this parental “safety net” may also have contributed to the high level of confidence seen in the answers of young adults. More specifically, high confidence levels may have been due to ASD specific perceptual deficits or could have been related to the general inexperience of all similar-aged youth.

Although the parents indicated less confidence in the ability of the young adults to complete complex tasks, there are many factors that existed that may have contributed to this perception (Ivey, 2004) such as in the past. Influence by past experiences with the young adult, a better understanding of social tasks, or simply habitual parental protectiveness (Mcintire, et. al (2004)). Conclusions on such issues had an impact in the parents' perspectives on the ability of young adults have yet to be made.

Postsecondary Transition

The survey, consistent with previous research, data yielded similarities and differences between the guardian and young adult responses. 14 guardians (54%) and nine young adults (56%) responded that postsecondary educational opportunities would assist young adults in the transition to adulthood. Eight young adults (50%) and 14 guardians (54%) believed that young adults would have a strong interest in postsecondary education programs. Griffin et al. (2010) and Camarina and Sarigiani (2009) depicted similar results. Seven guardians (27%) were unsure whether their young adult would pass the assessment.

Federal legislation requires a transition component for each IEP, but it may be that schools are not meeting this federal regulation for transition mandate. Another interesting similarity involved questions about the role of an IEP in the transition process. Both survey groups reported that the IEP did not include a plan for the time immediately after high school (fourteen guardians (54%) responded with a definitive "no" and three young adults (19%) responded "no" while seven young adults (44%) were unsure). Williams-Diehm and Lynch (2007) identified a similar trend. The data suggested that young adults involved in the study had little awareness of the transition component of the IEP, including the section on transition. The best-case scenario is that schools are not effectively involving or communicating with guardians and young adults regarding the IEP.

Postsecondary Education Barriers

Both groups of respondents reported encountering barriers when understand comprehending postsecondary options. 17 guardians (33%) indicated a lack of general information or guidance as a hindrance, while five young adults (28%) showed the same. Findings found in Griffin, et. al (2010) and Chambers et. al (2004) described insufficient resources and lack of effective communications as impediments for those interested in postsecondary options. Nuehring and Sitlington, (2003) reported communication and interaction between guardians, young adults and schools needed to improve with regard to postsecondary expectations. Lack of communication between among guardians and guidance at the secondary level may represent a significant stumbling block for those interested in postsecondary programs and transition options.

State Mandated Tests

Some noticeable differences between the young adult and guardian respondents included a question addressing the young adult passing a state mandated standardized test in order to graduate. Six young adult participants who responded to this question (60%) had or expected to pass the assessment; most guardians (38%) had not anticipated their young adult passing the test. This difference in perception may reflect increased, and perhaps unrealistic, academic confidence by young adult respondents and the responses by the guardians may represent a parental lens.

Responses indicated no clear consensus related to where to find information regarding postsecondary options. Responses varied and were highly divergent by both groups with 14 caregivers (15%) using online resources and 13 caregivers (14%) making use of other guardians, while seven (27%) of young adults reported relying on teachers and four young adults (15%) responded using friends as a resource. No one source of information for guardians or young adults emerged suggesting a lack of reliable postsecondary resources. Consistent results were found in Griffin, et al. (2010).

Postsecondary Education Programs

Background Information

The next section of the parent and young adult survey stood apart from the previous section of the survey by concentrating on postsecondary education programs. It was vital to include this section of the survey because as more young adults on the autism spectrum approach the age of postsecondary transition, postsecondary education is quickly becoming an option. Caregivers of young adults on the autism spectrum often know their children very well, and serve as important advocates for them. As such, it was vital to include and compare the viewpoints of young adults on the ASD spectrum and their parents on the various aspects of postsecondary education.

Parents of individuals with autism spectrum disorders (ASDs) (n=27), and young adults with ASD (n=16), completed a survey with questions related to postsecondary education transition and program choice (question numbers 36-42).

Interest in ASD postsecondary education programs

When asked if they would consider a postsecondary educational program designed for individuals' students on the autism spectrum (AS), 96% of parents (23/24 responders) responded that they would consider this option for their child. Young adults also expressed an interest in this option with 88% (7/8 responses) who considered this type of program as a post high school option.

Although parents and young adults overwhelmingly voiced consideration of support for a postsecondary program for students with ASD, 13 of responding parents (48%) thought it was very likely that their child would enroll in a postsecondary program. Five young adults (42%) responded that it was very likely they would enroll in a postsecondary program.

Postsecondary Program Design in Arizona

24 parents (89%) identified structured social activities as a vitally important aspect of a postsecondary program. 12 (75%) young adults surveyed identified structured social activities as a vital part to a postsecondary education program. Adreon and Durocher (2007) identified social skills as a top priority for students with AS in transition to postsecondary education, and the survey data supported that this was an area of concern for parents and young adults.

The top five program components identified by parents' as very important were: Structured Social Activities (89%- 24 caregivers), Focus on Employment After Completion of the Program (85%- 24 caregivers), Independent Living Skills

(84%-21 caregivers), Social Skills (80%- 24 caregivers), and Work Skills (79%-22 caregivers).

In comparison the top five program components identified by young adults as very important are: Structured Social Activities (75%-12 young adults), Independent Living Skills (75%- nine young adults. The reasoning for the percentage being off was that not every young adult responded to this question.), Individual Choice in Curriculum (75%-12 young adults), Certificate, Diploma, or other Recognition of Completion (69% nine young adults), and Focus on Employment after Completion of the Program (65% eight young adults).

Factors in Determining Program Fit

The factors that parents identified as being very important in a program for their child are Your Child's Safety (65%) and Focus on Employment after Completion of the Program (60%). The factors for young adults that were very important were Distance from Home (62%) and on Employment After Completion of the Program (60%). Focus on employment was very important to both parents and young adults, but a focus on employment may not be enough. Hurbutt and Chalmers (2004) stated that while a focus on employment was a critical program component, it was important that a program prepared individuals to utilize their skill set in the workforce.

Likely Placement Post High School

Seven (37%) young adults identified community colleges as the most feasible postsecondary environment while two (15%) identified technical or vocational programs. Parents were evenly split (12 (29%) identified community college, and 12 (29%) identified technical/vocational schools).

General Conclusions

Parents and young adults expressed an overwhelming interest in postsecondary programs for students on the AS; however, both groups reported the likelihood of attending such a program to be almost 50% less than their level of interest in such a program. Structured social activities were one of the most important program qualities to both groups (89% of parents, 75% of young adults), but 80% of parents reported social skills training to also be a top priority, only 38% of young adults were very interested in social skills instruction. Both groups identified a need for social engagement, but parents saw a need for programming as well as instruction, while young adults identified a need only for social programming.

The top five program components identified by parents are heavily weighted toward the development of social and work skills. By comparison, young adults had a broader top five-program component list that identified independent living, curriculum choice, and the awarding of a diploma or certificate in addition to social and work skills. Both groups saw independent living skills as an important program component. This finding suggested parents were not the only group thinking about the viability and importance of independent living. Overall, the breadth of young adult responses stood in stark contrast to the focused agreement of parents on work and social skills.

Employment was an important aspect of postsecondary program fit for both groups. Young adults were not as interested as parents on employment as a program component, but both groups saw a focus on employment as important in the fit of a program. Parents and young adults saw distance from home as important to the fit of the program (62% for both groups).

57% of parents and 47% of young adults predicted enrolling in postsecondary education after high school. A greater percentage of young adults believed they would be working post high school compared to parents. Graetz and Spaminato (2008), theorized that students with AS may suffer from poor self-esteem as a result of the young adult's high school experience and therefore may be less likely, similar to other marginalized groups, to pursue postsecondary education. Parents were evenly split among the different postsecondary options for students (Community college vs. vocational programs), but young adults showed a trend toward community college enrollment with one third who selected community college compared to one in ten who chose vocational programs.

Overall, an interest in postsecondary programs for students on the AS did exist, but differing sets of priorities between parents and young adults on what programs should include and focus on for students. Employment and social activities were important areas for both groups, but young adults had stronger beliefs on a more diverse set of criteria for program components than parents. Parents tended to see students with AS attending postsecondary education, while more young adults believed they would be working post high school. In contrast, parents showed an even variability in choice for opinions. Survey results projected young adults favor community college over vocational programs.

Implications

As more young adults on the autism spectrum approach postsecondary transition, emphasis must be put on what key players in the transition process view as vital components of a transition program. Two viewpoints that cannot be ignored are those of the young adults on the autism spectrum going through the process, and their caregivers. Current research is the first study that has extensively measured the viewpoints of these individuals. Implications for this in terms of future research, postsecondary program development, and postsecondary program implementation are endless. Survey results found many similarities and differences in the viewpoints of caregivers and young adults, which could be taken into consideration when addressing postsecondary programs for individuals on the autism spectrum.

Limitations

Despite the above implications, the current study does have several limitations. First, the study's population was limited to the Phoenix Metropolitan area. The study also consisted only of 27 caregivers and 16 young adults. Significantly more caregivers compared to young adults participated in the study, leading to an over-representation of parent surveys.

Two different versions of the parent and young adult surveys were administered during data collection. However, survey variance was strictly for survey editing purposes. Data analysis consisted of adjusting the revised surveys in order to account for data collection consistency. Caregivers and young adults noted that the surveys were very time consuming and took them longer than anticipated. When completing the survey, caregivers and young adults found an inability to complete sections designated for their caregiver or young adult.

A large percentage of young adults were Caucasian males falling between the ages of eighteen to nineteen. The majority of caregivers were Caucasian females between the ages of 51 and 60 years old. Limited diversity in survey respondents could have led to skewed results.

Future Research

Due to a limited population, the results of this study must be considered as preliminary results. Future research is needed that expands results to a larger, more diverse population from areas beyond Phoenix. The viewpoints of other key individuals in the transition process (habilitation workers, job coaches, school district staff, professors, career counselors, and college administrators) must be taken into consideration in order to get a full picture of the needs of a postsecondary transition program. During survey administration, researchers should address the issue of the surveys length, and ensure that during survey administration, caregivers have access to young adults, and young adults have access to caregivers to fill out their designated sections of the survey.

Summary/Conclusions

The success of transferring from a secondary to postsecondary environment will impact the overall quality of life of an individual on the autism spectrum. Current research has shown what this success looks like to caregivers and young adults on the autism spectrum. It is the researchers’ hope that this study will lead to further questions, investigations, and answers in terms of postsecondary education program development and implementation for those on the autism spectrum.

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APPENDIX A

PARENT SURVEY

Survey Name: Postsecondary Education Survey

About You: The Parent/Guardian of a Student with an Intellectual Disability

1. Relationship to student: ☐ Parent ☐ Guardian ☐ Sibling
☐ Extended family member ☐ Other: ___________________

2. Gender: ☐ Female ☐ Male

3. Age: ____ years

4. Zip code: _______________

5. Please choose the one ethnicity category that best describes you:

☐ White (non-Hispanic) ☐ African American (non-Hispanic) ☐ Asian or Pacific Islander ☐ Native American ☐ Other

6. What is the highest level of education you have completed?

☐ High School ☐ College ☐ Masters level ☐ Doctoral level

☐ None of the above

7. Are you currently employed?

☐ No ☐ Yes, part time ☐ Yes, full time ☐ Yes, seasonally/temporarily

8. What is your current occupation? __________________________________

9. What is your current marital status?

☐ Never married ☐ Married ☐ Separated ☐ Divorced ☐ Widowed

10. Have you ever been divorced ☐ Yes ☐ No

11. How many children do you have? _________

About the Child with an Intellectual Disability

14. Where does your child live?
15. ☐ Your home ☐ Supervised apartment
☐ Family home of another relative ☐ Group home
☐ Larger facility ☐ Other: _____________________

15. Zip code of child's residence? _______________

16. Gender: ☐ Female ☐ Male

17. Age: ____ years

18. Which of the following disability conditions does your child have? Please check the options that apply the best.
☐ Aspergers Syndrome
☐ Pervasive Developmental Disorder or Not Otherwise Specified (PDD-NOS)

☐ Autism spectrum disorder
☐ Other : ________________________________

19. At about what grade level does your child read?
☐ First or lower ☐ Second ☐ Third ☐ Fourth ☐ Fifth
☐ Sixth or higher ☐ Does not read

20. Does your child have health problems? ☐ 1 Not at all ☐ 2 ☐ 3 Somewhat ☐ 4 ☐ 5 Yes

21. Does your child have emotional problems? ☐ 1 Not at all ☐ 2 ☐ 3 Somewhat ☐ 4 ☐ 5 Yes

22. Does your child have behavioral problems? ☐ 1 Not at all ☐ 2 ☐ 3 Somewhat ☐ 4 ☐ 5 Yes

23. To what extent can your child perform the following activities? Choose only <u>one</u> response for each activity.

	1-Not at all	2	3-Somewhat	4	5-Very well
a. Walking	☐	☐	☐	☐	☐
b. Speaking	☐	☐	☐	☐	☐
c. Eating	☐	☐	☐	☐	☐
d. Preparing meals	☐	☐	☐	☐	☐
e. Taking medications (if applicable)	☐	☐	☐	☐	☐
f. Grooming/personal hygiene	☐	☐	☐	☐	☐
g. Performing household tasks	☐	☐	☐	☐	☐
h. Running errands	☐	☐	☐	☐	☐
i. Basic financial tasks (e.g. counting money)	☐	☐	☐	☐	☐
j. Participating in leisure activities	☐	☐	☐	☐	☐
k. Maintaining relationships and friendships	☐	☐	☐	☐	☐

24. Which one of the following best describes your child's most recent school setting?

☐ Fully inclusive ☐ Partially inclusive ☐ Segregated ☐ Special residential ☐ Home-schooled ☐ Work-based learning site ☐ Community-based instruction
☐ Other: ________________

25. Do you think your child likes high school?
☐ 1 Not at all ☐ 2 ☐ 3 Somewhat ☐ 4 ☐ 5 A lot

26. Do you expect that your child will pass the Arizona AIMS high school exit exam?
☐ I'm not familiar with the AIMS
☐ 1 Not at all ☐ 2 ☐ 3 Maybe ☐ 4 ☐ 5 Definitely

	1- No	2	3- Maybe	4	5- Yes
27. Do you think your child will graduate with a general education diploma?	☐	☐	☐	☐	☐
28. Do you think that high school has helped prepare your child for the future?	☐	☐	☐	☐	☐
29. Do you think that educational opportunities after high school would help your child transition to adulthood?	☐	☐	☐	☐	☐
30. Does your child seem interested in educational opportunities after high school?	☐	☐	☐	☐	☐
31. Has the school staff encouraged your child to continue in an educational setting after high school?	☐	☐	☐	☐	☐

32. Does your child's IEP include a plan for the time immediately after high school?

☐ Unsure ☐ Yes ☐ No

33. How aware do you think you are of the different options that are available to your child after high school?

☐ 1 Not at all aware ☐ 2 ☐ 3 Somewhat aware

☐ 4 ☐ 5 Very aware

34. How do you learn about the available options? Choose all that apply.

☐ Child's teacher(s) ☐ Child's guidance counselor ☐ Other high school staff
☐ School district staff ☐ Health care providers ☐ Social services providers
☐ Vocational Rehabilitation ☐ Other parents of children with disabilities ☐ Written materials ☐ On-line materials ☐ Friends ☐ Other: _________________

35. What barriers, if any, have you encountered in trying to understand all the options available to your child? Choose all that apply.

☐ I have not encountered any barriers
☐ Written and online materials were difficult to understand
☐ Lack of general information or guidance
☐ Staff in different services offered conflicting advice
☐ Staff in different services did not work together well
☐ School and other staff did not help me understand all the options
☐ Long waiting list for explanation of services
☐ Financial constraints

Across the country, universities, technical colleges, and other agencies have created and are developing different post-secondary school programs for students on the Autism Spectrum. Generally, they are 2-4 year programs that are specially tailored programs to meet the needs of students with Autism that otherwise would not continue their education after high school; they may be privately, locally or federally funded.

36. Would you consider this type of program as an option for your student after high school? ☐ Unsure ☐ Yes ☐ No

37. Do you think your child would be interested in attending this type of program after high school? ☐ Unsure ☐ Yes ☐ No

38. How likely do you think it is that your child might actually enroll in a post-secondary program after exiting high school?

☐ 1 Not at all likely ☐ 2 ☐ 3 Somewhat likely ☐ 4 ☐ 5 Very likely

39. For each item, please indicate how important it is to you that it is included in the development of a post-secondary program in Arizona.

	1-Not at all important	2	3-Somewhat important	4	5-Very important
a. Residential options	☐	☐	☐	☐	☐
b. Inclusive learning environments	☐	☐	☐	☐	☐
c. Individual choice in curriculum	☐	☐	☐	☐	☐
d. Structured social activities	☐	☐	☐	☐	☐
e. Access to a college campus	☐	☐	☐	☐	☐
f. Opportunity for certification in a vocational area	☐	☐	☐	☐	☐
g. Focus on employment after completion of program		☐	☐	☐	☐

40. For each item, please indicate how important it is to you that it is addressed in the development of a post-secondary program in Arizona.

	1-Not at all important	2	3-Somewhat important	4	5-Very important
a. Independent living skills	☐	☐	☐	☐	☐
b. Work skills	☐	☐	☐	☐	☐
c. Social skills	☐	☐	☐	☐	☐
d. Further academic enrichment	☐	☐	☐	☐	☐
e. Certificate, diploma, or other recognition of completion	☐	☐	☐	☐	☐
f. Experience similar to a typical college environment	☐	☐	☐	☐	☐

g. Focus on employment after completion of program	☐	☐	☐	☐	☐

41. Below are factors that parents consider when determining whether a post-secondary program would suit the needs of their child and family.

For each item below, please indicate how concerned you are about each factor.

	1-Not at all concerned	2	3-Somewhat concerned	4	5-Very concerned
a. Distance of the program's campus away from your home	☐	☐	☐	☐	☐
b. Cost of the program	☐	☐	☐	☐	☐
c. Your child's physical health	☐	☐	☐	☐	☐
d. Your child's safety	☐	☐	☐	☐	☐
e. Your child's ability to function without you	☐	☐	☐	☐	☐
f. Experience similar to a typical college environment	☐	☐	☐	☐	☐
g. Focus on employment after completion of program	☐	☐	☐	☐	☐

42. Which of the following options do you think your child will most likely be involved in after high school?

☐ Community college ☐ Technical/vocational school ☐ Full or part-time employment

☐ Community-based employment ☐ Sheltered workshop ☐ Other: ________________

43. What would help you make decisions about the options available to your child after high school?

____
____
____
____

44. What advice would you give to parents of younger children with intellectual disabilities to prepare them for the transition after high school?

____
____

45. If you could design a program for your child to participate in after high school, what would it look like? What would be the most important aspects of the program?

____
____
____
____
____

<u>Please respond to the following questions about your child's transition after high school.</u>

46. What do you think you child wants or wanted to do the year after leaving high school?

____
____

47. After your child has left or will leave high school, do you believe that your child would still want to go to school?

____
____

48. Who helps your child to decide what to do after having left or leaving high school?

____

____

49. Is there anything else you as a parent would like us to know?

____

____

____

____

Please ask your child to complete the following questions about his/her transition after high school.

46. As the child of the person who has completed this survey, I understand that I do not have to answer the questions below if I do not want to.

I understand that you will not tell other people my name when you talk about these answers. I understand that you will use my answers to help other students with disabilities to have more choices after they finish high school.

A check in the box means that I am over the age of 18, and that I have read and understood this: ☐

47. What do you want to do the year after you leave high school?

____

____

48. After you leave high school, would you still want to go to school?

____

____

49. Who helps you decide what to do after you leave high school?

____

____

50. Is there anything else you would like us to know?

____

____

____

____

APPENDIX B

YOUNG ADULT SURVEY

Survey Name: Postsecondary Education Survey

Young Adult Survey

About You: The Parent/Guardian of a Student with an Intellectual Disability

1. Gender: ☐ Female ☐ Male

2. Age: ____ years

3. Zip code: _______________

4. Please choose the one ethnicity category that best describes you:

5. ☐ White (non-Hispanic) ☐ African American (non-Hispanic) ☐ Asian or Pacific Islander ☐ Native American ☐ Other

6. What is the highest level of education you have completed?
   ☐ High School ☐ College ☐ Technical School ☐ None of the above

7. Are you currently employed? ☐ No ☐ Yes, part time ☐ Yes, full time
   ☐ Yes, seasonally/temporarily

8. What is your current occupation? ___________________________________

9. What is your current marital status?

☐ Never married ☐ Married ☐ Separated ☐ Divorced ☐ Widowed

10. Have you ever been divorced ☐ Yes ☐ No

11. How many children do you have? _________

About the Child with an Intellectual Disability

16. Where do you live?
    ☐ Your own home or apartment ☐ with your parents ☐ Supervised apartment
    ☐ Family home of another relative ☐ Group home
    ☐ Larger facility ☐ Other: ______________________

15. Zip code of your residence? _______________

16. Gender: ☐ Female ☐ Male

17. Age: ____ years

18.To what extent can you perform the following activities? Choose only <u>one</u> _response for each activity.

	1-Not at all	2	3-Somewhat	4	5-Very well
a. Walking	☐	☐	☐	☐	☐
b. Speaking	☐	☐	☐	☐	☐
c. Eating	☐	☐	☐	☐	☐
d. Preparing meals	☐	☐	☐	☐	☐
e. Taking medications (if applicable)	☐	☐	☐	☐	☐
f. Grooming/personal hygiene	☐	☐	☐	☐	☐
g. Performing household tasks	☐	☐	☐	☐	☐
h. Running errands	☐	☐	☐	☐	☐
i. Basic financial tasks (e.g. counting money)	☐	☐	☐	☐	☐
j. Participating in leisure activities	☐	☐	☐	☐	☐
k. Maintaining relationships and friendships	☐	☐	☐	☐	☐

19. Which <u>one</u> of the following best describes your most recent school setting?

☐ Fully inclusive ☐ Partially inclusive ☐ Segregated ☐ Special residential ☐ Home-schooled ☐ Work-based learning site
☐ Community-based instruction ☐ Other: ________________

20. Do or did you likes high school?
☐ 1 Not at all ☐ 2 ☐ 3 Somewhat ☐ 4 ☐ 5 A lot

21. Do you expect to or have you already pass the Arizona AIMS high school exit exam?
☐ I'm not familiar with the AIMS ☐ 1 Not at all ☐ 2 ☐ 3 Maybe ☐ 4

☐ 5 Definitely

	1- No	2	3- Maybe	4	5- Yes
22. Do you think that high school has helped prepare you for the future?	☐	☐	☐	☐	☐
23. Do you think that educational opportunities after high school would help you transition to adulthood?	☐	☐	☐	☐	☐
24. Are you interested in educational opportunities after high school?	☐	☐	☐	☐	☐
25. Has the school staff encouraged you to continue in an educational setting after high school?	☐	☐	☐	☐	☐

26. Does or did your IEP include a plan for the time immediately after high school?
☐ Unsure ☐ Yes ☐ No

27. How aware do you think you are of the different options that are available to you after high school?

☐ 1- Not at all aware ☐ 2 ☐ 3- Somewhat aware ☐ 4 ☐ 5- Very aware

28. How do you learn about the available options? Choose all that apply.

☐ Your teacher(s)
☐ School district staff
☐ Vocational Rehabilitation
☐ Friends
☐ Your guidance counselor
☐ Health care providers
☐ Written materials
☐ Other: __________________
☐ Other high school staff
☐ Social services providers
☐ On- line materials

35. What barriers, if any, have you encountered in trying to understand all the options available to you? Choose all that apply.
☐ I have not encountered any barriers

☐ Written and online materials were difficult to understand
☐ Lack of general information or guidance
☐ Staff in different services offered conflicting advice
☐ Staff in different services did not work together well
☐ School and other staff did not help me understand all the options
☐ Long waiting list for explanation of services
☐ Financial constraints

Across the country, universities, technical colleges, and other agencies have created and are developing different **post-secondary school programs for students on the Autism Spectrum**. Generally, they are 2-4 year programs that are specially tailored programs to meet the needs of students with Autism that otherwise would not continue their education after high school; they may be privately, locally or federally funded.

36. Would you consider this type of program as an option for you after high school?

☐ Unsure ☐ Yes ☐ No

37. Do you think you would be interested in attending this type of program after high school?

☐ Unsure ☐ Yes ☐ No

38. How likely do you think it is that your child might actually enroll in a post-secondary program after exiting high school?
☐ 1 Not at all likely ☐ 2 ☐ 3 Somewhat likely ☐ 4 ☐ 5 Very likely

39. For each item, please indicate how important it is to you that it is included in the development of a post-secondary program in Arizona.

	1-Not at all important	2	3-Somewhat important	4	5-Very important
a. Residential options	☐	☐	☐	☐	☐
b. Inclusive learning environments	☐	☐	☐	☐	☐
c. Individual choice in curriculum	☐	☐	☐	☐	☐
d. Structured social activities	☐	☐	☐	☐	☐
e. Access to a college campus	☐	☐	☐	☐	☐

f. Opportunity for certification in a vocational area	☐	☐	☐	☐	☐
g. Focus on employment after completion of program	☐	☐	☐	☐	☐

40. For each item, please indicate how important it is to you that it is addressed in the development of a post-secondary program in Arizona.

	1-Not at all important	2	3-Somewhat important	4	5-Very important
a. Independent living skills	☐	☐	☐	☐	☐
b. Work skills	☐	☐	☐	☐	☐
c. Social skills	☐	☐	☐	☐	☐
d. Further academic enrichment	☐	☐	☐	☐	☐
e. Certificate, diploma, or other recognition of completion	☐	☐	☐	☐	☐
f. Experience similar to a typical college environment	☐	☐	☐	☐	☐
g. Focus on employment after completion of program	☐	☐	☐	☐	☐

41. Below are factors that you might consider when determining whether a post-secondary program would suit your needs.

	1-Not at all concerned	2	3-Somewhat concerned	4	5-Very concerned

a. Distance of the program's campus away from your home	☐	☐	☐	☐	☐
b. Cost of the program	☐	☐	☐	☐	☐
c. Your physical health	☐	☐	☐	☐	☐
d. Your safety	☐	☐	☐	☐	☐
e. Your ability to function without you	☐	☐	☐	☐	☐
f. Experience similar to a typical college environment	☐	☐	☐	☐	☐
g. Focus on employment after completion of program	☐	☐	☐	☐	☐

For each item below, please indicate how concerned you are about each factor.

42. Which of the following options do you think your child will most likely be involved in after high school?

☐ Community college ☐ Technical/vocational school ☐ Full or part-time employment

☐ Community-based employment ☐ Sheltered workshop

☐ Other: ________________

43. What would help you make decisions about the options available to you after high school?
____
____
____
____

44. What advice would you give to parents of younger children with autism to prepare them for the transition after high school?
____
____
____
____

45. If you could design a program for yourself to participate in after high school, what would it look like? What would be the most important aspects of the program?

____
____
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____

Please complete the following questions about your transition after high school.

46. As a person who has completed this survey, I understand that I do not have to answer the questions below if I do not want to.

I understand that you will not tell other people my name when you talk about these answers. I understand that you will use my answers to help other students with disabilities to have more choices after they finish high school.

A check in the box means that I am over the age of 18, and that I have read and understood this: ☐

47. What do you want to do the year after you leave high school?

____
____
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____
____

48. After you leave high school, would you still want to go to school?

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____
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____
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49. Who helps you decide what to do after you leave high school?

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50. Is there anything else you would like us to know?

____

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____

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____

APPENDIX C

SURVEY EXPLENATION LETTER

Postsecondary Transition Needs Assessment: Perceptions of Parents and Individuals on the Autism Spectrum

Date

Dear Participant:

I am part of a Postsecondary Transition Team and a graduate student under the direction of Professor Kathleen M. McCoy in the Division of Educational Leadership and Innovation College of Teacher Education and Leadership at Arizona State University.

We are conducting a research study to determine perceived transition needs of individuals classified as Asperger Syndrome (AS) or High Functioning Autism (HFA) between the ages of 18 to 30 as well as the perception of parents of AS or HFA children in the development of postsecondary transition programs. We are inviting your participation, which will involve completing a 35 – 50 item survey. Completion of the survey should take approximately 15 – 30 minutes. You have the option of completing the survey online or through land mail.

Your participation in this study is voluntary. You can skip questions if you wish. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. You must be 18 or older to participate in the study. Although you may not benefit directly, your responses to the interview will be used to add information to the literature and provide direction for possible transition service options for young adults. No foreseeable risks or discomforts are associated with your participation.

No foreseeable risks or discomforts are associated with your participation in this survey.

Your responses will be confidential and pooled with the responses of other interviewees. Because you will be sending your information to us, your name will appear on the survey or in your email address. To maintain confidentiality you name will be coded to a master file and removed from the survey. The master file codes will be kept in a locked file drawer in Dr. McCoy's office and will be destroyed after three years.

The results of this study may be used in reports, presentations, or publications but your name will not be used. The results of this study may be used in reports, presentations, or publications but your name will not be used. Results will only be shared in the aggregate form.

If you have any questions concerning the research study, please contact the research team at Kathleen.mccoy@asu.edu or (insert name of one of the 5 Co-Investigators). If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Return of the questionnaire will be considered your consent to participate.

Sincerely,

APPENDIX D

TABLES

Table 1

Demographic Parent Survey Collapsed

Background	Demographic Information	Percentage
Relationship to student	26 Parent 1 Grandparent	0.96 0.04
Gender	22 F 5 M	0.81 0.19
Age	31-40: 3 51-60: 13 41-50: 8 >61: 2 Not specified: 1	0.11 0.29 0.48 0.07 0.04
Ethnicity	White (non-Hispanic): 23 Other: 4	0.85 0.15
Highest education	High school: 6 Some college: 1 College: 11 Masters: 6 Doctoral: 3	0.22 0.04 0.41 0.22 0.11
Currently employed	Full time: 14 Unemployed: 9 Part time: 4	0.52 0.33 0.15
Current occupation	Unemployed/homemaker: 4 Business: 4 Education: 4 Retired: 3 Medical field: 3 Law: 3 Retail/Manager: 2 Not Specified: 2 Full time Student: 1 Aviation: 1	0.15 0.15 0.15 0.11 0.11 0.11 0.07 0.07 0.04 0.04
Marital status	Married: 19 Divorced: 4 Widowed: 2 Never Married: 1 Engaged: 1	0.71 0.14 0.07 0.04 0.04
Number of children	1-2: 15 3-4: 10 <5: 2	0.55 0.37 0.04

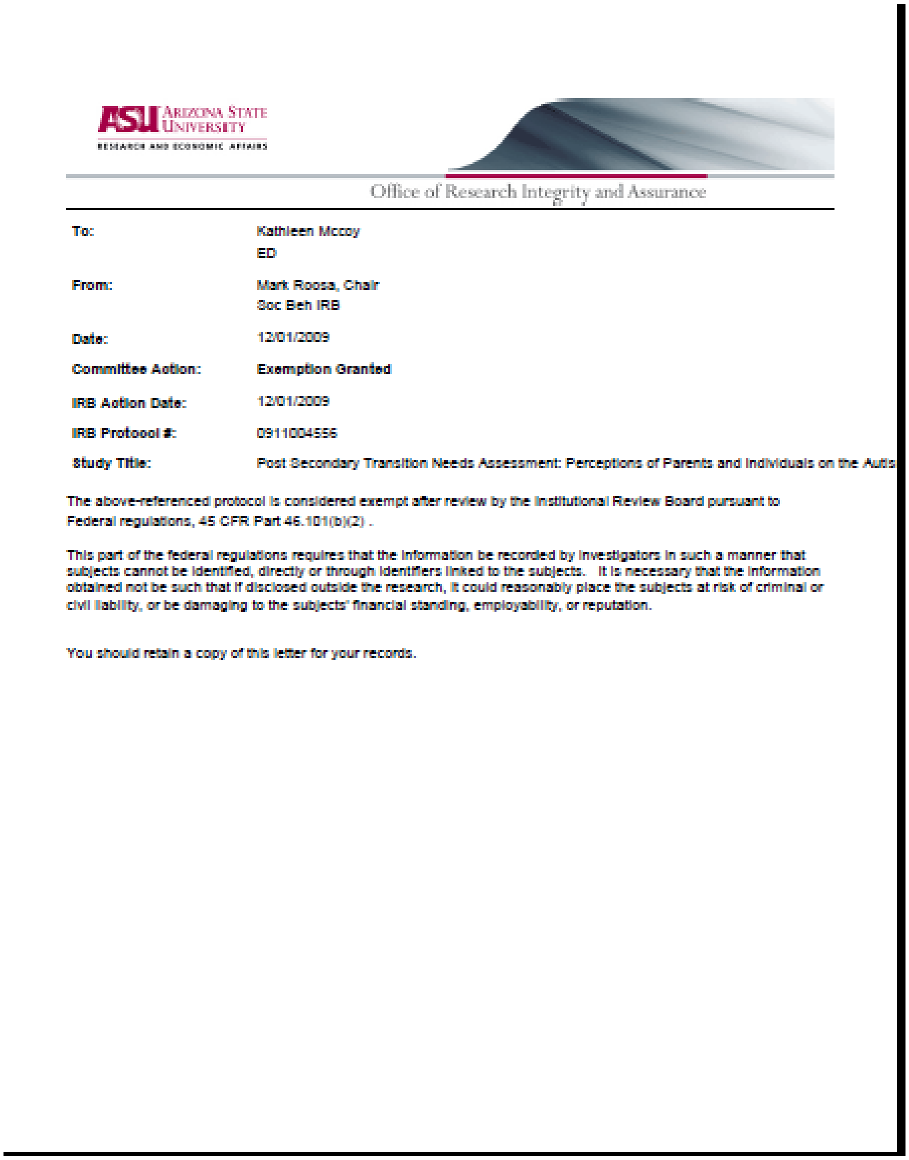
Table 2

Demographic Young Adult Survey Collapsed

Background	Demographic Information	Percentage
Gender	11 M 5 F	69% 31%
Age	18-19: 6 20-21: 5 22-23: 0 24-25: 1 26-27: 4	38% 31% 0% 6% 25%
Ethnicity	White (non-Hispanic): 14 Asian (Pacific Islander): 1 Native American: 1	88% 6% 6%
Highest Education	High school: 14 College: 2	88% 12%
Currently Employed	Unemployed: 11 Part time: 4 Full time: 1	69% 25% 6%
Current Occupation	Unemployed: 11 CVS: 2 Bag boy: 1 Staples: 1 Artist: 1	69% 13% 6% 6% 6%
Marital Status	Single (Never Marred): 16	100%
Number of Children	0: 16	100%

APPENDIX E

IRB APPROVAL



Arizona State University
Research and Economic Affairs

Office of Research Integrity and Assurance

To: Kathleen Mccoy
ED

From: Mark Roosa, Chair
Soc Beh IRB

Date: 12/01/2009

Committee Action: **Exemption Granted**

IRB Action Date: 12/01/2009

IRB Protocol #: 0911004556

Study Title: Post Secondary Transition Needs Assessment: Perceptions of Parents and Individuals on the Autis

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2) .

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.