VOICES OF YOUNG ADULTS WITH AUTISM AND THEIR PERSPECTIVE ON LIFE CHOICES AFTER SECONDARY EDUCATION

by

Susan Galler

Liberty University

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Of the Requirements for

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LIFE CHOICES AFTER SECONDARY EDUCATION

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APPROVED BY:

Anita Fauber, Ed.D., Chair Date

Bonnie Arnone, Ed.D., Committee Date

Barbara Luskin, Ph.D., Committee Date

Amanda Rockinson-Szapkiw, LPC, Ed.D., Chair of Doctoral Research Date

Scott Watson, Ph.D., Associate Dean, Advanced Programs Date
ABSTRACT

The purpose of this phenomenological qualitative research study was to explore how young adults who have an autism spectrum disorder perceive their life choices after secondary education. The focus participants in the sample were young adults with Autism Spectrum Disorder (ASD). For the purpose of this research, ASD includes autism and Asperger’s Disorder. Participants between the ages of 18 and 33 were located through purposive sampling in the states of Minnesota and Tennessee, as the author has previously worked in these states. Participants were asked five open ended focus questions during the span of two face to face interviews. Questions focused on their experiences of the transition from high school to their current placement and choices in activities, relationships, challenges and supports. The interviews were audio and video-taped, transcribed verbatim, and analyzed to determine themes through a causal comparative method.

Keywords: Autism Spectrum Disorder (ASD), Asperger’s disorder, Asperger’s syndrome, life-choices
Dedication and Acknowledgements

I would like to dedicate this endeavor of research to the following, without whom I would not have had the mental and physical capabilities.

- God, the Creator and sustainer of all. Through your love for me and daily prayer, I was given this opportunity.

- My dear mother, Desta Lena Galler, who provided nourishment for my soul and my body, care for our baby, and faith in me - with this comes a thank you to my late stepfather, Oliver Larson, who continued with “Go girl” until he left to be with our Creator, and to my late father, Alfred Galler, who helped me believe I could do anything.

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- To all of the participants and their families: You have educated me in ways that no one else could. Thank you for sharing your lives so that others will be able to improve the lives of individuals with ASD.
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List of Abbreviations

Autism Spectrum Disorder (ASD)

Individualized Education Plan (IEP)

Post-secondary Options (PSE)

Individuals with Disabilities Education Act (IDEA)

Individuals with Disabilities Education Improvement Act (IDEIA)

Diagnostic And Statistical Manual Of Mental Disorders, Fourth Edition (DSM-IV)
CHAPTER ONE: INTRODUCTION

This chapter will give a background of autism spectrum disorders (ASD) and the problems that individuals with ASD encounter. The purpose of the research and the significance of the study will be discussed. The research questions, the research plan, and the limitations will complete the foundation in this chapter.

Background

Autism is a neurobiological disorder characterized by impairment in social interaction, communication, and repetitive stereotyped patterns of behavior (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, 1994[DSM-IV]). Diagnosis of autism continues to increase in the United States and is considered to be a national public health concern without a known cause or cure. The Center for Disease Control and Prevention reported on their website, March 29, 2012, that the prevalence of ASD has increased from one in 150 in the year of 2000 to the 2008 rate of one in 88 (CDC website,).

ASD include Asperger syndrome, autism, and pervasive developmental disorder—not otherwise specified (Camarena & Sarigiani, 2009). ASD (autism spectrum disorder) will be used in this study as the term to describe the group of disorders. The defining information will be discussed in Chapter Two as part of the theoretical framework. For the sake of this research, individuals with a diagnosis of any of the above disorders on the spectrum will be included.

As reported by Camarena and Sarigiani (2009) and Hendricks (2010), the majority of autism research has focused on meeting the needs of school age children, although the demand for planning beyond the secondary years is increasing. Most of the
intervention programs are designed for children with autism, and this has greatly improved the possibilities for those who have received extensive services. It is also possible the interventions have contributed to the numbers of children with autism who want to pursue higher education (Nevill & White, 2011). Finding the best practices beyond early childhood and elementary school is particularly difficult, as reported by Hewitt (2011). Adaptations in the early grades contribute to the ability to thrive, but transitions to an environment with less support may present challenges. Individuals who appear to be higher functioning require different services when compared to programming for more severely affected individuals (Hewitt, 2011), but with support and structure, these individuals have excellent outcomes.

There is little known about how to provide support for adult ASD individuals, although the number of people with ASD continues to increase and impact education delivery (Hendricks, 2010). Griffin, McMillan, and Hodapp (2010) reported that “prospects after high school remain bleak for these students” (p. 339). A movement to provide an alternative to traditional college participation has been created by the offering of post-secondary education (PSE) programs at colleges in the United States (Griffin, et al., 2010).

As reported by Nevill and White (2011), the U.S. Department of Education began a five year funding program in 2010 to 27 post-secondary institutions to establish comprehensive transition plans for students with intellectual disabilities (Nevill & White, 2011, p. 1619). Promising practices in the PSE programs include “universal design for courses by utilizing flexible instructional materials, techniques, technology, and strategies that empower educators to meet these varied needs” (Hart, Grigal, & Weir, 2010, p.142).
In Hart, et al. (2010) mentoring, educational coaching, and practice in social pragmatics and self-advocacy were listed as essential tools for transition.

The minimal research that has been done regarding students with autism entering college has predominately been based on parent views (Griffin, et al. 2010). A review of the literature revealed that few studies specifically addressed the young adult’s perspective of beginning a postsecondary education, job, and living away from family. An exception is a qualitative study by Hurlbutt and Chalmers (2002) in which perceptions of life experiences from three adults with autism were investigated (p. 103). The three themes identified were the culture of autism, support systems, and what could make a difference in the lives of people with autism (Hurlbutt & Chalmers).

Renty and Roeyers (2006) measured quality of life for individuals with autism using the Quality of Life Questionnaire, a self-report scale. Support regarding accommodation, interpersonal relationships, daytime activities, and ASD information was examined. Findings revealed that quality of life was strongly associated with unmet needs for formal support (Renty & Roeyers, 2006). Saldana et al. (2009) also published results indicative of the need for supports and increased community-based resources. Another study (Felce, Perry, Lowe, & Jones, 2011), examined the impact of autism in community housing as reported by the caretakers. In this study, Felce et al., (2011) reported that adults with autistic spectrum disorders and severe challenging behaviors tend to have a similar variety of social, community, and household activities as other adults with intellectual disabilities without these additional behaviors. It is noted, however, that adaptive behavior influences lifestyle outcome and contributes to a more restricted life.
As discussed, colleges have just begun in the last few years to offer support and programming for students with autism. Issues interfering with success are many, including the challenges of navigating through social interaction problems and locating needed “specialized services” (Hewitt, 2011, p. 274). As students become more proficient through inclusion and complete lower level schooling, colleges will need to build academic and supportive accommodations based on information gained from those who are experiencing this journey. “Under IDEA (Individuals with Disabilities Act), which was authorized in 1990 as a federal mandate, children with disabilities have a right to an education” (VanBergeijk, Klin, & Volkmar, 2008, p. 1361). Furthermore, “every student who has a special education classification has the legal right to a plan for transition from the educational system to adulthood” (Geller & Greenberg, 2010, p. 98). According to IDEA, the transition plan on the Individualized Education Plan (IEP) must include a goal for post high school (VanBergeijk et al., 2008). The transition plan should include a “coordinated set of activities” (Roberts, 2010, p. 158). The coordination of agencies with key contacts, the specific services to be provided and the intended outcomes are needed for an effective transition plan. A plan for monitoring the implementation is also needed (Roberts, 2010).

A lack of information from the voices of the individuals with autism demonstrates a gap that was investigated by this contribution to research. Speaking “for” those with autism is changed to speaking “with” individuals who have ASD. It is a hope that hearing the perspectives and views on their life choices will assist in strengthening and building programs for success. Browning, Osborne and Reed (2009) found that former studies provided “little focus on obtaining the views of individuals with ASD
themselves” (p. 37) and sought to understand the perceived stresses as they leave school and perceptions of future problems by interviewing students with ASD. In a qualitative comparison study of perceived stress between typical adolescents and those with ASD, Browning et al. (2009) found that students with ASD described themselves as poor at dealing with stress concerning matters of transition from school.

Not hearing from the primary individuals whom are affected has contributed to this gap in available information. The participant’s life is affected in all areas and his experiences affect the planning and success of those who work with this population. Addressing the issue of lack of voice from those who live the experience could contribute to the presentation of accuracy in this matter, which has been partially missed in reports of others who spoke for the participant. If programs have the necessary knowledge to address what individuals with ASD want, the individuals are more likely to be motivated and to possess the desire to be engaged. Further study is needed to investigate the experiences of individuals with ASD (Browning et al., 2009). In order to bring this meaning of their experiences closer to our attention, “we must not lose sight of the fact that a person is present in perception, someone who perceives what is given, enters into an encounter with it, a person who may be awakened to a memory” (Moustakas, 1994, p. 71). We need to better understand the voices of the participant in order to assist in appropriate post-secondary transition planning. Focusing on the concerns expressed by those who have ASD might “lead to actionable finding in reducing some of the problems that develop post-school” (Browning et al., 2009, p. 37).
Situation to Self

I have worked in the field of ASD as a teacher, autism specialist, school psychologist, and private therapist for over 35 years in Tennessee and Minnesota where I have established relationships in the field of autism while striving to learn more as a lifelong learner through research and application. As I work with families through the stages of living with autism, the need for support of the individual’s personal thoughts and feelings in the planning process becomes more apparent. I have worn multiple hats in joining the world of autism. My personal assumptions from those former experiences were kept at a distance so that I was able to “fully describe how participants view the phenomenon” (Creswell, 2007, p. 61). In doing this, my philosophical assumption was ontological as I viewed reality through the eyes of the participant to bring forth the evidence of their perspectives (Creswell, 2007). Drawing on the disability theory derived from social construction, the focus on the disability is a recognition of the “dimension of human difference” (Creswell, 2007, p. 30). Characteristics of ASD are known to affect multiple areas and my experience and training allows me to recognize those needs.

Problem Statement

Young adults with autism are often in need of supports in order to make a successful transition into postsecondary placements of education, vocational programming, work, living arrangements, and possibly relationships or activities. It is a problem that the view of the individual with ASD has not been explored in relation to these needs. Supports can range from communication assistance, social interaction learning, or money management to learning how to manage a schedule for college. Speech and language therapy is the most often reported therapy, although occupational
therapy to address sensory needs and assistive technology for communication needs, are received by some (Hendricks & Wehman, 2009). Affected by social impairment, communication limitations, and often cognitive challenges, this population struggles in relationships, living arrangements, further education, and work (Hendricks & Wehman, 2009). It is a problem for those who plan for young adults with autism to not understand what the individual is thinking, feeling or what he/she needs. There is little information in the research following young adults with autism into adulthood, and there is a need to understand how they feel about the effects of autism on their lives (Hendricks & Wehman, 2009). The wide range of services and supports must be customized to fit individual needs. Post-secondary education, employment, and independent living arrangements present with many issues including competency in application of knowledge in varied environments. This research investigated the perspectives of the individuals with autism regarding their lives and life choices which surround these issues. This study shares voices of a group of individuals with ASD.

**Purpose Statement/Focus of Inquiry**

The purpose of this phenomenological study is to describe and understand the perspective of life choices after secondary education through the eyes of young adults with ASD. The focus is on their needs and supports through transitions related to school, work, relationships, living placement and hobbies. At this stage in the research, the phenomenon of the perspective of those with ASD will be generally defined as “the voices of individuals with ASD.”
Significance of the Study

VanBergeijk et al. (2008) observed that most of the academic literature has focused upon the “more severe forms of ASD” (VanBergeijk et al., 2008, p. 1359). Milder forms of autism, such as Asperger’s Disorder, have not received as much attention, but have become more prevalent than classic autism (VanBergeijk et al., 2008). As more children are being diagnosed and receiving intervention, it is possible that more of the students with this diagnosis will continue to a postsecondary education, more independent living situations, and relationships. VanBergeijk et al. (2008) suggested that “with a carefully planned transition, appropriate accommodations, and support, ASD students can be successful academically and socially in college” (p. 1359). Furthermore, student identified, focused transition goals are linked to improved academic and employment outcomes (Hetherington et al., 2010). The significance of this study may impact the outcome of transitions for this group of young adults through assistance to “future researchers who can influence policy and practice” (Hetherington, et al., 2010, p. 169).

Moreover, results of this study may have direct application to families, educational or vocational settings, independent living facilities, and teachers of adolescents with autism globally. Understanding the needs and the supports of these young adults who have multiple challenges presents an opportunity for in-depth planning prior to the transition itself. It is hoped that this study will fill a gap in informing the development of transition plans, which could provide direction or support for the young adult transitioning from a high school program to a placement as a young adult. It is also hoped that this study will provide direct support to the individual with autism through the
liaisons in the helping professions by instilling a desire to reach for the opportunity of
deeper autonomy, independent living and being his/her own agent of change.

**Research Questions**

The main research question framing this investigation was designed to elicit participants’ descriptions of their actual experiences (Creswell, 2007). Young adults transitioning into a greater independence are experiencing a phase of the family life cycle, which has been looked at as a growing sense of self (Geller & Greenberg, 2010). The intent was to explore the perception of the young adult’s life experiences through his/her eyes in order to increase public awareness of the need to improve transition planning and programming. The following question was the primary research core question that remained “viable and alive throughout the investigation” (Moustakas, 1994, p. 105).

1. *How do young adults with ASD describe their experiences after high school?*

The next two questions intended to break down the issue of life experiences of a person with ASD into “subtopics for examination” and to “advance the procedural steps in the process” of researching their perceptions of this experience (Creswell, 2007, p. 109). The following research questions allowed for responses to evolve and describe the phenomenon.

2. *What, if any, challenges do the participants describe as being part of their experiences after high school?*

3. *What, if any, supports do participants identify as being part of their experiences after high school?*
Common issues for the young adult with ASD include social difficulties, conversational skill struggles, and visual, auditory, tactile, and possibly intellectual challenges (Geller & Greenberg, 2010). Questions two and three help identify challenges and supports of the young adult’s experiences with the hope of learning how the supports, or lack of, could improve transitions. It was hoped that by investigating support and challenges, perceived control would be revealed.

The limited research addressing young adults with ASD continues to suggest that they will have continued interpersonal deficits throughout adulthood (VanBergeijk et al. (2008). The questions listed above intended to delve into the personal reporting of thoughts and feelings of the participants and create research that specifically addresses the voices of those making life choices on their own while dealing with the effects of ASD.

Young adults with autism have often struggled through the navigation of the system while advocating for services and supports. Other high functioning young adults may not believe they have a disability, making it difficult to provide the services that fit the need. Hendricks and Wehman (2009) and Renty and Roeyers (2006) found that current research on individuals with ASD who transition from high school to adulthood shows that they face significant obstacles in multiple areas. Young adults with Asperger’s syndrome or high functioning autism may have an excellent vocabulary, but do not understand that communication is a give and take interaction. The communication deficit impacts the social and academic endeavors. The impaired social functioning is lower than expected from the linguistic and cognitive abilities, which confuses peers.
Anxiety and depression have resulted from difficulties faced in the experiences of attempting to live in the typical world while experiencing difficulties in social information processing (VanBergeijk et al., 2008). Difficulties with anxiety are a common feature of autism spectrum disorders (Geller & Greenberg, 2010; Kuusikko et al., 2008). Although transitioning from high school can be an exciting time, it can be frightening and difficult. It is a time that is impacted by social isolation and mental health problems (Browning et al., 2009). “Transition is defined as to include education, employment, community living, and community integration” (Hendricks & Wehman, 2009, p. 78.) These transition components are considered to be critical for young people with ASD (Hendricks & Wehman, 2009). In many cases appropriate interventions in these stages of life can decrease the severity of these challenges and enable young adults with ASD to have positive outcomes and to live on their own.

**Research Plan**

Phenomenology was deemed the most appropriate research method, given that the purpose of this study was to describe the “meaning for several individuals of their lived experiences of a concept” (Creswell, 2007, p. 57). The act of giving “voice” comes from empowering people who have not had an opportunity to tell about their experiences in their lives for the purpose of change (Bogdan & Knopp Biklen, 2007, p. 214; Creswell, 2007, p. 22). A phenomenological approach allows for this as participants had the opportunity to control and share their experience firsthand.

**Limitations**

ASD impacts the expression of verbal language in some cases and may have prevented the participant from fully expressing his/her thought. In order to describe
his/her experiences of challenges or gains, a communication support, such as a speaking
device, was considered as a possible need. Although communication was limited for
several of the participants, verbalizations were their only method of communication.
Therefore, in this study, limited communication was considered as a limitation. A second
limitation is that the young adult may choose to be accompanied by a parent for
emotional support, which may cause the participant to feel inhibited in self-expression. A
third limitation is noted in that the autism spectrum includes a diverse population, but the
small sample size, along with the location of the sample, limits the possible perspectives.

Participants are from only two states due to the researcher’s professional
connections in the chosen locations in the southern U.S. and the northwestern U.S.
Although the sample size was small, it was hoped that strength would be noted in a
phenomenological intensive interview process. Every attempt was made to include a mix
of socioeconomic backgrounds, race, and gender. Despite the limitations, it is hoped that
this research will be a contributing endeavor to explore this journey and offer the voices
of those who share the experience of living with autism.

Young adults in this study were between the ages of 18 and 33. If under court
appointed guardianship, the legal guardian also provided permission for the research. In
the best interests of the participants, the consent form was reviewed by the in-state
doctoral committee to clarify the information.

Summary

As numbers increase in the prevalence of ASD, programming for young adults
with this disorder will be more desired. With the majority of services and research
focused on meeting the needs of younger children, the demand for information
surrounding the needs of young adults with ASD is crucial to adequate planning past the secondary education phase. This chapter provided an introduction to the background, identified the research questions and discussed the research plan.
CHAPTER TWO: REVIEW OF THE LITERATURE

Introduction

This chapter will give an overview of the literature investigated to explore the theme of life choices for young adults with autism after high school is completed. An outline of that research includes transition from high school, experience of college or work, change of living arrangement, social activities, and relationships for the young adult with autism.

Theoretical Framework

Theoretically, social cognitive theory (Bandura, 1989) is formed from the belief that “human expectations, beliefs, emotional bents and cognitive competencies are developed and modified by social influences that convey information and activate emotional reactions through modeling, instruction and social persuasion” (p. 3). The participants in this study and their life choices were examined through the framework of this theory considering how they are the agents of change and how they can influence the quality of their own life events (Bandura, 1989). How does the individual with ASD perceive the control and the challenges associated with decision making? The interpretive community of the disability theory also framed this study (Creswell, 2007). In the worldview of social constructivism, this theory was appropriate for this research due to the view of the ASD individual as being one with different needs (Creswell, 2007). Currently researchers focus on disability as a human difference (Creswell, 2007), but not a defect. ASD was not viewed as a defect, but was considered as a human difference.

Autistic Disorder will be defined as noted in the DSM-IV, Fourth Edition. The disorder is characterized by qualitative impairment in social interaction, qualitative
impairments in communication, and restricted repetitive and stereotyped patterns of behavior, interests and activities. Delays are also noted in social interaction, language as used in social communication, or abnormal functioning in symbolic or imaginative play (DSM-IV, p. 70).

Asperger’s Disorder is characterized by qualitative impairment in social interaction and restricted repetitive and stereotyped patterns of behavior, interests, and activities. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning (DSM-IV, p. 77). There is no clinically significant general delay in language. There is no clinically significant delay in cognitive development, age appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment. Criteria are not met for another specific Pervasive Developmental Disorder or schizophrenia (DSM-IV, p. 77). Opinions surrounding the difference between Asperger Syndrome and autism continue to indicate reasons for advocating toward a spectrum to describe the disorders (Witwer & Lecavalier, 2008). Autism is considered to be a life-long disorder, but effective training and preparation allows individuals, many with average or above average intelligence, to function in the community, in jobs, or college. In order for the person with autism to participate in employment, post-secondary education, and satisfactory relationships with others, support is needed to influence those life-choices. As Bandura, Caprava, Barbaranelli, Regalia, and Scabini (2011) reflect, support influences the events and quality of those experiences. It is essential that professionals plan for the transitions far in advance due to the wide range of supports needed.
Review of the Literature

A literature search was conducted, using a framework of the research guiding questions. The search was conducted using the following terms: autism and college, autism and post-secondary education, autism and speech prosody, autism and communication, autism and quality of life, Asperger’s and depression, autism and community housing, and perception of young adults with autism, autism and anxiety, vocational training and autism, employment and adults with autism, and autism and social skills.

Transition from High School into College, Vocational Training, or Work

A review of the literature revealed minimal information on the views of young adults with autism regarding postsecondary educational success. Parent, caretaker, and professional perspectives are found in the literature (Griffin et al., 2010; Hendricks & Wehman, 2009), but the voices of the individuals with autism are limited (Browning et al. 2009). Students with ASD may have intellectual disabilities that “prevent them from performing college-level work without substantial modifications” (Zager & Alpern, 2010, p. 152) and they often remain in high school with younger students for several years. The Individuals with Disabilities Education Improvement Act (IDEIA), 2004, requires that students with special needs receive an education with same age peers through high school (Zager & Alpern, 2010, p.152), but the same age peers have already graduated and moved on to higher education.

Hetherington et al. (2010) suggested that transition planning requires a coordinated set of activities designed to facilitate the student’s transition from school to the adult world and failure to include any one component can be the cause of poor
outcomes. Hetherington et al. (2010) found that 12 of the 13 students with ASD in his study were not aware of having been involved in their transition planning in school and felt the process was not effective. A disparity exists in planning contact between home and school. Students with ASD (Hetherington et al., 2010) felt that assumptions had been made about them. Family and professionals may think they know what is best for the individual with autism, especially if this person is their child, but this impedes independence (Geller & Greenberg, 2010). Where are the voices of the young adults? If the goal is independence, plans need to include how to help the person with autism to take control and to see potential problems. Identifying the needs from the perspective of this population in question will help to fill this gap. An adequate transition plan should include the student’s personal goals and aspirations based on his or her individual strengths which should be determined through appropriate assessment (Roberts, 2010). Knowing the adolescent is the foundation for the transition plan (Roberts, 2010).

Post-secondary education programs (PSE) to assist students with disabilities are growing on college campuses, making it possible for students with disabilities to attend college with typical peers (Griffin et al., 2010). “In PSE programs students learn academic material, expand social networks, gain employment skills, and develop independence” (Griffin et al., 2012, p. 339). Of those parents surveyed in Griffin et al. (2010) it was found that most parents (73%) lack general information about options available after leaving high school. Parents and students felt a lack of support during transitions (Browning et al., 2009). It appears that, for unknown reasons, programs in place are not able to provide the services indicated to be in place once a student leaves high school.
Although federal mandates require transition planning for students with disabilities, individuals with ASD will experience difficulty due to unmet needs in the transition. Transition from high school requires coordination based on the individual’s unique challenges and strengths. Primary components for successful transitions include “student involvement, parent and family involvement, family/student and school relationships, a meaningful curriculum and student oriented, outcome based goals” (Hetherington et al., 2010, p. 164).

Young adults with autism will have different needs based on their level of functioning. In recent years programming has focused on preschool and school age children with autism, while the number of students with ASD who are attending college has risen (Camarena & Sarigiani, 2009). There is an increasing need for information and programs to support success in the years that follow high school. “With a carefully planned transition, appropriate accommodations and support, ASD students can be successful academically and socially in college” (VanBergeijk et al., 2008, p. 1359). Recent research in this area (Griffin et al., 2010; Zager & Alpern, 2010) indicated that college programs for students with ASD are being developed across the United States. Camarena and Sarigiani (2009, p. 121) found that aspirations of parents and children with ASD indicate that 75% of the fathers, 57% adolescents, and 55% of the mothers stated that the goal would be for the student with ASD to complete a four year college degree.

Some schools are attempting to meet the challenges that have been identified in helping the students be successful. The issues include “social challenges, testing needs (extended time or modification), the need for sameness, daily maintenance, keeping organized, disruptive behavior and sensory problems” (Camarena & Sarigiani, 2009,
The comprehensive transition plan mandated by IDEA for all students with an identified disability at the postsecondary level includes college when possible, vocational training, and independent living. All students age 16 years and older with IEPs have transition plans, but they may not include the components listed above (Hetherington, et al., 2010).

Parents have indicated that needed supports are “academic accommodations, which includes assistive technology, increased time in the classroom work, and a quiet atmosphere for testing” (Camarena & Sarigiani, p. 123) with recommended coursework/curriculum improvements. Students and parents agreed on the most important needs as non-academic and listed transition planning, orientation to college and skills of daily college living. For a person with ASD to have the ability to exercise control over his/her own developmental course, he/she will need a great deal of social support and resources (Bandura, 1989). The extent of the societal system support determines “people’s opportunities to influence the course of their lives” (Bandura, 1989, p. 8).

Parents also focused on the adolescent’s social skills and the need for peer support and mentoring. Social Cognitive Theory (Bandura, 1989) supports this need in that individuals with ASD benefit from modeling which can have multiple effects. Through modeling, students with autism are able to develop new competencies, cognitive skills, and behavior patterns. Bandura’s theory reported that modeling “affects level of motivation and restraints over behavior that has been previously learned” (Bandura, 1989, p. 23).
Wenzel and Rowley (2010) explored modeling as one of the strategies employed by the University of Connecticut in a first year experience course for students with Asperger’s Syndrome who are beginning college. The course shares a curriculum with other entering students, but includes information focusing on social skills, adapting to a new schedule, a new environment, and allows students an opportunity to interact with other students who have similar challenges. Through a program which incorporates classroom learning of social skills and the practice of the new skills in extra-curricular activities, students receive an opportunity to make friends since many people with ASD do not make friends in high school. In the center for students (or CDS), classes are taught by staff members who have knowledge about the special needs of the population. Modeling is used by the professors to demonstrate a social skill and is a part of the multiple learning formats which also includes lecture, hands on practice and handouts.

College life is very different from high school in class size and the structure of the class function. A college class can have over 300 students, and a student with ASD would appear inappropriate if exhibiting behavior or dominating a classroom discussion, but in high school that may be acceptable (Wenzel & Rowley, 2010). Students with ASD must learn when it is okay to ask and answer questions in the classroom environment, or whether email might be more appropriate for the needed information.

Further complicating communication for students diagnosed with high-functioning autism and Asperger’s Syndrome is a greater frequency of disfluency and word revisions or inappropriate volume and pitch. Errors in speech and prosody also contribute to conversation skill issues. Korpilahti et al., (2007) found that abnormal prosody plays a crucial role in pragmatic, grammatical, and affective functions of speech,
as it includes pitch, stress, quantity, and pausing and, includes the modulation and the enhancement of the meaning of spoken language. Korpilahti et al. (2007) reported data suggesting “atypical neural responses to affective prosody in children with AS and their fathers” (p. 1539) as part of an investigation of affective prosody in one word utterances.

Difficulty in understanding the similarities in vocal expression, emotional words, and facial expression is relevant to understanding other people’s minds (Korpilahti et al., 2007) and the lack of ability to understand the mind that goes with the voice presents an impression of oddness in the communication attempts of people with ASD. This inability to consider the listener’s perspective causes confusion in the listener and reflects the speaker’s inattentiveness or acknowledgement to the listener’s interest (Zager & Alpern, 2010). Fragmented communication displayed through extreme literalism affects social skills and vocational success.

**Vocational or Job Training and Transition to Work**

Federal policies support and recognize the role of transition to and completion of postsecondary education, as well as obtaining employment (Stodden & Mruzek, 2010). The IDEA of 2004 focuses on preparation in secondary school and transition to postsecondary options of school and employment. The Americans with Disabilities Act (ADA) is to ensure equal access to learning and work environments through accommodations. The Rehabilitation Act of 1973 provides financial assistance and training support for improved employment outcomes (Stodden & Mruzek, p. 131). “All persons have a right to transition to an adulthood that fosters their strengths, supports their opportunities to contribute, honors their citizenship, and promotes their quality of life” (Stodden & Mruzek, p. 133).
Lawer, Brusilovskiy, Salzer, and Mandell (2009) found that adults with autism were more successful if they received on the job support, but were also denied services more frequently due to severe needs. The spectrum of vocational needs ranging from uneven cognitive ability to behavior and social abilities create problems in the workforce (Lawer et al., 2009). Schall (2010) conferred in her writing, “Positive Behavior Support,” that symptoms of “verbal and non-verbal communication, deficits in social interaction, insistence on maintaining routine, stereotyped motor movements and vocalizations, and unusual responses to sensory stimuli” cause individuals with ASD to be considered as “difficult employees” (p.110). The U.S. Department of Education, through the vocational rehabilitation system, offers services of assessment, counseling, job search assistance, assistive technology and on-the-job training (Lawer, et al., 2009).

Individuals with ASD may be assisted with competitive or non-competitive employment through the services offered by the vocational rehabilitation system. Competitive employment, or employment in an integrated setting, offers minimum wage or above the federal wage, while non-competitive or sheltered workshops offer less social integration and income (Lawer et al., 2009). Lawer et al. (2009) also found that those with autism were more likely to be competitively employed at closure of a vocational rehab program, but that services were more expensive than services for disabilities other than autism. The costs did not differ from costs involved with people diagnosed with mental retardation.

There is little research in the area of rehabilitation programs for people with ASD as found by Lawer et al., suggesting “that services provided through vocational rehabilitation programs are less than optimal for individuals with ASD” (p. 488). Lawer
et al. (2009) went on to describe one exception in a study by Schaller and Yang (2005) that demonstrated “815 of 1,324 individuals with autism who achieved competitive and supported employment outcomes” (p. 488).

Successful employment for individuals with ASD depends on support systems (McCabe & Wu, 2009). For those with ASD, a job coach provided by a placement agency, or by the employer, could provide the role of facilitator between the worker with autism and coworkers (McCabe & Wu, 2009). In the study reported by McCabe and Wu (2009), a parent, acting as work coach to her daughter, helped the daughter maintain employment as an aid in a library in China. The authors reported that no research was available on employment of individuals with disabilities in China and the research conducted was with a young woman who was 27 at the time. The parent, also one of the authors, acted as a liaison for her daughter and co-workers due to social difficulties. Training was not provided to the employees, but the parent was so thankful for the position that she was willing to have regular contact with those who had concerns. Perhaps this young woman could have been successful without a parent coach if she had the opportunity for appropriate transition programming.

High school work experience should be a starting point for young adults with autism with inclusion of exploring career choices and assessment for interest in work tasks (Hendricks & Wehman, 2009). Interpersonal skills are needed for positive work experiences and individuals need strategies for the building of those skills. “It is known that if persons with autism spectrum disorders do not find employment after their educational training, they have a 70% chance of not being gainfully employed throughout their life” (Chappel & Somers, 2010, p.118).
Linking vocational training to high school programs as part of the IEP process assures cooperative planning to guide students and professionals through the mandated transition process. When schools and vocational rehabilitation agencies make a commitment to work together, they can “work as partners to provide the needed services and supports” (Chappel & Somers, 2010, p. 119). The Postsecondary Education Rehabilitation Transition Program (PERT), a collaborative program between the Virginia Department of Rehabilitation and Virginia Department of Education and administered through the Woodrow Wilson Rehabilitation Center (WWRC), provides a transition program for students transitioning from high school to postsecondary options (Chappel & Somers, 2010). Students who qualify may attend a program to assess “vocation potential, daily living skills, recreational interests, and independence” (Chappel & Somers, 2010, p. 119). The findings are discussed at a cooperative IEP planning meeting and the IEP is put into effect.

For example, the following success story discussed by Chappel and Somers (2010) demonstrates the sequence of possibilities. One student who had difficulties with interpersonal skills entered the PERT program in the summer between the sophomore and junior years of high school. At the conclusion of the program he was recommended for business and clerical training, which were incorporated into his high school schedule. Later it was arranged for him to work in a local business with a job coach provided by the school. After graduation from high school with his modified diploma he was accepted for further training at WWRC in the business training program. He was able to obtain an office job upon completion.
Students need work experience in high school that provides an environment that matches their needs, and other persons in the work environment need education (Chappel & Somers, 2010; Hendricks, 2010). Individuals with ASD need opportunities in high school to work in groups as they may struggle with group collaboration (Chappel & Somers; Roberts, 2010).

Through programs such as the one described above, it is possible to determine a student’s specific needs, such as a preference to work alone, and provide assistance to the work location in order to meet those needs. An individual’s strengths and interests are determined by assessment in career exploration and can be completed in high school. Getting to know the student provides information for the development of the academic plan and further assistance for the vocational or college plan.

Employment is a goal for most individuals after their postsecondary years (Hendricks, 2010; Geller & Greenberg, 2010). Finding employment and keeping a job is difficult for people with ASD for the same reasons that make the college track a challenging process. The unique communication and social impairments complicate the achievement of the goal due to difficulty in “understanding directions, inability to read between the lines, read facial expressions or tone of voice, asking too many questions, and communicating in an inappropriate manner” (Hendricks, 2010, p. 127).

Impairment in social skills, as discussed previously regarding college needs, may include the misunderstanding of social rules, acting inappropriately with the opposite sex and not understanding how to take care of personal hygiene (Hendricks, 2010). Cognitive functioning deficits may impact the ability to be successful in job performance because of difficulties in maintaining attention, problem solving and organization (Hendricks, 2010).
Garcia-Villamisar and Hughes (2007) found that individualized supports on the job increased cognitive performance.

Employment for individuals with high functioning autism compared to those who have lower functioning, or IQ below 70, was only slightly higher (Hendricks & Wehman, 2009). Also, Cedurland, Hagberg, Billstedt, Gillberg, C. and Gillberg, I.C. (2008) reported that only seven of the 70 men in the Asperger group, who are often known as high functioning, held ordinary jobs (p.79). Hurlbutt and Chalmers (2002, p. 104-105) found that among the three participants in their qualitative study, all wanted to be employed and were educated to do so with college degrees. Two of the three held jobs and the other worked in a volunteer position (Hurlbutt & Chalmers, 2002, p. 104-105).

There are benefits to employment for individuals with ASD such as wages and health insurance (Hendricks, 2010). When an individual receives a paycheck, he is less likely to need assistance from the government or living support from a parent. The individual with ASD is more likely to require medication and psychiatric services which would be covered by the medical insurance. Therefore, a competitively employed person with ASD impacts the economy in a positive way and alleviates some of the financial burden on government funds (Hendricks, 2010).

**Social Activities and Relationships**

It is important to recognize the relationship between social skills and academic or work progress. Individuals with ASD may not appear to have problems to their peers until peers notice behavior caused by the disability and become frustrated and hesitate to socialize with the individual who has autism. People with autism have difficulty recognizing and interpreting nonverbal cues as a facet of communication skills, which
impacts learning. Eugene (Hurlbutt & Chalmers, 2002) expressed his frustration at not being able to read the body language and social cues of others, like neurotypicals do particularly in regard to his relationships with women (p.105). Joe (Hurlbutt & Chalmers, p. 105) stated an interest in women, but was not successful in attempts to start a relationship. He felt that he “drove them away by calling them so much” and not recognizing their feelings of being harassed (p.105). Hearing more from the individuals with ASD will be essential in the development of programs in which they will be motivated to participate.

The skills required for socialization are complex and opportunities to form support networks outside of the family are decreased by the impaired social and communicative skills of the individual with ASD (Nevill & White, 2011). Individuals may desire friendship, but lack the necessary skills (Hendricks & Wehman, 2009; Stokes, Newton, & Kaur, 2007). Robert Sanders, in his autobiography “On My Own Terms: My Journey with Asperger’s”, wrote of his desire for relationship, reporting, “That is one of my most important quests in life, to continue making some really good friends” (Sanders, 2004, p. 104).

Hillier, Fish, Siegel, and Beversdorf (2011, p. 271) reported on programming used to improve social and vocational skills with topics in the curriculum planned around community need. The study involved students with ASD at two colleges and results indicated reduced anxiety from individuals who participated in the eight week program. Anxiety, stress and depression are common in the population with ASD and may exhibit themselves in “social withdrawal, neutral facial expression, and self-injurious behavior” (Hillier, et al., p. 268). Jobe and Williams White (2006) found that individuals with
characteristics of autism do not prefer aloneness, and are typically interested in having friendships and sexual relationships.

Jobe and Williams White, (2006) demonstrated a relationship between long-term friendship and decreased loneliness, but long-term dating relationships did not decrease loneliness in this quantitative research. More characteristics of autism led to fewer friendships of shorter duration while, surprisingly, high autism scores were “related to dating relationships of longer duration” (Jobe & Williams White, p. 1486).

Social networks were found to be very limited by Saldana et al. (2009) in research regarding quality of life in adults with ASD in southern Spain. Mothers were reported to be the only member of the social network for seven percent of the participants and in 34 percent of the cases, adults with ASD had only two different people in their social networks (p. 309). In examination of a quantitative research project on social and recreational activities over half of the individuals in one study were reported to have no socialization with friends (Orsmond, Wyngaarden Krauss, & Malilick Seltzer, 2004).

On the other hand, inadequate social competence can cause inappropriate behavior. People with ASD may not understand the subtle distinction between harassment and appropriate courting. In a typical relationship one may ask another for date, call them, or send letters. A lack of awareness in what is and what is not acceptable courtship behavior can lead to stalking (Stokes et al., 2007). The deficits in pragmatic language and non-verbal communication often result in the individual’s naively engaging in inappropriate or intrusive courtship behavior in an attempt to initiate interpersonal relationships. The lack of appreciation for social cues, being egocentric and the overall lack of interpersonal relationships contribute to the ineptness.
In typical communication, people are “endowed with information-processing capacities for extracting linguistic rules and using them to encode and convey information” (Bandura, 1989, p. 17), but in ASD this is challenged by the difficulties with semantics and pragmatics (VanBergeijk, et al., 2008). Autism interferes with the ability to categorize and abstract similarities in language, therefore impacting social relationships. Students may not use appropriate volume or inflection (Zager & Alpern, 2010, p. 152). The underlying social communication deficits may improve or change over time, but do not go away. Being able to recognize and repair breakdowns in communication requires high levels of joint attention (Zager & Alpern, 2010). When one speaks, it is necessary to understand how to initiate and maintain conversation, demonstrate respect for the speaker, show interest in the speaker and recognize previous knowledge of others involved in the conversation. An inability to engage in attention or maintain shifting attention has been reported in ASD and this affects orientation to “both social and non-social information within their environment” (Keehn, Lincoln, Muller, & Townsend, 2010, p. 1252). Keehn et al. (2010) suggested that a “decreased efficiency of the alerting network is related to increased social impairment” (p. 1256). Incoming information is maintained by the alerting network and the “orienting network is responsible for the selection of information from sensory input” (Keehn, et al., 2010, p. 1251). Successful communication requires interaction between the networks of a multidimensional system (Keehn, et al., 2010).

Individuals with ASD who are high functioning often speak using a formal advanced vocabulary (Adreon & Durocker, 2007). Adreon and Durocker (2007) further describe communication characteristics of the person with ASD. They are not aware of
how loud or how softly they are speaking, may stand too closely and have difficulty engaging in reciprocal conversation, may interpret language literally and not understand the usual humor or sarcasm (Adreon & Durocker, 2007).

The success of interactions with people requires the connections of non-verbal and verbal information (Heikkinen et al., 2010). The expression of emotions is demonstrated through facial and body movements, speech prosody and voice quality (Heikkinen et al., 2010). Abnormal prosody is defined as the suprasegmental properties of the speech signal that modulate and enhance the meaning of the expression of emotions (Paul, Augustyn, Klin & Volkmar, 2005). Atypical prosody adds social and communication barriers to communication and interaction that already contains speech that is grammatically and pragmatically peculiar (Paul et al., 2005). The ASD individual’s communication is further compounded with difficulty in understanding the mental state from the vocal and facial expression of the speaker (Heikkinen et al., 2010).

For the person with ASD, conversation may be self-centered on a topic of personal interest and they may demonstrate a resistance to change the topic. The behaviors may be interpreted as “signs of disinterest, frustration, and anger” (Adreon & Durocker, 2007, p. 272) and body mannerisms such as rocking back and forth, moving hands in odd ways, blinking eyes, or other uncommon movements sets the person apart from peers.

The individual with ASD may benefit from having a peer mentor (Adreon & Durocker, 2007) due to the need for structure and sameness. The peer model could be provided to help the student through the situation of inflexibility in an ideal program.
For example, the person with ASD may demonstrate anxiety because another student or young adult is breaking a rule and may try to enforce rules on his own (Adreon & Durocker, 2007). Because of the many stressors involved in the social aspects of ASD, a higher functioning individual may focus on the academics at the expense of practical skills (MacLeod & Green, 2009).

**Living at Home or Community Based Living**

Autism continues to be an ongoing important area and topic of concern with the increasing numbers of individuals with this disorder who may need supportive services. Amongst those services are housing and support for housing needs. Where does the adult with autism live and why? Legal rights include the right to the IEP, which as previously discussed, is a document that should include a transition plan, and ideally, post-school living objectives. In a report by the Widener University School of Law by Kuangparichat (2010), the passage of the “Combating Autism Act” and the “Expanding the Promise for Individuals with Autism Act” (p. 175) has contributed to increased funding and services for autism. Autism state task forces have begun to develop subcommittees within task forces that concentrate on transitioning (Kuangparichat, 2010). Housing options are a component of this plan, which is supposed to be led by “self-determination and person-centered emphasis” (Kuangparichat, 2010, p. 179). In describing self-determination, the individual with autism has the right to take charge of choices and decisions with minimal influence from the outside (Kuangparichat, 2010), which can hopefully lead to a smoother transition.

It is a challenge to discover what the individual needs to become the agent of change as the primary influence over one’s own life (Bandura, 1989). Kuangparichat
(2010) listed the benefits of using self-determination as the leading factor behind a student’s IEP. The individual will be happier and more productive when influencing his/her own future and may “have the groundwork to lead a more successful adulthood than those students who are told what to do regardless of their needs” (Kuangparichat, 2010, p. 180). Making the life choices that influence his/her future regarding housing requires planning in multiple areas.

Living situations for adults with ASD were investigated by Krauss, Seltzer and Jacobson (2005) in which parent report compared results regarding the positive and negative aspects of in-home living and non-family setting living for their child with ASD. Parents living with their young adult with ASD felt that benefits included an enhanced quality of family life, the love shared in the family, and the comfort of knowing that their child was receiving unconditional love. Benefits for the son or daughter included the feelings of believing their child was happier at home and being part of the family activities. Negative aspects were reported to be problematic behavior of the young adult with ASD, not being free to go places sometimes, and the concern that the dependence of the son or daughter prevented him/her from wanting to stretch and grow (Krauss et al., 2005). In regards to parents who have young adults with ASD living apart from the family, both negative and positive aspects were noted. Benefits included the family being able to have a calmer and more normal life, improvement in marital relationship, and benefits for the siblings. The young adult with ASD was reported to learn new skills with increased confidence and independence. Negative aspects included problems with the chosen out-of-home living situation, untrained people working with the young adult and not enough activities for their child (Krauss, et al., 2005).
Community housing and the impact of autism were investigated by Felce et al. (2011) and found to correlate with more restricted lives. The process of deinstitutionalization is being replaced with community accommodations, but research is still limited on the “quality of outcome in supported housing in the community for people with particular characteristics” (Felce et al., 2011, p. 96). It has been noted that severe challenging behaviors can be the cause for exclusion from placement (Allen, Lowe, Moore, & Brophy, 2007).

Living independently comes with a set of difficulties for individuals with ASD, despite being intellectually advanced. An “uneven profile of strengths and impairments” makes transition to adult life difficult (Geller & Greenberg, 2010, p.93). What may seem to be simple, such as organizational tasks, keeping food in the house, paying bills on time, and maintaining personal hygiene may be too much for the individual with autism to handle (Geller & Greenberg, 2010). Housing for an individual with a disability may be available through various programs such as “The Quality Housing and Work Responsibility Act of 1998” (Kuangparichat, 2010, p. 189). Through programs such as this, accommodations and supportive services may be available with financial assistance. However, due to waiting lists and a limited range of options, supported housing may not be an option. When young adults are not eligible for housing assistance, they must locate housing and pay for it on their own.

Research on autism and living accommodations is very limited. In Saldana, et al. (2009) 87% of the participants with ASD lived with parents (p. 312). Saldana et al. (2009) reported none of the adults in their study lived independently (p. 312). Some lived in residential housing, but none were in supported housing (Saldana et al., 2009).
Although Saldana’s (2009) research did not indicate cognitive level of the participants, it is possible that the outcome was related to cognitive ability. In a study involving higher functioning adults with ASD, Renty and Roeyers (2006), reported “Despite their intelligence and often good levels of functioning in other areas, more than three-quarters of the participants lived with their parents” (p. 518). Independent living depends on the level of skills one has and the ability to access and apply available resources.

Contributing factors are many, some of which have been discussed in this paper.

**Summary**

Research reporting the voices of young adults with autism is limited. Parents and professionals have reported the majority of information contributing to prior research. The research has focused on defining characteristics of Autism and not enough on hearing about the experiences first hand. Recent literature has begun to touch on experiences of individuals with autism in college (a relatively new option), and their multiple obstacles, but many gaps are present to meet the needs discussed. Findings are consistent in that young adults with ASD are faced with communication and interaction deficits in every area of their lives. The symptoms of ASD may change over time and some individuals experience a worsening of specific symptoms, “particularly in social communication” (Schall & McDonough, 2010, p. 82). Young adults with autism deserve to be heard and their voices can contribute to solving the challenges they face in transitioning to postsecondary education, jobs, housing and relationships. Schall and McDonough (2010) reported that “research in the area of transition is becoming critical” (p. 87) and that the development of scientifically-based practices must be developed in order to improve the outcomes of those with ASD.
CHAPTER THREE: METHODOLOGY

Introduction

The purpose of this phenomenological research was to describe and understand the perspective of life choices after secondary education through the eyes of young adults with ASD. The examination included a focus on their needs and supports through transitions related to school, work, relationships, living placement and hobbies.

Qualitative research was chosen to allow for an in-depth investigation and a deeper understanding of the lived experience (Creswell, 2007). The findings of this study could provide schools, parents, and young adults with Autism assistance in appropriate transitions with proper support in hope of a successful outcome. Through the voices of participants with autism, challenges and successes were investigated through life choices and social cognitive theory. This chapter will explain the research methods utilized, provide an explanation of the design, describe the participants, setting, and identify how the research data were collected, stored, treated, and analyzed.

Research Design

Phenomenology aims to “understand the meaning of events and interactions to ordinary people in particular situations” (Bogdan & Knopp Biklen, 2007, p. 25) in this case, by gaining entry into the world of the perspectives of young adults with ASD. It was the goal of this search to determine what the nature of life choices mean for those who have experienced it (Moustakas, 1994). The process of phenomenological research allowed the participant to be the instrument of interpretation of their thoughts, feelings, and actions.
A phenomenological model, as described by Moustakas (1994) demonstrates an emphasis on “deriving knowledge from a state of pure consciousness” (p. 101). Transcendental phenomenology is applicable in presenting a scientific study while allowing “pure subjectivity” (Moustakas, 1994, p. 49). This method was chosen to describe what the “participants have in common as they experience the phenomenon” of life choices as one who has ASD (Creswell, 2007, p. 58). As the purpose of the study was to hear the perspectives of the participant living with autism through the transitions of life choices, this method was appropriate.

The nature of this study aspired to gain the perspectives from the voices of those who live in the experience of the challenge of autism (Creswell, 2007). Does the participant feel in control of his or her life or is it felt that decisions are made by other people, such as parents? Prior research (Griffin et al., 2010; Hetherington et al., 2010) used survey instruments with ASD students and parents to better understand thoughts on post-secondary education. Questions that were used in this study were open ended and invited the participants to “think deeply and express themselves fully and in-depth about their experiences and perspective” (Bogdan & Knopp Biklen, 2007, p. 107) in an accepting atmosphere. Expecting someone to feel free and accepted so that they will share information requires a level of trust with a non-judgmental focus. The questions were presented during loosely structured interviews in the participants’ homes or library and grounded in an atmosphere of acceptance, support and respect.

**Research Questions**

The main research question framing this investigation was designed to explore and describe the participant’s perceptions of their actual experiences (Creswell, 2007).
The second and third questions intended to break down the issue of life experiences of a person with ASD and allowed for responses to evolve and describe the phenomenon (Creswell, 2007). There were three questions to be answered through this research in an effort to describe the experiences of an individual with ASD for the purpose of improving transition programming.

(a) How do young adults with ASD describe their experiences after high school?

(b) What, if any, challenges do participants describe as being part of their experience after high school?

(c) What, if any, supports do participants identify as being part of their experience after high school?

The strength of qualitative research lies in the meaning of the participant experience and, in following the transcendental approach, the phenomenon is “perceived and described in its totality, in a fresh and open way” (Moustakas, 1994, p. 34).

Participants were invited to share documents which included awards they have received, diary excerpts, pictures, or other meaningful written work in their lives. Allowing the participants to speak freely, adding thoughts that may not have surfaced before this time, and discussion surrounding any documents listed above, made it possible for them to “give meaning” to the interaction as they have perceived it to be (Bogdan & Knopp Biklen, 2007, p. 27).

Participants

A flyer describing the study and method of gathering information (interview, audio recording, and documents) was emailed to chapters of The Autism Society of America in Knoxville, Tennessee and Minneapolis/St. Paul, Minnesota (see Appendix
A). Flyers were posted in the offices of programs serving students with ASD at colleges and vocational rehabilitation service programs in Minnesota and Tennessee. Respondents made the call of interest and packets containing the geographic form and consent form were emailed to the caller.

Participants had a diagnosis of a disorder in the Autism Spectrum Disorders and were between the ages of 18 and 33. The original IRB approval gave permission for participants between the ages of 18 and 30. When participants over that age contacted the researcher and stated their interest, a “change in protocol” was requested and granted by the IRB (see Appendices B, C, D). Participants include those who have completed a regular education or special education high school program. Some have made transitions into post-secondary education or vocational training. Some have transitioned from their family home into another living arrangement. The 15 young adults live in Tennessee and Minnesota and were selected through purposeful and snowball sampling.

**Setting/Site**

Interviews took place in the participants’ homes or a library. The participants live in the state of Tennessee or in Minnesota due to researcher’s connections in those settings. The setting of each interview was chosen by the participant in an attempt to prevent anxiety or focus difficulties for him/her. Participants should be in an environment where they are not hesitant to speak and share honestly and comprehensively (Creswell, 2007; Moustakas, 1994). Fieldwork is typically gathered in the participant’s living or work place (Creswell, 2007).
Procedures

It was planned to include 15-17 participants who met the criteria for diagnosis, age, and independent interest in self-participation. As reported by Creswell (2007), phenomenology interviews with five to 25 people who have experienced the phenomenon were recommended (p.121). Purposeful sampling, complimented by the snowball approach, intended to allow for the selection of individuals who can “inform an understanding of the research problem and central phenomenon” (Creswell, 2007, p. 125). The 15 participants who responded had experienced transitions in leaving high school. Some participants continued on in an educational program, such as a transition program or college. Others began a work placement while living at home, or separate from their parents in an independent or assisted living arrangement.

Participants made the first contact and stated an interest. The investigator emailed to ask if the participate met the age and diagnosis criteria. The participant was also asked if he/she is his/her own guardian. Interviews were scheduled by email at the time of the contact. Packets containing a demographic data form and consent form were emailed (see Appendices E, F). Prior to the first interview, the in-state committee member reviewed the consent form by phone or email with the participants. The committee member reported the understanding to the investigator. In the first interview, the demographic data form was collected, the consent form was signed and the first two open ended questions, along with the ice-breaker question, were asked and answers discussed within a time frame of one to two hours (see Appendix G). In the second interview, approximately one week later, any documents, diaries or written information was shared.
with the last two open ended questions, which allowed the participant to add anything he or she desired to the interview.

**Researcher’s Role**

As the researcher and human instrument in this study, I am a skilled interviewer trained to listen, prompt, encourage, and elicit elaborations of the experiences told by the participant. My training as a school psychologist and therapist prepared me to offer this environment for the interviews, although practicing the interview process was necessary. I put aside preconceived ideas by bracketing my experiences with individuals with ASD so that each participant’s view was free of my preconceptions and beliefs (Moustakas, 1994). My personal assumptions from those former experiences were kept at a distance so that I was able to “fully describe how participants view the phenomenon” (Creswell, 2007, p. 61). In doing this, my philosophical assumption was ontological allowing me to develop multiple realities through the individuals and report how those participants view the experience differently (Creswell, 2007; Moustakas, 1994).

In a phenomenological study, the researcher understands that the person being interviewed is the expert and is treated with respect and given the opportunity to share as they wish. In viewing this study through the lens of social cognitive theory, it is understood that “people are neither driven by inner forces nor automatically shaped and controlled by their environment” (Bandura, 1989, p. 8). Instead, people contribute to their own outcomes within a system of interacting influences (Bandura, 1989). It was my hope in this study to view the participant as the agent of the influence (Bandura, et al., 2011).
An advantage to conducting research in different parts of the country is the allowance for exploration of the perspectives of individuals in the southern part of the U.S. and the northwestern part of the U.S. Available programs are different throughout the U.S. and various perspectives may offer comparisons to those in search of resources.

The information obtained was written as notes and video/audio recorded. Permission was sought to copy any documents that the participant wished to share, such as pictures, poems or an award.

Data Collection

The interview was the main method of data collection used in this phenomenological study with a framework of interviews (Creswell, 2007). Entering into this process required a unique view of the new and the ability to see from a pure fresh open sense labeled as the Epoche by Moustakas (1994). Epoche, the first step at the beginning journey into transcendental phenomenology, permitted the researcher to see the phenomena from a “transcendental ego” (p. 33) and allowed common judgment or knowledge to be set aside (Moustakas, 1994). Next was the Transcendental Phenomenological Reduction in which “textural descriptions of the meanings and essences of the phenomenon” (p.34) were derived. As recommended by Creswell (2007) and Moustakas (1994), this process of developing significant statements, grouping the statements into categories or themes and ending with the writing of the descriptions of what the participants experienced and how it happened is the most useful and practical approach for phenomenological analysis.

Once permission was granted from the IRB, an expert, who is a psychologist, piloted the interview questions with a small sample of two people with ASD. Clarity and
wording of the questions were reviewed for any possible changes to be made prior to completion of the interviews. The pilot responses were not included in the research.

Prior to the first interview, the participant received the geographic form and the consent form. Both of these items were sent through email. The in-town committee member reviewed the consent form by phone or email. During the first interview the participant completed the consent form and demographic data form of name, address, and diagnosis. Anonymity was discussed and questions were answered prior to signing the consent form as recommended by Creswell (2007). The consent form assured participants that all data would be filed in locked cabinets with pseudonyms instead of actual names. The consent form also explained that demographic sheets, with names, would be kept in a separate locked facility. Storing of the audio and videotaped interviews was reviewed so that participants understood the tapes would be kept in a separate locked cabinet away from the written notes and demographics. It was also explained that all tapes and notes would be destroyed after the three year maintenance rule. The first interview began with the first two questions, after rapport was established through the ice-breaker question. The second interview consisted of the third open ended question and the fourth question, which gave the opportunity to share anything else they wished to share. At this time primary sources such as pictures or other personal written information regarding the participant’s life choices were shared during the interview. The primary sources included personal art work, awards, and poems (Creswell, 2007).

The interview notes were written as the participant spoke while being recorded on video tape and audio recorder. Data was collected from the two semi-structured in-depth interviews with each lasting one to two hours. The results were reported in an exhaustive
narrative format after the audio tape transcriptions and field notes were analyzed by the investigator.

Member checks or a review with the participants were used for verification at the end of the second interview. Table one is listed below with a review of the interview questions. The strength of qualitative research lies in the meaning of the participant experience and, in following the transcendental approach, the phenomenon is “perceived and described in its totality, in a fresh and open way” (Moustakas, 1994, p. 34). Allowing the participants to speak freely, adding thoughts that may not have surfaced before this time, and participating in discussion surrounding any documents made it possible for them to “give meaning” to the interaction as they have perceived it to be (Bogdan & Knopp Biklen, 2007, p. 27). Participants were invited to share documents and awards they have received, diary excerpts, pictures, or other meaningful written work in their lives. In summary, the data collection included:

1. Collection of mailed demographics and the consent form (also, collection of the reports of the review of consent form by in-state committee member and participant).

2. Interview notes from focus questions.

3. Transcripts for audio and video tape.

4. Study of primary sources.
Table 1

*Open Ended Interview Questions*

Interview 1

(a) Tell me what it is like to have ASD. Prompts: What does a typical day look like for you?

(b) Tell me about your experience of completing high school and the transition to what you are doing now. Prompts: Work, school, spiritual or religious involvement, living arrangements, hobbies, and relationships.

(c) What are the challenges and supports that you have had in regards to those experiences?

Interview 2

(a) How much do you think you control what happens in your life? Prompts: Who or what else controls what happens in your life?

(b) Tell me anything else that you would like to include in this interview and share any documents that you would like to share (pictures, diary, or awards).

At the end of the interview, a review was conducted as a member check for verification of information that had been given.

The questions were developed to gather data that would lead to textural and structural descriptions of the experience to provide a clear understanding of the shared experiences among the participants (Creswell, 2007). Questions were open ended as recommended by Moustakas (1994) and “aimed at evoking a comprehensive account of the person’s experience of the phenomenon” (p. 114).
The purpose of question one was to establish rapport and break the ice. The next two questions, pertaining to the participant’s transitions after high school, were to gather information about challenges and supports related to leaving high school and going on to higher education, work, and social experiences. Including the possibility of spiritual involvement as a prompt was to add additional information that may be related to support. Using the prompts was meant to encourage continued sharing of the experience and prompts were added as needed.

If religion was found to be a support, it was important in this research to present those views in comparison to previously reported views. Deeley (2009) reported that the lack of coherence and executive problems in autism might present the inability to assign meaning and relevance to experiences in the environment in a way that would allow adaptive responses, thus problems preventing the understanding of religious concepts. Is comfort found in religion by those with ASD? As discussed by Dubin and Graetz (2009), individuals with ASD may exhibit normal intelligence, but have the deficits as described above by Deeley (2009). Dubin and Graetz (2009) explained the difficulties for people with ASD to attribute meaning to a higher being than themselves due to impaired secondary representation, shared attention and protodeclarative communication, even with normal or gifted intelligence.

Prior information reported that the person with ASD may not have the ability to differentiate his/her point of view from others and may not accurately interpret behavior and intention of other people in a situation (Dubin & Graetz, 2009). Research has shown that the presence of religion may be linked to reduced stress and improved mental health.
outcome (Dubin & Graetz, 2009). Exploring this aspect in the questions contributed to the purpose of seeking the perceptions of support from others or a higher being.

More information was needed due to the lack of research in the post-secondary aspirations of youth with ASD (Camarena & Sarigiani, 2009). There is little available research on the experiences of higher education and what is helpful to that population (Camarena & Sarigiani, 2009). The questions were developed to gather information to address this gap.

The third question was to learn the depth of how the participant with ASD perceives himself as the controller, or agent of change, as described by Bandura (1989) of his own life. Hurlbutt and Chalmers (2002) found that in three adults speaking out on perceptions of life experiences, four patterns emerged equally supported (p. 104). Theme one revealed that ASD adults take pride in their ability to educate others about autism. In theme two, all of the participants reported that support systems contributed to their self-worth. Theme three described their opinions about group living arrangements, behavior, and employment. The fourth overall theme and conclusion was a thread that was throughout all perceptions. The individuals want to be “considered experts on, have opinions on, and be consulted on issues related to autism” (Hurlbutt & Chalmers, 2002, p. 109). Individuals with autism want to have the opportunity to have their opinions known about issues which affect their lives.

The fourth question was to allow participants to add anything that they wanted to share that had not been included in previous questions. It also presented an opportunity for participants to share items that were meaningful to them, such as diaries, poems,
pictures, or awards they have received or any other personal information. “Meaning is at the heart of a transcendental phenomenology of science” (Moustakas, 1994, p. 56).

**Data Analysis**

The video/audio tapes were transcribed immediately by a professional transcription secretary following the interviews in order for the researcher to continue the data familiarization process. All participants were referred to by their pseudonyms through the process. The successful outcome of qualitative research, reflected by Bogdan and Biklen (2007, p. 119) relies on “detailed, accurate, and extensive field notes.”

Moustakas (1994) previously described method of analysis was utilized, also illustrated as a constant comparative method of data analysis, by Maykut and Morehouse (1994), in which the researcher examined each bit of information by characteristics and through comparison and grouped by similarity. Steps in this process included familiarization and organization of the data with a continuation into a coding and recoding process of the grouped gestures, actions, words, phrases or sentences (Creswell, 2007). This process was further defined by continuous refinement as initial categories changed, merged, or were omitted, and new categories were generated.

Moustakas (1994) described the process as horizontalizing or treating every frame of information as equal in the beginning of the process, and leaving the horizons after overlapping similar phrases are placed together. Clustering the horizons into themes and organizing the horizons and themes into a coherent textural description of the phenomenon completed the steps of “phenomenological reduction” (Moustakas, 1994, p.97). The “Imaginative Variation” (p. 35) step, as termed by Moustakas (1994), followed the Transcendental-Phenomenological Reduction as the meaning seeking
process. The final step in the process was putting the meaning and essence together to make up the synthesis of the experience into the “unified statement” (Moustakas, 1994, p. 100).

A member check was completed with the participants, in that the participants had an opportunity to review notes with the researcher for clarification. Along with the member check, the audit trail of the outlined research process consisted of ongoing consultations with committee members. To summarize the analysis of data:

(a) Researcher became familiar with data: reading/rereading.

(b) Reflections were added to notes.

(c) Audio tapes were transcribed and video tapes were reviewed.

(d) Key ideas were noted.

(e) Coding schemes using open coding was utilized for common gestures, words, phrases and sentences/ pseudonyms were assigned.

(f) Synthesis began to formulate meanings.

(g) Synthesis continued to relating categories and themes to analytic framework.

(h) Examined the audit trail through the process.

**Trustworthiness**

“Evidence from phenomenological research is derived from first-person reports of life experiences” (Moustakas, 1994, p 84). The scientific investigation is valid when the information is clarified into a meaningful experience (Moustakas, 1994). Dependability was established by presenting accurate descriptions of the findings, and by reporting the truthfulness of the participant’s experiences. As discussed previously, the researcher’s bias and pre-conceived judgments were hopefully set aside or “bracketed” (Creswell,
The participant review provided clarification of the information contained in the documents and interviews. Multiple types of data were related to support or contradict the interpretations as “structural corroboration” (Creswell, 2007, p. 204). The amount of evidence became the convincing credibility. Dependability and confirmability were created through an auditing process (Creswell, 2007). The participants’ voices of their needs and support systems were analyzed in detail so that transferability to others in a similar situation will be applicable. An accurate audit trail of chronological narrative entries, pre-entry conceptualizations, entry efforts, analytic activities assists in assuring accountability and will increase the possibility of replication of the research (Creswell, 2007).

**Ethical Considerations**

The specifics of this study were reviewed by the Institutional Review Board at Liberty University. The review took place before any data was collected. It was important to assure that there were no identified risks for the participants. Informed consent was required of all participants. Although the participants were over the age of 18, they were required to either provide proof of their legal right to sign or have a parent guardian sign with them. The consent forms were reviewed by the in-state committee member and a written report of the review has been kept with the locked documents. A guarantee of confidentiality throughout the study was given in written form as part of the consent, with an agreement that any participant may withdraw at any time. All contact information will be destroyed after the required three year maintenance rule.
CHAPTER FOUR: FINDINGS

Introduction

Prior to this study the minimal research that has been done regarding students with autism entering college has predominately been based on parent views (Griffin et al., 2010). A review of the literature revealed that few studies specifically addressed the young adult’s perspective of beginning a postsecondary education, job, and living away from family. Griffin et al. (2010) reported that “prospects after high school remain bleak for these students” (p. 339).

As stated in Chapter One, the study reported here examined the perspective of life choices after secondary education through the eyes of young adults with ASD. There were three questions to be answered through this research in an effort to describe the experiences of an individual with ASD for the purpose of improving transition programming.

(a) How do young adults with ASD describe their experiences after high school?

(b) What, if any, challenges do participants describe as being part of their experience after high school?

(c) What, if any, supports do participants identify as being part of their experience after high school?

This chapter is organized in terms of the research questions which were posed in Chapter One and listed above. First it reports how young adults with ASD describe what it is like to have autism spectrum disorder. After the rapport building question listed above,
the study reveals their experiences after high school through the challenges and supports they identify as being part of those experiences.

The questions were piloted with two young adults with ASD in order to help determine if the questions would allow the participants to share their perspectives. The two young men, one 26 years old, and the other 25 years old, agreed that the questions would allow for independent answers from the participants. A total of 15 participants were interviewed through face-to-face meetings which included audio and video-taping. The audio interviews were transcribed verbatim by professional transcriptionists. The researcher viewed and studied the video-tapes for additional recall. The data were analyzed to identify the reoccurring themes through the previously described method of analysis (Moustakas, 1994), also illustrated as a constant comparative method of data analysis, by Maykut and Morehouse (1994).

**Description of the Participants**

The research sample consisted of 15 young adults with ASD. Each participant responded to the flyer or contacted the researcher through the snowball approach in which he/she heard about the study through another person. The diagnosis and race of each participant is included in Table 2. The participants ranged in age from 19-33 and included four females and 11 males. The sample included participants with varying degrees of ability, as the intelligence quotient was not a determining factor for participation. Education level is reported in Table 3, as well as living accommodations. Participants lived at home with their parents or other family members, in an apartment, house or in a supervised living accommodation in the state of Tennessee or Minnesota. Six participants lived in Tennessee and nine participants lived in Minnesota.
Table 2

Demographic Characteristics of Participants (N = 15)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Race</th>
<th>Age</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Christopher</td>
<td>M</td>
<td>Korean</td>
<td>24</td>
<td>MN</td>
</tr>
<tr>
<td>2. Kayla</td>
<td>F</td>
<td>Caucasian</td>
<td>30</td>
<td>MN</td>
</tr>
<tr>
<td>4. Arwell</td>
<td>M</td>
<td>Caucasian</td>
<td>25</td>
<td>MN</td>
</tr>
<tr>
<td>5. Larry</td>
<td>M</td>
<td>Caucasian</td>
<td>19</td>
<td>MN</td>
</tr>
<tr>
<td>6. Carl</td>
<td>M</td>
<td>Caucasian</td>
<td>19</td>
<td>MN</td>
</tr>
<tr>
<td>7. William</td>
<td>M</td>
<td>Caucasian</td>
<td>25</td>
<td>MN</td>
</tr>
<tr>
<td>8. Caden</td>
<td>M</td>
<td>Caucasian</td>
<td>21</td>
<td>MN</td>
</tr>
<tr>
<td>9. Sherry</td>
<td>F</td>
<td>Caucasian</td>
<td>25</td>
<td>MN</td>
</tr>
<tr>
<td>10. Uri</td>
<td>M</td>
<td>African-American/Asian</td>
<td>33</td>
<td>MN</td>
</tr>
<tr>
<td>11. Justin</td>
<td>M</td>
<td>Caucasian</td>
<td>26</td>
<td>TN</td>
</tr>
<tr>
<td>12. Bobby</td>
<td>M</td>
<td>Caucasian</td>
<td>33</td>
<td>TN</td>
</tr>
<tr>
<td>13. Allison</td>
<td>F</td>
<td>Indian</td>
<td>22</td>
<td>TN</td>
</tr>
<tr>
<td>14. Zayden</td>
<td>M</td>
<td>Caucasian</td>
<td>22</td>
<td>TN</td>
</tr>
<tr>
<td>15. Karen</td>
<td>F</td>
<td>Caucasian</td>
<td>19</td>
<td>TN</td>
</tr>
<tr>
<td>16. Matthew</td>
<td>M</td>
<td>Caucasian</td>
<td>28</td>
<td>TN</td>
</tr>
</tbody>
</table>
Table 3

Social Characteristics of Participants (N=15)

<table>
<thead>
<tr>
<th>Number</th>
<th>Diagnosis</th>
<th>Level of Ed</th>
<th>Residence</th>
<th>Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Christopher</td>
<td>PDD</td>
<td>1 yr. college</td>
<td>with parents</td>
</tr>
<tr>
<td>2.</td>
<td>Kayla</td>
<td>Asperger’s</td>
<td>2+ yrs. college</td>
<td>independent</td>
</tr>
<tr>
<td>3.</td>
<td>Arwell</td>
<td>Asperger’s</td>
<td>1 ½ yrs. vocat</td>
<td>independent</td>
</tr>
<tr>
<td>4.</td>
<td>Larry</td>
<td>Autism</td>
<td>high school</td>
<td>with parent</td>
</tr>
<tr>
<td>5.</td>
<td>Carl</td>
<td>Autism</td>
<td>high school</td>
<td>with parent</td>
</tr>
<tr>
<td>6.</td>
<td>William</td>
<td>Asperger’s</td>
<td>college degree</td>
<td>with parent</td>
</tr>
<tr>
<td>7.</td>
<td>Caden</td>
<td>Autism</td>
<td>high school</td>
<td>semi-assisted</td>
</tr>
<tr>
<td>8.</td>
<td>Sherry</td>
<td>Asperger’s</td>
<td>in college</td>
<td>independent</td>
</tr>
<tr>
<td>9.</td>
<td>Uri</td>
<td>Autism</td>
<td>2 yrs. college</td>
<td>independent</td>
</tr>
<tr>
<td>10.</td>
<td>Justin</td>
<td>Asperger’s</td>
<td>Ph.D.</td>
<td>with parents</td>
</tr>
<tr>
<td>11.</td>
<td>Bobby</td>
<td>Autism</td>
<td>high school</td>
<td>sv resident</td>
</tr>
<tr>
<td>12.</td>
<td>Allison</td>
<td>Autism</td>
<td>high school</td>
<td>sv resident</td>
</tr>
<tr>
<td>13.</td>
<td>Zayden</td>
<td>Autism</td>
<td>high school</td>
<td>sv resident</td>
</tr>
<tr>
<td>14.</td>
<td>Karen</td>
<td>Asperger’s</td>
<td>high school</td>
<td>with parent</td>
</tr>
<tr>
<td>15.</td>
<td>Matthew</td>
<td>Asperger’s</td>
<td>3 yrs. College</td>
<td>with parent</td>
</tr>
</tbody>
</table>

Key:

1. sv: supervised residential setting
2. vocat: vocational school
3. transition pro: transition program
The conversation ice-breaker used to establish rapport and ease into the interview, was: “Tell me what it is like to have ASD.” The ice-breaker presented an opportunity for reflections on growing up with autism before the main questions began. Challenges with communication and relationships were common threads in the lives of those with ASD and most described themselves as different. Several participants described that society did not treat them as equals and that others did not understand what made them different. Difficulty looking at people and lacking social skills contributed to problems with interactions and with relationships. Below are participant responses from the ice-breaker question. Each participant is identified by their pseudonym and their words are identified in quotes.

Sherry communicated that “Having autism means not seeing if someone is frustrated and not understanding if someone is joking,” as she recalled a situation which placed her in danger because she did not understand that the statement being made to her was sarcasm. As she questioned another bus passenger about the unusual stopping time and location, she was told that a fatal shooting had taken place and that everybody needed to get off of the bus. She didn’t understand sarcasm, body gestures or movements and the fact that no one else was leaving the bus. Sherry said, “Okay” and attempted to leave the city bus.

Sherry recalled a ride on a light rail in a large city when she heard the loud piercing sound to warn people that the door was about to close. She said that she was used to people making fun of her and tried to cope with it, but covered her ears and began to rock back and forth. Stress overtook her body and she heard people laughing and calling her names, such as “retard” under their breath. “Watching the popular kids have
fun while sitting alone in the school cafeteria as a burger flies through the air and at my head while I’m hearing bouts of laughter,” she reported and continued with the fact that even those who were usually nice, laughed at her. Sherry continues to have difficulty going out a lot and does not try to make new friends unless they have Asperger’s Syndrome.

One participant described the sadness revealed by his parents upon his diagnosis as a child. Christopher described the feelings of how everything in his life changed that day. Each of his responsibilities was taken away, one by one. “You realize your parents don’t treat you the same and then that kind of like makes you lose faith in a lot of family life. That was huge for me.” Although this young man had experienced difficult years in school, he eventually found strength in autism and wonders why society can’t focus more on the uniqueness found in autism, rather than the focus on not fitting into the guidelines and being looked down upon as a bad thing. Christopher found that having ASD had advantages and that success depended on realizing potential and what he could accomplish. He cited famous people who have or may have had ASD and other challenges, such as Einstein and Bill Gates.

Kayla described ASD as having a different way of thinking about things, a blank facial expression, obsessive compulsive disorder, and problems with communication. She was unable to have friends, except for one and was easily manipulated by the friend. “Beginning at age six, I would come home from school, sit in my room and think about all the mean things people had said to me all day and I would just cry.”

Kayla disclosed a life of not knowing her diagnosis and dealing with confusion regarding the issues she faced in communication and relationships. A friend encouraged
her to consider talking with someone about Asperger’s syndrome and she received a diagnosis at age 28, which came as a relief and explanation of why she was the way she was. She suffered from diagnosed depression during her childhood and young adulthood, but experienced many accomplishments through the trials. During her high school years, Kayla played violin and ice hockey, which helped to provide some support in her life. She hadn’t received a diagnosis of ASD yet and had only one friend. She described a photographic memory which helped her academically, but recalled issues at work, which focused on communication and interaction.

One participant, William, disclosed severe issues in the areas of communication and interaction when younger, but after many years of working on the concerns with the help of others, stated that most people probably do not realize he has ASD. “I think people see the difficulty communicating and they just can’t quite pin what the cause is”, William revealed. As he shared his thoughts he disclosed that people may think there is something different, but they don’t ask.

Carl recognized his differences and has worked hard to control what he labeled self-stimulation or fetishes, which included self-talk about specific topics that he may have learned from movies. He admitted that these were irritating to other people and misinterpreted. Having autism for Carl meant trying to figure out why people were mad at him. He reported that he might have said the wrong thing, but didn’t understand the problem with what he had said. Carl was bullied at this level and described it as heartbreaking to watch peers high-five each other as peers threw food at him. It was especially hard because it took place without any intervention from teachers nearby.
Allison suffered from being bullied and reiterated Sherry’s statements of being made fun of and laughed at. She divulged that she was attacked and beaten by peers in “every school, every grade and this continued through elementary, middle, and high school.” She described girls as “evil” and does not like to choose them as friends. Allison described having autism as being complicated and amazing because she has been made to feel dumb by others, but believes that in many ways, she is very smart and autism contributes to special abilities.

Uri was abused by his family and other people he met through the years. He struggled with motor planning challenges and described having autism as, “a stick shift in an automatic transmission type society.” Although he didn’t escape the abuse until he was old enough to get a black belt in Ty Kwon Do, which was unusually difficult due to the motor planning issue, hopefulness penetrated the young man’s determination to become an independent member of society.

Karen, like most of the other participants, faced challenges of being bullied. She recalled that she was so terrified in school that she would urinate on herself when scared. After transitioning from a typical public school into an adaptive education program in another public school, she became more secure because she felt that she received more attention. She hopes that children with autism will have different school opportunities than she had.

That will change within a few years and there will be more schools like the adaptive program I attended. I don’t want anyone to go through what I did. It was horrible. I would rather die than go back to a normal school- absolute torture for
us. There are kids there that are free to bully the fire out of you while the teachers are looking right at you. The teachers are not your friends. There is no control.

One of the younger participants, Larry, who is 19, described his way of thinking to be simple and felt that other people think more deeply. He described that having autism affected his ability to understand more abstract thinking, such as algebra and sometimes the use of a computer. Hope and a positive outlook was shared by this young man who said, “It’s that really, so basically we’re all just people here and we all have to work together and nobody’s really useless and once people with autism are given a change people can really be amazed.” Zayden told about a day in the life of ASD by describing his schedule which included eating breakfast and going to a day program. He reported that having ASD is “Something as us great and I like it.” He also explained that “Um . . . it’s like . . . I can’t figure out.” Similar thoughts were shared by Caden when asked to tell what is like to have ASD. “I don’t know it’s kind of confusing—it’s hard to describe I guess. Like I, it’s impossible for me to answer since I really don’t know myself.”

Bobby’s responses were short phrases without descriptions, but he attempted to respond to questions and prompts. His response to the question above was “fine,” and he also listed the sequence of what a day consisted of through prompts. Bobby explained that he liked to listen to music, eat breakfast, and get ready to go somewhere. He did not expand on challenges or supports through the interview, but responded to questions and each prompt with a phrase, which made it possible for the researcher to extrapolate basic information regarding those areas. Communication and interaction challenges appeared to be present through his verbal output and the appearance of his emotional state was calm.
Matthew explained ASD as a spectrum of different levels. He described his day with “I like to play video games a lot and I read some,” although he reported that he felt he had difficulty concentrating on reading. He talked about difficulty in eye contact when talking with people and how this affected attention to the conversation, therefore communication and interaction were affected. “So I don’t make eye contact a lot cause I can’t concentrate on one thing for a long time, so. So I kind of like make a few seconds of eye contact and look away, so.”

A typical day was described by Arwell when asked about life with ASD. He reported a schedule of waking up and completing a regular routine which included caring for the baby with his fiancé. He recalled his diagnosis in middle school, “It was very tough.” Arwell also spoke of difficulties with having eye contact and the challenge with social interactions.

Justin spoke of ASD coming with “a certain toll because it’s like well mom and dad were always pressuring me to do well on things.” He continued with a breakdown of the years of living with autism and a focus on interaction. “Well I’m going to say that, that, the social skills thing is definitely something to be talked about. And you know I remember when I was growing up sometimes someone would say something and I wouldn’t understand what it meant. Or I would say something and it’s like it wouldn’t come off the way I wanted it to.”

A day in the life of having ASD and experiencing challenges and supports through choices made by the 15 participants and others who participated in decisions for them was described in the responses above. Hearing the voices of young adults with
autism and their perspective on life choices after secondary education is described in detail in the following.

The Challenges of ASD

As previously mentioned, participants were asked, “What are the challenges and supports that you have had in regards to those experiences?” Four common themes were described by participants as challenges throughout transitioning from high school up to the current situation; they were the challenges of communication, relationships, depression or struggles with emotion, and not being prepared for what they desired to do in their lives. This included not having control in many areas of their lives including not being able to choose what they wanted to study in high school, therefore, increasing the difficulty to choose the path they wanted to follow upon completion of high school. For some, this meant extended living with the family at home, and for others, this meant living on their own, but with uncomfortable and often, dangerous conditions. This lack of control will be discussed more extensively. Dependability will be established by presenting accurate descriptions of the findings, and by reporting the truthfulness of the participant’s experiences.

The Challenges of Communication

During the transition planning in high school Christopher was not asked what he wanted to study or do later in his life, but was assumed to not be able to achieve anything and that his potential was not considered. Communication with the school team was difficult and not effective and he was not given the opportunities to make choices for himself.
As Christopher described his transition out of high school as “oppressive dealing with special education,” he also felt that it was somewhat “uplifting” to be treated as everyone else in a program called Transfer Plus upon exit from high school. He described that he realized he was not getting an education from the transfer program designed to help him learn skills and wanted to go to college where he felt normal. He reported that the “train of thought was to put him in a group home on state assistance for the rest of his life.” An emotion of fear was described by Christopher and the possibilities for the future were not communicated to him in a way that made planning for the future reasonable.

I asked to be in regular classes, but they would not let me be in them. They basically called me stupid and said you can’t do this because you aren’t getting 100% in all these other things so this is why we aren’t putting you in regular classes. I think the biggest thing special education teachers need to work on is listening to the students.

Being successful in academics through high school prevented Matthew from getting transition assistance. Since he was not identified with ASD until after high school, Matthew moved through the process of honor classes without guidance. “I was shy and not social, so. Well people thought I was different in some ways but if, if you made okay grades they wouldn’t give you any special help.” He was diagnosed with attention deficit disorder, but he graduated with a regular diploma and began the struggles and attempts at being successful in a college placement. Unable to focus for long periods of time or attend through completion of assignments prevented Matthew from being able to complete classes in college. He was unable to get any support in college and continued to struggle with communication and social skills through interactions with others. Matthew
reported that doctors and psychologists kept telling him that it was a high stress period for all young men it was normal to struggle during that period of growing up. After being diagnosed with depression, he did not want to take the medication because he did not like how it made him feel.

Caden remembers transition from high school happening to him and not with him. He described how he wished people had communicated with him. Caden reported an account of transition as:

I remember I was angry. They could have told me about where I was going. They literally told me on my birthday and I thought I was going to have the summer off. Tell me about it before. Tell me about it beforehand so I’m well aware of it.

In talking of transitions in school, jobs, or other life changes, Sherry detailed communication concerns. She stated that she has preferred to remain quiet instead of attempting to communicate with people who do not understand ASD. She reported, “That’s pretty much why I get really quiet because I’m worried I’m going to say something really stupid.” Not understanding sarcasm or when people are upset were described as communication issues that made it hard to make friends. Sherry expressed how she did not know how to initiate a conversation or say appropriate responses back to a speaker. She did not understand when it was appropriate to speak.

Sherry accepted an opportunity to participate in a transition program for two years following high school and did not receive her diploma until completion of that program. She was able to taking cooking and sewing class, music class, learn how to budget her money, shop and become independent. Again, communication and figuring out what
people meant when they spoke to her posed roadblocks for Sherry when the transition program assisted her in finding employment.

Sherry worked temporary jobs at chain stores where she had misunderstandings with her employers, which she described as needing to have sentences rephrased, told in different ways or different tones. She did not want to be made to feel like an idiot but she wanted to be able to understand what was being said to her. An example that occurred was when Sherry told her boss that she had the flu and her boss said, “Yea, you can go home just because you have a stomach ache.” When she clocked out, she was told, “I didn’t say you could go home. Did you already clock out?” Sherry responded, “You said I could go home.” Her employer admitted that he was being sarcastic.

The difficulty of making eye contact was mentioned by most of the participants. Communication was affected because making eye contact and concentrating on what was being said by the speaker at the same time was extremely difficult. Sherry reported that eye contact has improved since childhood, but it is still hard to concentrate and continue eye contact. “You know sometimes I just don’t understand what people are saying, not being able to process the information, needing people to repeat the sentence. She reported that she could not understand the nonverbal part of communication. She detailed a TV program that she watched to learn non-verbal communication. She studied what it meant when the speaker touched their face or used other gestures. When people called me a moron, I said, “I don’t know what I don’t understand, I just don’t understand it.”

Kayla expressed that she has learned how to appear to be looking at the speaker, such as looking over the speaker’s head, because it is too painful to look at the eyes. Kayla reported that she continues to practice eye contact and figuring out when to look at
the person’s eyes and when to look away. Kayla described difficulty in communicating and interacting through school and work transitions. She was told by another person that she was incapable of communicating with other people.

Kayla also believed that everybody thought she was weird. Diagnosed with depression at age 17, medications became a way of life. Kayla recalled how she watched all of her peers crying at graduation because they were hugging and talking about not seeing each other again. She remembers how no one hugged her and said they would miss her. Kayla reported her communication issues as speaking in a monotone and not understanding how to change tones for questions or parts of sentences. “While I’m talking, I would have been monotone and not animated.” She described how she would accidentally be offensive when she talked with people and unable to understand that communication had many components. “I would be totally clueless that I had said something offensive or that I had annoyed them in some way and then it would just turn into this huge, huge thing and I would say, where did this come from? Why does this person hate me? What is wrong with them?”

Being undiagnosed at the time, she did not receive school assisted help in decision making for her future. The transition out of high school presented her with new challenges. Communication issues persisted through transitions of high school, college, and jobs. Kayla struggled with making friends, financial needs, and depression.

As a recent graduate, Larry is comfortable with his transition program and states, “When I’m learning something for the first time, I feel like I struggle with it and I don’t know what to do and I need to ask for help.” In Larry’s current program, he feels supported and is learning how to complete job applications, interview, live on his own,
and plan for the next step. Larry did not state communication issues as a problem, but stated that he does not talk to people very much. He appeared comfortable and spoke at ease, with smiles and pleasure at participation. Other participants, like Zayden, did not speak of communication as a particular issue, but used short phrases often. Zayden reported that “Some people don’t speak what, like we do and uh talk different.” He described that others were hard to understand. Bobby responded to prompts in the questions with one word or short phrases, but did not elaborate on challenges.

Uri described communication as being direct.

I have my own method. I have my own way of communicating. Um, I’m I’m very analytical and I, I think things more like, more like algebraic equations rather than, rather than like nuances. I was confused because they weren’t direct with me. They’re pretty much talking in variables when I was looking for a straight answer.

Some participants described moving away from home as transitions that were not fully understood at first. The transitions were described as exciting and scary by multiple participants. Allison felt that her mother had taught her how to cook, how to take care of her clothes and take care of her room, but she described the transition to the group home as a part of life when she needed to learn how to do more on her own and it “has helped my life a lot.” She described “sparks” when she didn’t understand what she was supposed to do in relationship to her contributions in the group home. Her biggest challenge was getting along with the staff. Getting along with a boyfriend provided additional challenges, although Allison and her friend have worked on “combining thoughts and working things out instead of screaming at each other.” Trying to decide what to do and
when to do it or making plans in general lead to times of miscommunication. She expressed thoughts of romance and a future with her friend and expressed a desire for a marriage. Family relationships also posed concerns for Allison, but those were intertwined with gains of lasting friendship and relationship with her parents and brothers.

When participants talked about transitions in school programs, communication or lack of communication was described in the process. Transitioning from one high school program into another high school was a relief for Arwell because of the abusive situation in a behavioral class for the emotionally disturbed. Communication was not directed to him in the meetings, but to a parent. There was a lack of reciprocal communication with him.

It was very tough when I got the diagnosis of Asperger’s Syndrome in seventh grade. They didn’t have anything for people with autism and they’d lock me up in a back room and I would sit in the dark. And they’d leave me there for a couple of hours at a time. They just didn’t know what they were doing.

When he attempted to get into the classes that he wanted, he was told that he could not choose what he wanted.

My mom started going to the IEP meetings with my social worker and he spoke up for me as he asked me what I wanted. The teachers never asked me what I wanted and they only talked with the social worker or my mom.

Karen did not use the word communication but described it in this way, “Yeah, all my life, any normal person that I’ve tried to talk to it was very, very rare that I would
make friends with them.” Karen described feeling hurt because of the lack of communication and acceptance with other people.

Karen, like Caden described situations of surprise and disappointment when the transition plans did not take place as they had planned or understood due to communication differences. Karen stated that she did not believe she was ready to transition from the program and that she had not learned what she should have learned.

They said that they would help me and they would get people to teach me these things, but they never did. I don’t even know how to take a bus. I can’t drive. I just wish there was more time given to older people with autism, not just to little kids with autism.

Caden, in a similar situation described earlier, was upset to find out that a transition plan had been made for him upon leaving high school, but had not been communicated to him. “And I was trying really hard to keep calm,” he revealed.

Carl experienced a situation due to a behavior issue which prompted the school to request him to accept his diploma and prevent him from being able to accept the financial assistance that was needed for a college or life preparation program. He noted that communication regarding the future was not clear when he and his parents met with the school team. The transition meeting was, as Carl described,

“Not clear—I didn’t know what transition was. I’ve never done it before. They’re unfair. The IEP didn’t say anything about that. We had no idea. We weren’t prepared. I just don’t know why they did this to me. I didn’t deserve this.”

Carl’s life preparatory program was for one month, but he desired a longer program. He reported that his parents were the only people who could help him because
he no longer had the support of friends in high school or anywhere else. Apparently, once
he accepted the high school diploma, he would be financially responsible for remaining
in the transition program and it was too expensive. The program would allow him to live
there and work or go to a college from that program. He reported that he had not
understood what it meant to accept the diploma until after it was done, therefore
communication was an issue.

William talked about communication being “definitely difficult with peers, teachers and everybody” as a young child. He reported that he had worked on that area
for years with teachers and counselors. He explained that any current issues in
communication are working on social skills pertaining to jobs and interviews.

Justin described times of not understanding what others meant or saying things
that were not what he meant to say. He explained that he invested his time in math. “I
was gifted in school and when I was a kid, my dad brought an algebra book home. So I
gobbled that up and it’s like wow, I understand all this stuff and I’ve never had it.”

Communication, which involved frequent misunderstandings and getting along
with others, appeared to be the underlying challenge in the experiences reported by all of
the participants as they made transitions through their lives. Participants described how
blocks in communication channels contributed to not feeling prepared after high school.
In some cases, it was communication that was not understood by the participant due to
the effects of ASD and in other instances communication did not take place on the part of
the school, as explained by participants. These individuals have explained how
communication affected work, school performance, activities, family, and contributed to
the challenge in relationships.
The Challenge of Relationships

It was a shared experience for the participants to feel, as Karen previously described, that people believed her to be different and did not invite her or choose her to participate in social functions. She feels that she was left behind as other peers went off to jobs, college, and fun activities. Her friends are “now too busy for me, they are learning how to drive, cook and how to get a job, and even though I am older than they are, they are moving ahead of me rather quickly.” Karen explained how it is difficult for her because some people are able to learn those things on their own and people with autism can’t do it without help in learning.

Karen goes to church, but does not have a connection to friends there. She is much older than the younger teens there and thinks that she is perceived as a pervert for trying to talk to them. “It’s like they can sense the weirdness coming from me. The only people that I can try to remain in contact with are my friends with mental illness. They understand me.” She described how it hurt to be thought of as stupid or something wrong with her head, or just a freak. Attempts at relationships with “normal prissy girls” consisted of hearing them say, “Look at her, she likes video games, look how she’s eating, she says cool man.” She tried to be social, but felt it wasn’t the right kind of social, and it would backfire and people would alienate themselves further from her.

Karen decided that the normal people are the freaks because they talk on the phone for hours, don’t like games, don’t like to draw, and are weird. She reported that she liked her autism because she could see things out of the box, but she also misunderstands meanings because she couldn’t see what is in the box. Challenges occur when people are annoyed with her because her reactions are not typical reactions when someone talks to
her and asks for her opinion. Karen believes that people think she is weird when she does not react or respond in the ways they may expect.

Her perception of her transition out of high school was, “They knew that I was going to graduate and they thought I would be okay. They started paying attention to the other people who were going to stay in school longer.” Karen had decided to graduate at 18 and begin to work, but sensory overload prevented her from being successful in a store setting so she was forced to quit. She had accepted the chance to graduate at age 18 instead of continuing the special education program and did not realize what it meant. She looks forward to further training so that she can be successful in becoming independent.

Sherry expressed the difficulty in making friends was due to not knowing how to start conversations, and not understanding what is appropriate or not appropriate to say. She gave an example of sitting in class while roll was called and upon hearing a girl’s name, she related it to a song and began to sing the song about the girl. Her peers became angry and she talked with the person later and apologized. Although this situation did not lead to a position of being bullied, other situations did. Sherry and others admitted that body language, gestures, facial expressions, and words may be missed and misunderstood.

Having a long term relationship with her current partner or people who become her friends has created a different communication issue of continuous talk for Sherry, “I don’t even know when someone wants me to shut up. I always think that they’re kidding, unless I am told in a frank way.” She described situations of thinking aloud and saying random and inappropriate comments, not to anyone, but saying that she had forgotten
where she was at the time. When teachers would ask questions, she would raise her hand and when her name was called, she would respond with, “I don’t know. I thought that was normal for some reason. I talked to myself or I talked too much. It was hard.” Sherry continued to express difficulty getting along with people, but finds strong support in her cat, “you know, they’re less picky on who they care about and you know my cat’s always been there for me and some people feel I saved the cat and I was like no the cat saved me.”

Sherry didn’t know if someone was joking so her responses may have alienated her from others. She said that body language, facial expressions, and gestures were parts of communication that she missed unless it was very exaggerated and this affected relationships. If a situation becomes overbearing, such as noise, she may cover her ears and rock back and forth to prevent a more noticeable meltdown which would result in people making fun of her.

Sherry reported that her relationship with her boyfriend was affected by the meltdowns, although he has Asperger’s and experienced sensory overload at times. Sherry and others like to have friends with ASD also.

You know having other friends with Asperger’s Syndrome makes it so much easier because people with Asperger’s Syndrome you know understand us more than, more than even shrinks do or people who are psychologists sometimes because you know I mean they read about it, but . . .

She described how she had eaten to try to feel better because she was bullied and made fun of due to her challenges with ASD. “It’s an invisible disorder. People have told
me that this diagnosis is an excuse to act stupid and I say no it’s not. People think I am immature when I don’t understand something.”

Kayla also experienced problems with boyfriends. She reported that learning about codependency, and learning that it could mean her happiness depended on the happiness of her mate, changed the way she lived relationships. Understanding more about herself made her realize that she was “just trying to fix them” as she experienced relationships with many boyfriends who have some type of addiction. The boyfriends were described as people who didn’t mind if she took care of them and picked up after them. Each relationship ended as the man became tired of “being nagged to change their behavior and the man broke up with her.”

Kayla detailed situations of misinterpreting the relationship signals and being overly trusting of men. She was raped in a date rape relationship in which she perceives she missed important communication cues. She wanted to have a boyfriend and did not think about wanting to know about the past of the person, “and you know these are kind of signs that you should maybe stay away from this guy and I recognize that now and I learned that you should really know somebody’s past.” During another time in which Kayla described communication problems she described that she used cutting to get away from a situation in which a partner was drunk and out of the hotel room and she wanted to try to “escape”. “So I sat in his room and I uh found this pop tab off of a can of pop and I sanitized it cause I’m like I don’t want to die of an infection, but I’m going to cut
myself with this and he came into the room.” That was Kayla’s last time to cut. She believes that she started to change her outlook on life at that time.

Kayla’s work relationships were affected by her difficulties with communication in such a way that she was told by a boss that she could not work in the same room as others. She reported that her boss had told her that she was incapable of communicating with others and she had to email her questions to the boss and limit her interactions. Multiple coworkers complained about their issues with Kayla which prompted the boss to make her work in a room by herself.

A coworker told her that there was something wrong with her and the other employees began to avoid her. Although Kayla sought the help of an agency which could provide a work coach, it was not allowed by her boss. Kayla began to pray for her boss upon the advice of a friend. After she solved a computer issue in her company she was given a specialized job and gained a new type of respect from her boss. She began to watch programs on television and practice facial expression and gestures. Before becoming attentive to making changes, she realized that she spoke in a monotone with almost no change in facial expression, as described earlier in Kayla’s description of communication.

As Kayla learned more about ASD, she began to realize that her parents had characteristics of ASD also. She knew from her own experience of sharing with her parents that neither of them would want to talk about themselves with an outside support person. Her relationship with her mother and father has proved to be supportive through the years with emotional and financial help. Her mother first recognized Kayla’s depression and took her for medical assistance and a diagnosis of clinical depression.
Relationships with friends were rare throughout her twenties, although she attended college and worked several jobs. She was often teased for choices she had made, such as the color of the lipstick or the way she dressed.

Carl, just out of high school, talked about relationships through high school woven into his hobby of playing an instrument in the high school band. After being in the band, traveling and marching with a large group as a well-training functioning member, he had made friends with teachers and students. He had also studied German for four years and traveled to Germany with the class in high school. Friends and teachers supported him when he needed help. “In middle school I didn’t feel like I had anybody, but in high school that changed quickly in the band. I was seen as one of them. It just felt great. I mean I hadn’t felt so alive.” Most of the people have moved on now and he has been unable to continue most of the friendships. Carl spoke of a relationship with an out of town brother whom he enjoys seeing when they are together. He talked about liking particular movies and hobbies that were specific to him and not of much interest to others. Relationships that were developed through the German club and marching band dissolved when school was over.

Living independently brought new challenges for relationships in Justin’s life. Living in a college dorm meant living with a roommate,

Well, I remember my - - I got along pretty well with, with my first roommate for the most part. And then well second year there was , there was David and he was well I remember things like, like the Sopranos and it’s like, it’s like, (laughter), it’s like it’s okay, it’s like it’s okay to look at beautiful women, Jack. It’s like well I don’t feel comfortable gawking at them.”
Justin recalled that it was common for him to visit faculty in their offices and talk with them. A close friend of the family had been a friend to Justin in the past, but now he voiced it this way. “Well, I must say that well whenever, whenever I want to do something with somebody and it’s like they, they never want to do it because they say they’re too busy all the time, it’s like I, it’s a real, it’s a real disappointment.”

Friendships after high school did not exist for Matthew, as shared above by Justin and Carl. Matthew felt that not having a driver’s license made it more difficult to get around, “Well I mean I don’t – I can’t do it well enough to be safe, so.” Although Matthew had gotten a license when he was younger, he did not ever drive alone due to anxiety and discontinued driving that same year. Relationships revolved around parents, siblings, and extended family members because friendships did not continue past high school, although Matthew had been a member of the school track team.

Living in supervised housing provided friendships within the residence. Bobby responded to prompts of hobbies and activities that he likes to do by answering “go places.” Further questioning prompted him to say “basketball, bowling.” Allison and Zayden also participated in activities through a residential setting. Each of these participants discussed friendships in the setting and family relationships. Allison participated in a day program, “We volunteer, we do activities, we sometimes hang out there, eat lunch, and we go swimming.” Allison reported getting together with family members.

Larry reported that he met people through his day program and in Special Olympics, but did not get together with them outside of those programs. He did activities with his family during leisure time. Caden, who lived independently in a semi-supervised
apartment setting, and attended a transition program, reported that his hobbies consisted of movies and writing at home. He also reported getting together with family members for traveling and other trips in the community, but does not get together with others outside of the transition program.

Christopher reported that he did not have friendships growing up and was taunted. “I’m gay, they’ll be in love with at first but then they realize you’re different and you act it out in public and maybe you don’t get along.” He has established relationships with people through martial arts, car racing, school, photography and being involved in a policy making group to change laws regarding special education funding. He reported that he felt he needed to change his behaviors in order to get along with people and then find that when he started to be himself, the friendship would end. “Sometimes I do that but more or less I’d uh try to uh get along with anybody and everybody.”

Arwell reported that in the past he had developed a relationship with his dad, but had not talked with him in a while. He expressed that his relationships consisted of mostly family with his fiancé and children. He described situations where he had been taken advantage of by friends when they stole his belongings. Arwell also described situations of staying with friends and ending up in a dangerous situation where someone tried to kill him with a sword. He detailed that he has learned to read cues and expressions well now and he has current relationships with extended family.

Uri’s relationships with women were revealed as challenging because “I didn’t get. “ I didn’t really get what social boundaries aren’t appropriate and what social boundaries were appropriate. Uh because of that, I’ve had a few times where I almost got slapped in the face. I stole a base.” He revealed that he had disobeyed social norms and
rules and sometimes didn’t know they were there. Other times he admitted that he knew the rule. He reported a current relationship with a woman whom he lives with and he voiced the difficulties in trying to understand each other’s issues.

A focus on keeping in shape by lifting weights and working full time was expressed by William. He indicated his strength was in maintaining the Dean’s list in college but is not sure if it has been helpful in maintaining work. “It’s kind of how you socialize, how you network and I think that’s the struggle I’ve had and I think others with autism would definitely have.”

I like to keep a small group of friends, it’s just I like to be able to trust people with a lot of information and they trust me and we’re close, we have a lot in common. Honestly, I don’t tell them I have autism and they do not have autism. I think they might see I might have a little issue here and there, but they don’t ask, if they did I don’t think they’d care.

Relationships proved to be challenging for the participants and difficulties were explained in making friends, losing friends after high school, or not having friends until much older. Friendships required learning about communication and interaction, and sometimes included sadness, anger or depression.

The Challenge of Depression and Struggle with Emotions

As described above, Sherry overate to gain comfort from the sadness and physical feelings that she experienced from ASD. Sherry used the term *drug* to explain how she used high calorie foods, such as donuts, to help her relieve the pressure. “By age 16, I went up to 350 pounds. I was huge and unhealthy. I was bullied and sometimes I walked away and cried.” Sherry reported that depression due to being bullied “caused thoughts
of suicide, but the few friends I had talked me out of it. Her friends helped her to understand that being different was accepted because other people were boring.

Depression was described by six of the 15 participants and anger or struggle of emotions was described as challenges for five of the participants at different times in their lives. Some were treated for clinical depression with medication and others were treated for anxiety. The hopelessness was conveyed by Christopher through his poems. He continues to tell his story through words such as these:

You told me no
    I told me yes
You told me I couldn’t
    I thought what if
You told me to give up
    But I kept going
The hell I lived and the toll I paid
For daring to be different and not thinking your way
You told me I was different and not okay
Threw me in a separate classroom like I had no brain
    Had me ride a short bus for hours at a time
Just to face discrimination where you tore me apart
The tears were like showers for many of the nights
    Showers I faced under the darkness of light
    Showers of my regret
    Showers of lacking light
    Showers full of pain, needles, and spite
I was just a child then, I had no choice
To stand up for myself or to put up a fight
I was only thirteen I cried myself to sleep
    Nobody there, not even a peep
    Barely a friend, no one to teach
No one to teach me the correct way to speak
No family that cared as it seemed at the time
    No one to relate to
    So much to despise
    Soaking in my regrets
    In a world so cold
    Alone at night my emotions ruled
    There’s one person there
    And that person was you
    Abusing me because you saw me as weak
I was just a child then but you took that away
Made me despise myself in any ways
I spent countless nights staring at knife
Dreaming of the day I wouldn’t have to put up a fight
As I cried myself to sleep for many of the nights
I couldn’t stop thinking of taking my own life
The pain I felt, the horrible feelings
The way I kept dreaming of the day I’d stop breathing
I was told no, don’t take your own life
It’s a selfish decision, you should put up despite
But they were the ones that were truly selfish
Wanting me to go on living in pain
Dealing with depression in the hardest of ways
But I overcame those feelings eventually one day
Years after I graduated high school I deal with the pain
There are a few questions that I have for you
Did you realize my pain, what’s your excuse?
How could you treat a child like that?
Put them through hell with no one at bat
But as time passed I realized the lies
That you told a child that ruined his life
  I’m stronger now
  I realize the pain
That you might still be giving to children in equal ways to this day
So I’m going to make sure that people like you
Stop getting the chances to destroy our youth
  Never to teach
  Never affect lives
This is one thing I will always do
Because I despise the way you affected me and told me these lies
But now I will go on living my life
But there’s one last thing that I have to say to you
Would it hurt or mend your heart if I told you that I forgive you

Consideration of suicide and self-injurious behaviors were discussed by several participants, as relayed in the poem by Christopher. Kayla used medication and therapy for many years and currently thrives on her faith and Christianity as her support. She escaped temporarily through cutting behavior in which she inflicted herself with multiple cuts on her body during times of depression. She described her years of medications as, “the pills would make me feel like I wasn’t myself. I would feel like in here I’m really
depressed, but out here it looks like I’m not because something is making me be not who I am.” Negative medical reactions led Kayla to frequent prescription changes and eventually to ending the medication usage.

Christopher used drugs and alcohol to “try to escape reality.” He used, in his words, “illegal street car racing to begin to gain confidence in myself as a person, and chose that stage as the time to “come out of the closet and let others know I am gay.” Christopher expressed the desire to have relationships and sought drug use as the avenue, “I wanted friends and I wanted a way to escape and that’s why it felt good back then. We live in a society that pumps drugs in us all the time and then that holds us back.” He thought about suicide through childhood and wrote of it in his poems.

While at school Christopher described psychological abuse by the teachers and teasing or bullying by the students.

I didn’t have any friends, so you have no friends, you have no life with the teachers and you don’t feel like you have any relationship with your family so then you think of killing yourself. That’s a good part of what I thought of doing for a while, just taking my own life.

Struggles with anger were reported by Arwell, who, as reported earlier, was abused by a teacher, and was “treated like an outcast.” He was expelled from high school and anger was expressed through physical punishment to his siblings. “Through my body language, others saw that I was different from them and treated me like an outsider.” He lived in multiple places after difficulties trying to live with one parent and then the other. Stepparents were also abusive and he began to live with friends. Arwell’s life was
changed by a social worker: “He showed me that he cared.” As he spoke of his anger, “Um, he would just give me ways to deal with that to get out of the house.”

Being bullied, abused or experiencing other devastating transitions created emotional difficulties. Allison, adopted from another country at age six and bullied through her school career, explained that she handled depression through wearing black makeup and using a black marker to draw tears down her face. She said that it was to tell people to “back off and leave me alone.” Her reaction was the choice to refrain from having female friends.

Transitions such as losing his dad, going in and out of relationships with women, having a friend move, and then losing friends created so much stress that Uri contemplated suicide.

I couldn’t deal with the stress of having A.S. I blurted things out that might not be related to anything to friends and I lost them. Relationships were involvements with women who didn’t have my best interest at heart and her ex came back and tried to kill me.

Growing up in a family where abuse was part of a highly controlled religious group motivated Uri to learn martial arts. After multiple attempts to physically hurt and control him, he awoke to find someone on him trying to choke him. If he did something wrong, he was seriously beaten by family or church members. “I hated them. I hated them.” Uri was homeschooled during most of his high school, but returned to school for a short time. He was punished by his family or church when he offended someone, but wasn’t told what was offensive. “I didn’t understand. I could get marks in my church as someone who was not to be associated with.” He continued to be threatened if he didn’t
behave in a certain manner. Uri reported that he went to the internet as an escape from the abuse and created an online persona. “Eventually, like after slowly eroding that control away from that church, like my id finally leaked out into my super id ego and that’s when I started being wayward.” Uri’s dad began to support him emotionally in growing up, but died almost as soon as the support began and his mother tried to force him into staying with the church.

Carl also reported anger in this feelings and behavior at those in control of his transition and high school programming.

They didn’t tell me anything. They told me on that day (what was going to happen after high school). I feel stupid. I felt horrible. I felt hurt. They may have well as said, you are a stupid retard, you have no future,

Carl felt manipulated into making the decisions that were mentioned earlier and believed that the school district didn’t want to be responsible for any further expenses, although he was entitled to further training after age 18. He does not feel that he is prepared for the future and described feelings of hurt and anger as he attempts to plan for the next step.

Larry did not talk of sadness, anger or depression. He voiced, “I don’t really feel ashamed or anything, I mean I just I know that nobody’s perfect. Larry spoke of wishing that he could have more control over some of his life decisions. Caden talked about experiencing multiple transitions when his father died and moving into assisted living. He said that it was hard. He described anger, as mentioned before in communication, during the transition from high school, “I remember I was angry, I managed, I remember I broke stuff . . . .”
As revealed earlier, Bobby responded to questions and prompts. An example of his response: “How much do you control what you do in your life?” Bobby responded with “me.” Bobby did not mention anger, sadness or depression. He said that he liked his assisted living situation. Zayden expressed sadness during the transition from his parent’s home into the assisted living, but like Bobby, did not express anger or depression while talking about his life.

Karen described frustrations, being helpless and being sad in her transition from high school and not being able to do the things that she thought she would be doing at this stage in her life, such as driving. She expressed “I’m terrified about trying to learn how to use a bus.”

Matthew revealed that he had dealt with diagnosed depression and received prescription medication, but he didn’t like to take it because of the way it made him feel, as Kayla described earlier. He reported that a doctor told him that it was probably because he didn’t know what it was like to feel normal because he was not used to feeling normal. Another doctor told him that he was in the stage for the highest rate of suicide, but he still elected to refuse medication.

Neither William, nor Justin talked about anger or depression. Both spoke of support or how they had worked through difficulties on their own or by seeking out knowledge. They share commonalities in that both have college degrees and are living at home. They are planning to live on their own.

Depression and struggles with emotion were described by multiple participants as they experienced transitions through relationships, living arrangements, jobs, and school or training programs. Some individuals described thoughts of suicide or self-injurious
behaviors. Others took medication in hope of improvement and drugs were thought of as a support to get through difficult periods. Anger was an emotion that was common among the participants during situations of abuse or times of misunderstandings in communication.

The Challenge of Not Being Prepared for the Future

Some of the participants voiced concerns about the future, such as feeling unprepared or having had education and still being unemployed. Another step was the transitional step, in hope of a job or improved situation.

One example of feeling unprepared was described by Carl, who had attended a two month transition life training program after high school. He felt that more time was needed in preparation for college, but financial support was not available for a longer program. Academically, he feels qualified to complete college classes, but does not feel he had adequate pre-college training for successful living on his own. He had taken non-adapted classes, but not everything that was needed to get into the college program he hoped to attend. He was left to try to learn on his own at home because of miscommunication with the high school transition team and, with the support of his parents, will seek out the next step.

Karen, like Carl above, described her top challenge as not having support once she graduated from a special education placement in school and expressed discouragement.

I don’t know how to take care of myself. There’s going to be more and more people living with their parents, not having a job and when their parents die they’ll probably be homeless or I don’t know. I don’t want that to happen. I would
say that there needs to be more companies or programs that will step up and be happy to help young adults. Don’t just help the little children.

Although Matthew did not attend any special education classes in high school, he felt that he could not be successful in college. He believed that his symptoms of ASD worsened over time in that he developed tics, anxiety, and more severe attention difficulties. He described that he didn’t feel that he was good enough and as he attempted college after college, he dropped out. Matthew and his parents felt that the system had failed him, as he was not diagnosed until recently. Making it through high school and then trying to continue in a different world out there was devastating, according to Matthew. Without a diagnosis, Matthew repeated this lack of support in trying to go to college. He found that he was unable to take care of himself and did not know how to cook, wash his clothes, or use public transportation.

A high school counselor was helpful for William and suggested that he volunteer in a local law enforcement program. Although he received support from the school team, he felt a dedicated autism program would have helped him through his struggles. William stated that it would have been helpful to have a program in high school to teach communication that was needed in order to be successful in job interviews and career training searches. When talking about the interview process and lacking those skills, he communicated:

They want to see that you’re confident when you talk and have that calmness and composure in stressful situations. I think with this disorder that I have, I’ve had to work on that because I am a little nervous. I have been able to work on that through my experience in the field.
Neither Christopher, nor Arwell, felt prepared for life after the transition from high school. Neither had been encouraged to study or prepare for what they wanted to do. Christopher had to work much harder, he described, than would have been necessary if he had the college prep classes that he had wanted to take. He listed social skills as a deterrent when moving on.

No one ever taught it, but they just expected me to know it. If you’re in special ed. and there are special ed. kids that have problems with other people and getting along with other people, how do you ever expect them to develop social skills when they’re around people that have no social skills as it is?

Being prepared for the future means learning how to think for oneself. Christopher felt that part of the problem was that he was never given the chance to be independent. His description of the classroom in high school was, “Christopher, let’s talk for you and never really let you think on your own.” Living in a dream world was a way to escape, as he described his creative alter life.

For Arwell, the time spent in special education classes was “very tough.” After being caught with a knife on school grounds, he left that city to go to his dad’s home where he described abuse by his stepmom. After moving from there, he spent time “couch hopping” living with friends or wherever he could stay, including homelessness. Arwell disclosed his current relationship with his fiancé and how her relatives were able to get a job for him as a welder. He had received training in high school and excelled at the job. Arwell reported that he was currently “laid off.” Arwell expressed that he had achieved most of what he was told that he would never do. He did not express that he was not prepared for the immediate future.
For Justin, it was difficult trying to manage his time, figuring out how to manage money on a budget, and having functional relationships with people in college. Justin found that he was not prepared, but had to figure it out for himself with the help of whomever he could find that would be willing to answer questions. He had been considered to be high functioning academically, so was not considered to need other services to help him plan for the future. Justin believed that his Ph.D. prepared him to do a job, but described that he has not been able to find work. He worked temporarily in a career center putting together ball bearing joints and was very disappointed in the below minimum wage pay. Not being prepared for the future was described by Justin as not knowing how he would pay off school loans and being able to live by himself again someday, as he had done while in college.

Preparation for those who went into an assisted living accommodation appeared to be similar to those who moved out and went to college or into a job and lived on their own. It was sad and hard, as described by Caden, Allison, Bobby, and Zayden. Although some of the self-care skills had been learned, communication and social skills were lacking. Allison felt that her parents had taught her self-care skills, but following the social norms in her new residence was a challenge. Caden, who was participating in a transition program, learned to make food in his microwave and take care of his apartment. The others learned how to be a part of a “team” and contribute to the household. Learning to take care of a home, cook, manage money, and communicate with new members of a residence was found to be a challenge.

Living without a diagnosis, as Kayla and several others had done, placed them in a position of wanting to be like normal people, as they described, and not knowing what
was wrong. Transitioning from high school without a diagnosis meant leaving one difficult situation for another. Searching for support, within themselves or from others was a journey. Kayla described that she wasn’t prepared, but worked through the issues after much difficulty.

Sherry reported that she was prepared for the future by attending a transition program after high school. She described cooking class, sewing class, learning how to shop and how to do basic math. Through this program, she participated in a work program in the community. Sherry described difficulties in communication and relationships as part of concerns in being prepared for further work.

Poor motor issues were described by Uri as preventing him from being successful in numerous jobs. He was told that he could not keep up with the quota. “Once I get something routine, I could just do it like that.” He voiced that he was a physically strong person, but that his mind could be thinking one thing and his body thinking another. Uri disclosed that he felt that homeschool and involvement in his mother’s religion prevented him from being prepared to live on his own and be independent. “My dad was preparing me to have to like eventually transition to like be my own person.” Uri’s dad died and he continued to live with his mother until he was in his 20’s. He expressed that his mother had encouraged him to accept disability benefits and he was now in vocational school so that he could end the benefits.

Larry, currently in a transition program and just out of high school, described that he was becoming prepared. He articulated that he was learning how to work in the community and was receiving training in skills for independence. He described living
with his family and being part of the family team by contributing to the work load, saving money and paying for what he wanted to buy.

As the participants with ASD transitioned out of high school and into transitional programs for preparation of further education or living, they experienced challenges in communication, relationships, and struggles with emotions and depression. For some, it meant feeling unprepared for the future. Having ASD often meant not understanding what people meant when they talked or trying to change his/her own behavior in order to make friends. For some it meant trying to escape through the use of drugs or self-inflicted wounds. For all, it meant trying to transition through struggles.

Supports

Participants described their hobbies, work, and relationships with support in mind. Two common themes emerged as supports. Support from family or others and self-reliance, which included a desire to educate others about autism. The self-reliance led to hope for the future and where they are now. Some participants shared personal thoughts and documents when given a chance to share and talk about their choice of topics. As personal thoughts were shared, control from outer sources and self-control was woven throughout the discussion.

Support from Family and Others

Participant responses to questions regarding control over their lives covered their life span from childhood through the present. About half of the participants described complete control over their lives while the other half lived lives of shared control with caretakers or parents. The proclamations regarding control were intermingled with the
support received during times of struggle. Several participants spoke of faith during prompts on religion.

Although several participants described a lack of control because parents controlled parts of their lives, they attributed support to be from parents. Karen’s memories of growing up with sensory overload were reported with deep appreciation for her mother.

I thank her very much for it. I’ll tell you, I’m surprised that she’s put up with me the way she did. When I was little I was so violent and unpredictable that my own family was too afraid to keep me when my mom went to work.

Karen’s mother was named as the primary controller for the current time, but Karen hopes to be more in control of her life after she learns additional skills. Karen described her dream program for a high school transition; although she loved parts of her high school program, she felt unprepared to be on her own.

They need to have some kind of program where they can maybe literally like a large house for autistic people to go to have assistance in learning how to take care of themselves. Maybe some classes in that place um, um, you know like the school that I am trying to get into. They need more of those, lots of those. And they need it for everybody, maybe a few in every state. The closest one is in Nashville. Karen did not feel the high school program had taught her how to be independent.

As previously discussed by Christopher, parents provided support, but didn’t push him to do what he needed to learn to become more independent when he was younger. Christopher said that his parents provided financial support and that he has been able to
come back to live at home when needed. His support came through gaining confidence while street car racing and then from a sense of family in a drug treatment center. A second community of family came from the training in martial arts where he felt the family did not see his disability. Although Christopher has felt fleeting support from partners, he expressed that it has been difficult to have long term relationships. He reported that he had mixed emotions about the support from partners because he felt he was used to not being accepted and often didn’t trust what might happen next.

Christopher stated that school support did not exist, and support came from himself. They never understood the fact that you don’t want to be going to a group home for the rest of your life like some of the others. They don’t teach you anything in special education. The IEP is so dumbed down because they don’t want to make you uncomfortable. Heaven forbid him actually get an education and see what he’s made of because obviously you’re disabled you can’t accomplish anything. It was kind of hard and I didn’t have the support at home either. So support became myself, I guess a lot of times. So supporting myself through my entire life was kind of on myself for a good part of it. Hobbies were a support for me because it helped me to escape reality too.

Drugs and alcohol were described as supports for Christopher during times of trial because he had difficulty making friends during teenage years.

William, who has been to college and is employed, saw his parents as guides who helped him when others could figure out life by themselves. He praised his parents with, “There’s not enough I can do. I can’t thank them enough.” Through the years, William
received guidance from counselors to help plan for his future. He gave credit to family and others for teaching him to become self-reliant.

Kayla reported that her support from God, family and hobbies has contributed to her ability to be different than she was five years ago. During the past few years, as she made transitions through life, she has relied on her faith to help her make better choices. She recounted prayers and learning how to communicate as she became more aware of her need to communicate more effectively and how to pay attention to things she hadn’t noticed before. Kayla’s journey of support is described in detail in the section of hope and self-reliance.

Bobby felt that he made decisions with his caretakers. When asked about control he answered “me.” He responded with, “Like it here,” as we talked about who supported and helped him through his day. In his supported living housing arrangement, he made some decisions on his own while his daily schedule was set by the management, which included 24 hour care. Bobby responded with short 1-3 word phrases in response to questions and prompts. When he said that he liked gospel music, he said “Me like the Lord.”

Arwell, now in a relationship which requires joint communication, spoke of shared control with his fiancé. Although he said he is basically in control of his decisions, he described how they communicated through talking over situations before they came up with an agreement about issues. When he was younger, school had taken over much of his control and he is pleased with his decisions at this time in his life.

Several of the participants, such as Larry, Zayden, and Caden, perceived that most of the control over their lives came from parents and others. Details involving their lack
of control included the thought that the parents seemed to know how to make better
decisions most of the time. However, Larry expressed his desire by saying, “I guess a
little bit of me just wants to maybe just try to make my own decisions at times.” Zayden
and Allison, who lived in supported housing situations, described how much they had
learned to be independent in the housing. Control was spoken of in ways of being needed
to assure the cooperation of all in the housing unit, and the fact that outer control meant
that they could not see friends each time they asked or go shopping anytime they asked.
The decisions needed to be made with the housing manager, who would arrange for
someone to take them to the places.

Sherry perceived her support to be the strongest from a boyfriend, her family, and
her faith.

You know Jesus made me the way he wants me to be. He likes me being different,
you know it helps me be stronger and learn how to cope better. Another support is
my family who has always been there for me.

Sherry explained that her family helped her to understand what might be
inappropriate and strategies to use to correct problems. “They understand me, almost as
much as I understand myself.” She reported that she is trying to change her ways of
coping by explaining ASD to people. “I guess people control how they accept me, but if
they don’t even try to understand then they’re not really worth me . . . they’re not really
worth my respect.”

Justin’s support came from his parents through childhood and high school. Being
gifted and having ASD created challenges that his parents guided him through. Justin
described a situation where his parents fought to keep him out of some special education
classes and in regular classes. Despite his high I.Q. and his gifted ability, special education had been recommended for some areas, but not others.

Uri described support from his partner and hobbies, such as learning Ty Kwon Do, which has made him feel safe. He described his conversation with his mom when he told her he wanted to play hockey after his brother had hold him that he thought he wanted to play hockey to “handle those rebellious white kid,” (anonymous, December 7, 2012.) He told his mother, “That’s why I want to play hockey, so as soon as I started to get some money, I started to play hockey.” Uri spoke of the relationship challenges because others thought he was so weird. He was afraid of the puck and was afraid of falling through the ice, so he wore protection that he called his “suit of armor.”

After his experiences in a religious group where he had been abused, Uri left the church. He became a militant atheist in his words.

I truly did not believe in God, but then over time I knew what it was like to be poor, starving, no home, and no one to help me. While I was going through that, no humanists were there to help me. Just the churches stepped forward. They helped me, they fed me, they gave me food and a pep talk every Saturday night-provided support. And because of that I decided, I decided, you know what, I believe personally in the goodness of the human spirit and I believe religion is an expression of the goodness of the human spirit, especially Christianity. And that’s how I converted to Christianity.

Justin shared that his parents had provided support while he was growing up and again at this time. Although he described periods of being pressured by his parents to do well, he described how they remained as his advocates during his school years.
Now I remember they were trying to get me into the CDC (comprehensive development class of all special education students) version and apparently that didn’t float my boat and so dad and I fought tooth and nail to get me into the regular class and I actually got an “A” in the regular class.

Justin described his transitions as family based and disclosed that his dad was watching all the time. Going away to college was “like a breath of fresh air.” He reported college teachers as supports in his life. While being away at college, Justin learned to be his own support through challenges of money management, time management, and relationships, as mentioned previously.

Matthew described his parents as support people and reported that he has found that he needs them to help him with day to day living. He also finds support within himself. He and his family feel that they will need to look for an assistant to help him as they get older.

**Hope and Self-Reliance: Where They Are Now**

The last question was, “Tell me anything else that you would like to include in this interview and share any documents that you would like to share.” Participants reflected on hardships and what they did to overcome those difficulties. Some spoke of the future and the steps they are taking to get there. Others addressed control over their lives and hope for others who have ASD.

Living in a supervised group home made it possible for Allison to work in a volunteer position, such as a food shelf. She assists others in filling boxes with items for the homeless and for families who need assistance in providing for their children. She describes her work as, “Yeah, because I love, I love helping people that are like that, and
people who are really needy.” She isn’t sure if this living arrangement is a transition to something else, but talks about having a permanent relationship with a man in the future. Her hope is in her transition that she has made to the current assisted living where she has learned to be more independent. She studies other languages and is learning phrases of greetings. Other hobbies that she enjoys include reading and skateboarding, which can be done at her home.

Allison expresses her creativity in the writing of poetry in which she describes memories and thoughts of her experiences. In the day program she attends, she is able to work a few hours a week in a store where she stocks shelves. She reported that she is paid for her work, but did not give further information regarding money.

In her opportunity to share anything else that she would like to share, Allison spoke to others who have ASD. She reminded people with autism to “Be who you are”. Her advice included, “Remember that you, that you to have to, don’t be somebody you’re not, Just because you have a diagnosis of autism doesn’t mean, doesn’t mean you’re stupid or anything like that.”

Christopher has had hobbies of working out, martial arts, hockey, and helping a state representative run his media campaign. In recent years he has directed his attention to his college program where he studies photography. He also works in the field as a self-employed photographer and hopes to do this work professionally in the future for a company such as National Geographic. Some of his work has won awards when displayed in gallery shows. In one competition he was the only photo student to merit in the professional photo competition. Christopher has published some articles and poems while writing as an editor for a newspaper.
At this time Christopher is planning to write a book which will utilize his creativity in writing through science fiction and technology. He shared his perspective on control as,

After high school, I realize I control everything in my life, my emotions, everything I see, the relationships I have. And what really, like if I want something I can get it. It’s just a matter of realizing that. The only thing I can’t control is um, like different relationships with certain people. It’s all about confidence I think and how you carry yourself too.

He discovered that the more he learned about the financial allocations of special education funds regarding the cap on college assistance when one is receiving disability benefits, the more he wanted to change what was happening. He is currently in a training program for policymaking through a governor’s counsel to learn how to advocate and change laws.

He expresses hope and a sense of what he has overcome in the poem below. He described his wish for society to not see negatives of having autism, but to see the positives in being able to see things differently and accomplish things that other people cannot.

For all those sitting in society that are forgotten
For all those society betrayed and branded rotten
    For all those who sit in a room and get wasted
    For all those society paint as tasteless
    For all those looked down upon wherever they go
Those who are always good but different though
    Those who break the status quo every day
You are my people and we are the same
They branded me worthless my entire life
Segregated me into a separate classroom for most of my life.
Robbed me of an equal education because I’m not the same,
    A little different in the brain.
But coming from a society that drops bombs, murders the innocent
And then blames Islam
Tells us that they are the ones who are righteous
Even though they kill first before considering logic
They control us and want us to all be the same
If you’re different they will tell us you’re not okay
Brand you as retarded and push you to the side
Then wonder why you never accomplish anything in your life
They throw drugs at you at a ridiculous numbers
To make a profit, destroying your mind in the process
And if you dare to speak up they tell you you’re crazy and to shut up
But they can’t kill your spirit, humanity, passion
Hope is what I live on and it’s a dangerous weapon
Because I was never taught to be the same
I think different every damn day
Look at how wrong and messed up society is
And then I realize it truly is not me who’s sick
So I challenge and break the stereotype every day
My heart bleeds for the Middle East and disabled in many ways
I cheer up when I turn on the TV and watch a slaughter
Or you think a bumper sticker that supports the troops makes you a hero
You never think, you are mindless robot, a zero
Free thought is freedom
You are not a robot
If you are angry as much as I am then come with me
Let’s work together to set society free
Enough of waiting for others to make a difference
That logic is a poor excuse for not making a difference
If you embrace the thought of fighting for peace and freedom
Then you truly will make a big difference
(personal communication, November 30, 2012)

Kayla relied on her faith and expressed the following:

I was like crying and driving and praying all at the same time and uh, I
was just saying God I don’t, I can’t do this anymore. I don’t, I don’t want
to do this. I don’t want to put myself in this situation again. I don’t want to
make this decisions, I don’t want to make these mistakes again. You have
this. You can take this from me. I don’t want to, clearly I’m not capable,
and uh, I like, I wanted to cut (referring to when she used to cut herself),
because I was hurting (from a recent relationship breakup), I would use it to control. I would use it as a way to punish myself and I would use it as a distraction from the mental pain, because then I could just focus on the physical pain. I wanted to cut, but I said no, I’m not going to do it. I have been praying for these scars to go away, they’re just getting darker and darker and I’ve been putting these creams on it and nothing is working. Why would I do this? But, then within a few days, I noticed my scars were not there anymore. They were. They were gone. And uh, that is why my tattoo is a Jesus foot and Isaiah 53:5, which says, He was pierced for our transgressions, crushed for our sins; the punishment that brought us peace was upon him, and by his wounds we are healed. I want to work for you, I want to, so to be able to go where you want me to go I need be debt free so I need to pay off my debt. Um, if you want me to like to be, uh, able to have relationships like friendships with friends outside of the church, you need to make me more normal (laughter). That’s what I’ve done.

Kayla has continued self-taught programming to improve in the areas that were difficult for her. She watched television programs and sat with a mirror to practice facial expressions and eye contact. When someone talked with her about dancing lessons, she decided to try it. She has continued to try new things and does not worry about what others think as much as she did when she was younger. Kayla reported that becoming bilingual and speaking Spanish has improved her use of facial expression because the tone of voice and expressions are important
in the use of another language and as she learned how to use expression to speak Spanish, she realized that she could do the same when speaking English.

Before the diagnosis and self-work that Kayla implemented, communication prevented her from being successful in her job. Currently, Kayla is employed in a company that provides interpreters to other corporations. She also teaches karate and is interested in continuing to do mission work. She has worked on establishing friendships in different areas of her life. When speaking of control over her life, she spoke of God’s control and her free will.

The support of a social worker provided strength for Arwell to get through the roadblocks while still in his teens. He experienced behavior issues in the high school and was asked to leave. At that time he moved to a smaller school district, which he described as more supportive. He described counselors who took him places and had him watch people and learn how to read signals, gestures and communication. He completed high school, job training and became a welder. Currently, Arwell has hope and self-reliance in finding another job, getting his license and welcoming his new child. Arwell described his hobbies of gun and knife collections, fishing, and enjoyment from his work in welding.

At the time of a planning meeting in high school Arwell was told the following: They told me I couldn’t get my license, could never hold a relationship, couldn’t hold a job or couldn’t have kids. The only thing that’s true about what they told me so far is I got my permit, not my license and I’m working on getting my license. Other than that I’ve proved them wrong on all of them. I’ve been with my fiancé for five years now. We have one kid together and another one on the
way, everybody says I’m doing fine. He has found support in his fiancé, his mother, and himself.

William is a college graduate who is working fulltime and is looking at other career options in the area of law enforcement. He notes that in reality it is difficult for people without ASD to find employment in this field through this period of budget cuts. Enjoying his current job is a plus and he continues to increase his skills in areas he needs to improve. Hobbies include getting together with friends to work out, play video games and go to movies. He expressed the importance of keeping physically fit:

I like the challenge of being able to push myself as hard as I can while at the same time trying to be as safe as I can. To sum up William’s hope for the future: I definitely feel like I’m very competent now you know with my training, education and experience. His self-reliance is demonstrated with: I know I can get good at anything I put my mind and efforts towards. I know what to expect and that’s a good thing.

Karen, who is hoping for acceptance into a Tennessee transition training program, looks forward to learning how to be more independent through skill training in transportation, cooking lessons, and other self-care classes. Her hope is that this transition program will be what it claims to be and she will learn the skills listed above. At this time she does not feel in control of many decisions, but has hope. Karen shared her talent of art when asked if she would like to share anything else during the interview, she talked about her future. She loves to draw and would like to be a cartoonist or game designer, perhaps getting additional education in the art field after attending the skill training program. Her precision in art was depicted in drawings which told stories of make
believe. Sharing the numerous drawings and describing them revealed an extremely advanced gift of art.

Caden, who lives in an semi-assisted living center, cooks for himself, does his laundry, cleans his apartment, and makes decisions for himself when home alone. When asked about control he said, “My mom controls most things. She buys stuff for me, tells me the rules, and schedules stuff for me.” He revealed components of his day program as “helps me to prepare, helps me prepare for a job skills for a job. I go on the computer, write.” Caden shared his hobby of writing stories that he has written at home and sometimes in the training program. His writing, like Allison’s and Christopher’s, demonstrates strong ability to develop stories that reflect a world of strength in creativity. In his goal for the current program he attends, he expressed a desire to have “good skills for a job.”

Carl has hopes of continuing his education and becoming an architect or historian after further training in a preparation program. Due to the special education program in high school, he has not had the required classes for admission into the college programs for which he is interested in applying. He plans to take the requirements in a junior college. He feels that control over his life belongs to his parents at this time, but he is gaining more control as he learns to cook and become more independent in self-care. He contributes to the household by caring for animals on their farm. He continues his art classes and enjoys drawing detailed pictures of cathedrals and trains. Some of his art work reflects architecture he saw while in Germany, which he has researched and transformed into his own drawings.
Uri is attending a vocational program and works three jobs. He works in a restaurant, helps find work for a construction company and works security at events in a stadium. He has his driver’s license and owns a car. He hopes to get different job in the future. Uri continues to focus on working for his second degree black belt and the long term relationship with his partner.

After recently getting a Ph.D. and living away in another state, Justin is searching for a job and planning for the future. Getting physically fit has been important so exercising with weights, walking and using an exercise bike are hobbies. He currently lives at home with his family, but has experience, as discussed earlier, living on his own at college in an apartment and student housing.

Hopefulness is communicated by Larry in his belief that all people are different and need to work together.

Um well if there was anything to say I guess that just because somebody is, just if somebody has like autism, or they can’t move their legs, or they can’t really do this one thing, that doesn’t mean they’re useless. I mean lots of people everywhere we’re all different people. It’s that really, so basically we’re all just people here and we all have to work together and nobody’s really useless and once people with autism are given a change people can really get . . . people can really be amazed.

When given an opportunity to share, Larry disclosed his participation in Special Olympics. He has won multiple medals in the three sports of floor hockey, swimming and track. Being involved in Special Olympics was expressed with pride and hopefulness. He
hopes to add a fourth, bocce ball, to his interests. Larry brought out all of his medals to show during the interview.

Neither Bobby nor Zayden discussed the future, but both of them proclaimed that they had control over some choices and other people at the assisted living residence shared their control in decision making. They spoke of being able to do things for themselves and being able to choose activities in the day group. Their self-reliance was described as independence.

Sherry revealed that she hopes to work in her church after she completed administrative assistant training. She described that she is proud to be different and works hard at trying to cope. Her hope has been her faith. “Faith has helped me cope with Asperger’s Syndrome.” Sherry spoke at length on her control over her physical shape, her mental thoughts, disappointments and frustrations. Her self-reliance on the choices she made included work on learning how to read non-verbal communication, which she mentioned numerous times during the interview. She also described self-reliance in this way. “I may not be able to control a meltdown, but I can control how I cope with them.”

Summary

The results presented above clearly proclaimed the joys and struggles of living a life with Autism Spectrum Disorder. All fifteen participants had commonalities and differences which included varying levels of issues of challenges in communication, relationships, struggles with emotions, and the challenge of not being prepared for the future. Two themes of support emerged to include support from family and others, along with hope and self-reliance. Thoughts of different types of support, hope and self-reliance were shared with voiced thoughts of control and who made decisions in their
lives as a component of the support or self-reliance. A more detailed summary and discussion of the findings are presented in the next chapter.
CHAPTER FIVE: DISCUSSION

Summary

This study examined the perspective of life choices after secondary education through the eyes of young adults with Autism Spectrum Disorder. There were three questions to be answered through this research in an effort to describe the experiences of an individual with ASD for the purpose of improving transition programming.

(a) How do young adults with ASD describe their experiences after high school?
(b) What, if any, challenges do participants describe as being part of their experience after high school?
(c) What, if any, supports do participants identify as being part of their experience after high school?

A review of the methodology was disclosed in Chapter Three. Participants were interviewed in their homes or in a library conference room. Two of the individuals chose to have a parent in the room for a part of the interview. All interviews were audio and video taped. None of the participants used augmentative communication. Each participant used verbal language in response to the questions.

The purpose of this phenomenological study was to describe and understand the perspective of life choices after secondary education through the eyes of young adults with ASD. The focus was on their needs and supports through transitions related to school, work, relationships, living placement and hobbies. In this research, the phenomenon of the perspective of those with ASD is defined as “the voices of individuals with ASD.”
Discussion

Hearing the voices of the individuals with ASD presented an opportunity for those affected with the disorder to divulge descriptions of their actual experiences. The transcendental phenomenology was applicable, as it allowed “pure subjectivity” of the participants. Since the majority of former research has communicated how to meet the needs of younger children with ASD, as reported by Camarena and Sarigiani (2009) and Hendricks (2010), it was important for this research to specifically address the young adult’s perspective of beginning a postsecondary education, job, living arrangement away from family and the seeking of friendships or activities with needs or supports in mind.

As found by Browning et al. (2009), former studies revealed “little focus on obtaining the views of individuals with ASD themselves” (p.37). Investigating this gap led to a divulgence of recollections of memories from early childhood up through the present, which contributed to answering the core question that remained “viable and alive throughout the investigation” (Moustakas, 1994, p 105). The core question of “How do young adults with ASD describe their experiences after high school?” guided this research through a process of discovering how young adults with ASD describe their experiences after high school. In the opening ice-breaker question, participants shared their emotions through depictions of their differences which interfered with their lives by telling about a day in the life of having ASD.

The method of phenomenological research was chosen to describe what the “participants have in common as they experience the phenomenon” of life choices as one who has ASD (Creswell, 2007, p. 58). A diagnosis of a particular type of ASD, namely pervasive developmental disorder, autism disorder or Asperger’s Disorder did not appear
to be relative because all participants, regardless of the label used for their particular diagnosis, depicted similarities in their lives. For the most part, participants concluded that all diagnoses fell under “autism” or “ASD” as chosen for this research.

As each participant addressed his/her experiences of growing up and making the transition out of high school and into the next phase, support, or a lack of, was addressed through prompts. This study was unique in that it sought to hear their voices, rather than the opinions of teachers or parents. Examples of struggles due to being affected by social impairment, communication limitations, and often cognitive challenges, were rendered in these voices. The findings of this research confirmed, as formerly detailed by Hendricks and Wehman (2009), that this population struggles in relationships, living arrangements, further education, and work. Of 15 participants, four female, and 11 male, all shared commonalities of issues in communication and relationships. Many of the participants shared the afflictions of depression or struggles with emotions and feeling unprepared for the future at some time in their experiences. Furthermore, there is a need to understand how they feel about autism affecting their lives (Hendricks & Wehman, 2009).

In light of former research (Hewitt, 2011) individuals who appear to be higher functioning require different services than those who are more severely affected. This research finding further correlates with the former study in that support and structure help provide the necessary assistance for excellent outcomes (Hewitt, 2011, p. 273). Several of the participants in the study received early childhood special education services, which possibly contributed to the desire to pursue higher education, as contemplated by Neville and White (2011). When compared to those who were diagnosed at later onset, some of these students had learned skills that others needed to begin learning in adulthood.
Several participants received less service or no services in transition planning. It is a challenge for schools to understand how students who are achieving high grades and high test scores may need services, which has created deep issues for students with ASD.

**Interpretation of the Findings**

**Theoretical Implications**

Social cognitive theory (Bandura, 1989) is formed from the belief that “human expectations, beliefs, emotional bents and cognitive competencies are developed and modified by social influences that convey information and activate emotional reactions through modeling, instruction and social persuasion” (p. 3). The participants in this study and their life choices were considered through the framework of this theory while examining how they are the agents of change and how they can influence the quality of their own life events (Bandura, 1989). This study examined how the individual with ASD perceived the control and the challenges associated with decision making. The interpretive community of the disability theory also framed this study (Creswell, 2007). In the worldview of social constructivism, this theory was appropriate for this research due to the view of the ASD individual as being one with different needs (Creswell, 2007). Currently researchers focus on disability as a human difference (Creswell, 2007), but not a defect. ASD was not viewed as a defect, but considered as a human difference.

Amazingly articulate young men and women who felt that society had given up on them focused on their disability as the “dimension of human difference” (Creswell, 2007, p.30). Disability theory views disability as social construction (Jones, 1996) which argues inclusive thinking through a commitment to diversity and the elimination of oppression. Consideration of a disability in this theory frames the thoughts of
Christopher and others who felt that they were not treated as equals. As voiced by Larry, People with ASD are not useless. “Listening to people with autism,” in Christopher’s words, is the prime way of helping them. As Christopher voiced, “Like I never would have been interested in poetry unless I heard this guy speak out that inspired me to do poetry.” Furthermore, he believed that creating programs to help them realize their potential and to spark the inspiration they are capable of would instill motivation for success.

The participants in this research spoke repeatedly about equality and wanting to be respected as people who could give to society in unique ways, not as people with a disability, but as those who could think differently. Ontological assumption allowed the researcher to consider the differences in those thoughts, (Creswell, 2007; Moustakas, 1994). Former research supports the belief that people with ASD want to be considered knowledgeable and an expert in what could make a difference in the lives of others with ASD (Hulbrutt & Chalmers, 2002, p. 107).

Hearing the voices of those affected by ASD provided an invaluable source of information for building programs for success. Memories of participants who were non-verbal as young children and diagnosed with a disorder of unknown affects in communication and interaction proved that people with ASD are most likely cognizant of what is happening to them and will later tell others about the experience. Vivid thoughts of experiences in special education created periods in the lives where students did not feel they had been given a chance to progress to their best potential and were capable of much more advanced study if they had been given the best support.
Relationship of the Findings to Prior Research

In the scheme of the reoccurring themes detailed earlier through data analysis, the findings of this study revealed challenges as communication issues, relationship difficulties, and not being prepared for life after the transition from high school. Information obtained from the participants dealt specifically with their individual life experiences.

In the first research question to be answered, “How do young adults with ASD describe their experiences after high school?” participants moved back and forth between their lives as children growing up and adulthood. This main research question, designed to elicit descriptions of their actual experiences (Creswell, 2007) was to explore the perception of the young adult’s life experiences through his/her eyes in order to increase public awareness of the need to improve transition planning and programming.

The other two questions to be answered in this research were stated as: (2) What, if any, challenges do the participants describe as being part of their experiences after high school? (3) What, if any, supports do participants identify as being part of their experiences after high school? The last two questions to be answered in the research, also questions for the participants, intended to break down the issue of the experiences of a person with ASD into sub-topics to allow for responses to evolve and describe the phenomenon. The research question findings indicate correlation with prior research and deeper information from the voices of the individuals with ASD.

Communication-Relationship Issues

Challenges and support. The background given by participants provided textural perceptions of being taunted and bullied through their education, interactions, and work.
In prior research of perceptions of adults with autism (Hurlbutt & Chalmers, 2002) it was found that growing up was hard for others with ASD. As one participant in a former study (Hurlbutt & Chalmers, 2002, p. 104) articulated, “I was made fun of for eight years straight.” Trying to fit in was common and the three interviewees in the prior study struggled with the same issues as participants in this current research. Another participant in the same study (Hurlbutt & Chalmers, 2002, p. 104) struggled his whole life trying to interact appropriately during communication and interaction with others, but says “There are these social skills that foul me up!” His inability to read body language and social cues in the same way as neurotypicals has forced him to end a desire to be with women (Hurlbutt & Chalmers, 2002).

Reading body language as social cues, an integral part of effective communication, presented similar battles for most of the participants. Kayla and Sherry spoke at length about their quest to learn these facets of communication, as well as Christopher, who talked of social skills, “No one ever taught it to me but they just expected me to know it.” Learning skills on their own proved to be a journey full of difficulty and some despair. Christopher developed skills in his own ways, through trial and error in street car racing, martial arts, and meeting homeless people. As he voiced earlier, he had never been allowed to be in regular classes and expressed that being in special education kept him with special ed. kids that have problems getting along with other people. He questioned, “How do you ever expect them to develop social skills when they’re around people that have no social skills as it is?” Social interaction is best learned with typical peers and when given that opportunity, the individuals with ASD will demonstrate increased social interest (Schall & McDonough, 2010).
Kayla reported that her challenge in communication was remediated through prayer and self-taught skill education. She indicated that she is a different person now who can communicate better and who has a real facial expression and not a blank one. Spirituality, addressed as Kayla’s support, appears to be linked to her ego development and overall health, as discussed by Dubin and Graetz (2009). This appeared to be true for Sherry, as well, who reported how her faith helped her deal with spirituality.

Prior research supported the involvement in religion and spirituality for some participants. Several participants, such as Sherry, Uri, and Kayla, spoke briefly of being a Christian and how that affected their lives. This leads one to believe they received comfort from the connection. The connection was not discussed at length by others, except in the cases of Kayla and Sherry. Hurlbutt and Chalmers (2002) confirmed in their research of three participants that “the spiritual aspect of their lives and their connection to a church provided comfort and support.” Although individuals with ASD may have impaired cognition, religious learning may be addressed through a concrete format, reported Dubin and Graetz (2009, p. 37). “While their path to spiritual understanding may develop differently, their exploration of faith may promote their sense of connectedness with others and with the divine” (Dubin & Graetz, 2009, p. 36). Deely (2009) reported that the lack of coherence and executive problems in autism might present the inability to assign meaning and relevance to experiences in the environment in a way that would allow adaptive responses, thus problems preventing the understanding of religious concepts. The current research does not support that in its entirety due to the comfort found for several participants. Kayla, Sherry, Bobby, and Uri expressed their support as being found in a higher being.
While some individuals have been able to embrace college and work, the majority of those interviewed have been unable to transition to adult living with work and personal relationships, apart from family. Almost half of the research participants designated family relationships to be their main outlet for social interaction. Bobby, Allison, and Zayden lived in group homes with organized volunteer work and occasional social trips. Relationships were formed within the living arrangement, but outside relationships were with family only. Karen, Matthew, Larry, Marcus, and Carl, regardless of high school friendships, shared that they no longer have outside activities with peers, but they do participate in social outings with their families.

Relationship with predominantly family members and a lack of friendships correlated with prior research of Saldana et al. (2009) and Neville & White (2011). Although most individuals with ASD desire friendships, they have not received training for developing social communication and relationships, as reiterated earlier by Christopher. The interviews revealed that many of the participants were thankful for the support from their families although they were not sure they were understood or prepared for their future by them.

One participant graduated from college and is working in a field related to his desired job. Other college graduates have not been able to remain employed due to various issues, either related to ASD or due to difficulty in finding a job for other reasons. Kayla, Uri and Justin discussed issues regarding communication and behavior in their employment. In typical communication, people are endowed “with information-processing capacities for extracting linguistic rules and using them to encode and convey information” (Bandura, 1989, p. 17). As confirmed by the participant, with ASD,
communication is challenged by the difficulties with semantics and pragmatics (VanBergeijk et al., 2008). Schall (2010) found that positive behavior supports at the work place reduced the problem behaviors and helped teach new behaviors. The semantics and pragmatic issues were defined repeatedly by the participants in this investigation. Kayla, as described earlier in this study, had an opportunity for a work coach to assess her situation, but her employer refused to allow the assistance.

The current employment (five of 15) addressed by the participants in this research is higher than the former research mentioned below. Although two others had college experience, they did not have jobs at the time of this writing. Cedurland et al. (2008), reported that only seven of the 70 men in the Asperger group, who are often known as high functioning, held ordinary jobs (p.79). Hurlbutt and Chalmers (2002) found that among the three participants in their qualitative study, all wanted to be employed and were educated to do so with college degrees. Two of the three held jobs and the other worked in a volunteer position (pp. 104-105). In the current research several participants, one with a Ph.D., desired work and others did volunteer work.

**Not Being Prepared for Life after High School/Depression**

**Challenges and support.** Dumbing down education and not receiving the chances at education they deserved was a common topic amongst the participants. Christopher’s thought that current special education was not made to help people succeed. He reported that, “Transitions are designed to make someone live on the system for the rest of their life,” when asked to talk about his transition from high school. He went on to speak of the disengagement of the educational society from the needs of students by saying, “So imagine what will happen when you start tapping into potentials
of people with autism. I think it’s crucial for the survival of our humanity and the betterment of society to make that happen.” This young man described that his mental growth had been stunted by the belief that he was dumb, as he was told repeatedly by the actions taken in his educational planning. As reported by Geller and Greenberg, (2010) individuals with ASD may exhibit great difficulties, but can also have advanced intellect and be hard-working. Hetherington et al. (2010) found that students with ASD felt that assumptions had been made about them in transition planning. This appears to be the experience of Christopher and others in this research.

From the results of this research, it has become apparent that students did not feel they were prepared for independence in their future. Was the intellect that these participants possessed realized? Christopher, Kayla, Arwell, Larry, Carl, William, Caden, Sherry, Uri, Justin, Bobby, Allison, Zayden, Karen, and Matthew were possibly examples of inadequate educational programming. Although cognitive functioning was at varying levels, it seemed that it was assumed they would not be successful in the same way as those without a diagnosis. The ineptness in social skills and communication described by Christopher, Kayla, and the others most likely would have been improved by social skills training along with communication training. Because of the strengths these individuals displayed, their issues may have been interpreted to be willful acts or character flaws instead of reflections of a disorder such as ASD (Geller & Greenberg, 2010).

According to Geller and Greenberg (2010), “Society sees an individual who appears to be intellectually able enough to accomplish much, but is socially immature for his or her years and frequently has some unusual and /or characteristics that others may
not understand,” (p.94). As in the cases of those who were not diagnosed through their early school years or even in high school, such as Kayla, Sherry, or Matthew, the problems existed, but they were able to make it through the hoops of completing high school. However, they experienced horrific conditions as they articulated through their interviews.

An example of an undiagnosed person with ASD, Matthew completed high school, but suffered from anxiety type problems. He didn’t want to use the recommended medication because he didn’t like how it made him feel. Neither medical professionals, nor those involved in Matthew’s educational planning shared any thoughts of another diagnosis of Matthew’s problems, except for possible obsessive compulsive disorder. Although this is a common component found in ASD, Matthew was not diagnosed until his late 20s.

Educators speak of qualifying for special education when exhibiting delays which impact educational development. Therefore, when a child is evaluated, delays in social emotional and adaptive development may be overlooked. Unfortunately, “some individuals with ASD experience periods of regression in the areas of behavioral challenges and insistence of sameness” as noted by Schall & McDonough (2010, p.82). Matthew, who was not diagnosed in high school, may be an example of this regression as demands of adulthood, along with college, were entirely different from anything he had experienced before. Apparently he was a student who was succeeding academically and social issues, including social communication and interaction in relationships, were not investigated by the educational team. Social ability issues would not be seen as an
impediment unless they impacted academic success and would not qualify an individual for special education, as reported by Hewitt (2011).

Schall and McDonough (2010) noted that social communication impairment continues into adulthood. This appears to have been a factor in the lives of most of the participants in this research and this communication component has continued to affect all areas of their experiences, regardless of the belief that cognitively normal students do not fit into the realm of special education. According to Hewitt (2011), social thinking requires high order complex information processing. For students with ASD making transitions into college, this processing is a challenge. As participants described their transitions, some were exciting and frightening, as previously found by Browning et al. (2009).

The question remains, “Is the student with higher functioning ASD cognitively normal?” VanBergeijk et al. (2008) reported that “typically students with AS (Asperger’s Syndrome) have a deficit in their nonverbal skills,” (p.1360). This is shown in their IQ scores on the performance portions of tests when compared to the scores on the verbal portions (VanBergeijk et al., 2008). Executive functioning deficits, although typically present, may not be considered in high school students with ASD. In order to decrease the possibility that students may not be able to deal with independent tasks such as laundry, managing schedules, or interacting in the community, attention needs to be given to generalization of the skills in real world practice (Hewitt, 2011).

Getting support during the times of transitions from high school to college, or job, or separate living arrangement was left to the individual and their parents in most cases described in this research of the voices of individuals with ASD. Some parents, as
expressed by Hewitt (2011) chose to help their child by getting counseling through the school or in private therapy. Others received no support from their high school or college. Hewitt (2011) stated that more expertise is needed in transition services for higher functioning individuals with ASD. Furthermore, “if services are not meeting the need, families may need to advocate for different or better transition services” (Hewitt, 2011, p. 275). Parents and students often do not know how to advocate for better transition services. This was indicated in the cases of Sherry and Carl.

Research has concluded that more help is available for students with ASD as they transition into postsecondary education (PSE) options. As sited by Griffin et al. (2010), Hart’s work found that “PSE programs offer these students an alternative to traditional college admission and participation,” (p.339). Students learn academics, focus on social skills, and learn how to be more independent. Unfortunately, the programs are expensive and many families are unable to bear the expense, as noted by participants in the voices of individuals with ASD. Although programs such as this were utilized for a few of the participants, most of the others did not have the opportunity, or the funds, for this type of transitional curriculum. Carl spoke of the summer program, but the length of the program prevented him from being able to cover the curriculum covered in the longer and more expensive program. Programs such as these can cost $40,000 a year.

Most of the participants in the current research faced, either clinically diagnosed depression, or struggles with emotions at different points in their transitions through their experiences. Anxiety, fears, sensory integration disorder, and thoughts of suicide or self-injurious behavior were among the trials of living with ASD. Disappointment accompanied these factors for some individuals who did not feel prepared for their future
after completing high school. Hillier et al. (2011) reported research is limited on depression in those with ASD and symptoms of such may be masked by known characteristics as social withdrawal, neutral facial expression, and self-injurious behaviors. This study supported the finding of depression and thoughts of suicide to be a great risk in people with ASD (Hillier et al., 2011).

A feeling of not being prepared for their future was accompanied by feelings of other people controlling their lives and their decisions in many participants at the stage of transition from high school. Life choices were not their own due to IEP decisions and special education team decisions made with parents without consulting the individuals with ASD. Christopher described how he had been forced to take classes designed for special education students. Justin, with the support of his parents, fought against the placement in academic special education classes. As a gifted student, he may have benefited from social communication/relationship support. Sherry, an obviously gifted artist, described her inability to take a bus, manage money, or take care of herself due to not having had a program to teach self-reliance as a transition out of high school. These are issues in the area of rehabilitation services that could lead to improvement in employment and community living, as reported by Schall and McDonough (2010).

A consideration in this research was the possibility of differences in the lives of individuals with ASD living in Minnesota and Tennessee, when compared. The main difference appeared to be that more individuals with ASD in Minnesota attended transition programs than described in Tennessee. This may relate to availability of programming, as experienced by Karen, or perhaps, more individuals chose the programming in Minnesota.
Summary

The answers that this research sought to discover were provided by the participants through different views and similar or shared thoughts. Dependability was established by presenting accurate descriptions of the findings, and by reporting the truthfulness of the participants’ experiences. Questions 1 and 2 sought to gain information regarding their perspectives on information related to challenges and supports through life transitions after high school. Question 3 was to learn the depth of how the participant with ASD perceived himself as the controller or agent of change in his life (Bandura, 1989, p. 52).

This investigation correlates with prior research in that individuals with ASD are affected by social impairment, communication limitations, and often cognitive challenges (Hendricks & Wehman, 2009; Hendricks, 2010). These often present struggles in relationships, living arrangements, further education, and work (Hendricks & Wehman, 2009; Hendricks, 2010). Participants in this investigation divulged their experiences in all of these areas through defined challenges and supports.

Through multiple challenges, participants with ASD in this research have continued to grow in strength and self-reliance. As previously demonstrated by decisions in life choices, many participants in this study have become their own agents of change influencing the quality of their own life events (Bandura, 1989). This study examined how the individual with ASD perceived his/her control and the challenges associated with decision making. It has been apparent that most have contributed to their own outcomes within a system of interacting influences (Bandura, 1989). Almost all of the participants felt that control of their adult lives was a large percentage of their own, although some
relied on parent assistance and others are still working on gaining more control and independence. Decision making was affected by plans made for them while in high school and those decisions, which did not include their input, contributed to post high school problems.

**Limitations**

In order to describe their experiences of challenges or gains, a communication support, such as a device that would allow the individual to type words or speak words would have been accepted, but none of the participants used a device. All were independent in the use of verbalizations for communication, but a few of the participants had limited communication. This was considered a limitation, in that responses were communicated in single words or short phrases. It is possible that the participant was unable to say all that he/she thought about the topic. A second limitation was that the young adult had a choice to be accompanied by a parent for emotional support, which may have caused the participant to feel inhibited from self-expression. Two of the participants chose to have a parent present for parts of the interviews, but the parent went in and out of the room. In some cases, the participant asked the parent to leave or accepted the offer when the parent offered to leave. A third limitation was noted in that the Autism Spectrum includes a diverse population, but the small sample size, along with the locations of the sample, limited the possible perspectives.

Participants were from only two states due to the researcher’s professional connections in the chosen locations in the Southern U.S. and the Northwestern U.S. Although the sample size was small, the strength was apparent in the descriptive data, which was obtained through the phenomenological intensive interview process. Every
attempt was made to include a mix of socioeconomic backgrounds, race and gender. The representative sample included a mixture of race and gender. Socioeconomic backgrounds were not revealed by participants, but it is the writer’s opinion that a mixture was included. Despite the limitations, it is hoped that this research will be a contributing endeavor to explore this journey and offer the voices of those who share the experience of living with autism.

Young adults in this study were between the ages of 19 and 33. Several of the participants were under court appointed guardianship of their parents. In these cases, the legal guardian also provided permission for the research. In the best interests of the participants, the consent form was reviewed by the in-state doctoral committee to clarify the information.

**Implications**

In light of what participants have said, listening to the voices of those affected by ASD is at the heart of helping to solve the problem stated in this research. As educational professionals, we must realize that people with ASD have unique potential and tapping into those traits is a gift for us all. To improve the transitions of those with ASD as they leave high school and enter college, we must:

- Examine programming through elementary, middle and high school to assure continued communication and interaction training. Prior research and this research have shown us that students may be high functioning and suffer from inability to communicate and interact in the same ways as neurotypicals. It is possible for a child to show no delays in typical speech and language testing, but to have clear communication and interaction issues.
• Provide support and adaptations for people with ASD to take part in classes of their choice. This research revealed that in most cases, special education programs did not allow for those with an IEP to take part in what were considered to be classes for the college bound student. Students in this research were at a disadvantage when entering college and were forced to take additional preparation classes.

• Include research based programming such as video modeling, peer-mediated approaches, social stories, comic strip conversations and self-management strategies to teach communication and social skills. Implement positive behavior supports at school and in the work place.

• Develop transition programs beginning in middle school and high school to allow for apprenticeship positions in vocations and professional situations.

• Include the student as the agent of change and help him/her to become more active in their transition planning

**Recommendations for Future Research**

• A qualitative study to examine the role of spirituality in adults with ASD would be useful in further examination of the support or lack of support that is found in religious or spiritual involvement

• This research did not examine the quality of the educational programs of the participants due to the large age range. Examining the programs and the level of progress or student success may be helpful in distinguishing which programs provide particular types of assistance and how students in each faired in comparison.
• Quantitative research to examine students with ASD who receive communication/interaction support through high school as high functioning students who do not qualify for such supports according to state department of education guidelines compared to similar students who did not get the supports or qualify for the services would contribute to prior research regarding students who suffered from communication difficulties, but did not qualify for help.

• Qualitative research involving the interviews of younger students with ASD and their parents to investigate their experiences with church and the acceptance or adaptability of the church to include the young person with ASD may prove helpful in determining missing links for religious groups.

• Research to compare students who serve as apprentices in jobs or students with job coaches to ASD students who have not had these services and attempt work after graduation may contribute to school preparation programs.

• A study involving parents and students who volunteer to be IEP mentors so that other parents and students are better prepared to ask for what they need in transition IEP meetings may provide further education for school teams, parents, and students.

**Conclusion**

As the researcher, I have concluded that more is to be learned about the perspectives of young adults with ASD in regards to their life choices after secondary education and their experiences in transitions. Transition to adulthood is a challenging period for young people in their quest for independence. The struggles for individuals with ASD may be more difficult in that these individuals will most likely need assistance.
I have only touched the surface of the potential of those who were interviewed. It is clear that thoughts expressed were his/her own and I was left in awe to have had the opportunity to hear the first hand descriptions of those experiences. As an educator, I felt embarrassed and humble at times. As I listened to those who were mistreated and left to learn nothing in special education classrooms, I prayed that I would have further opportunity to affect young educators in the future in hope of change. In my conclusion, I fall to God’s leadership with Numbers 20:2-13, making decisions under his direction and being proactive verses reactive. When faced with decisions which influence the future of young people with ASD, it will mean, as Maxwell (2007, p.181) said, “Get your cues from God and the mission He has given you. Ask yourself these questions:”

1. Am I a reactor or a creator when I lead?
2. Do I play defense or offense when I lead?
3. Am I people-pleaser or a God-pleaser when I lead?
4. Do I boss my calendar, or does someone else choose where I give my time?

As educators it is normally a requirement to be a part of a team who makes decisions regarding the future of young people with ASD. For me, I hope to remember from where my cues are coming. For those who receive guidance from this research, may transitions “start where the client is” (Geller & Greenberg, 2010, p. 96). According to Geller & Greenberg, 2010, this means to take time to carefully listen to the young person and develop an understanding of the person within a multisystemic context including cultural, familial, spiritual, psychosocial strengths, concurrent stressors, and other dimensions (p.96). Simply stated, listen to the voices.
REFERENCES


APPENDICIES

APPENDIX A: Flyer for Participants

PARTICIPANTS NEEDED

FOR AUTISM SPECTRUM
DISORDER
RESEARCH
ADULTS WITH ASD
MUST BE 18 YEARS OR OLDER
AND UNDER AGE 34

15-17 participants with Autism Spectrum Disorder are needed for research on the perspectives of life choices after completion of a high school program. The research requires two face-to-face interviews, which will be video-taped and audio taped and conducted within 7 days of each other.

Purpose of Research: To gain the perspectives of young adults with autism regarding their lives after high school in hope of improving future transition planning and programming for others.

If interested, please contact:
Susan Galler, Doctoral Candidate of Liberty University
865 384-2326 or email: Mountlake2002@aol.com
APPENDIX B: IRB Approval

November 14, 2012

Susan Lynn Galler
IRB Approval 1439.111412: Voices of Young Adults With Autism and Their Perspective on Life Choices After Secondary Education

Dear Susan,

We are pleased to inform you that your above study has been approved by the Liberty IRB. This approval is extended to you for one year. If data collection proceeds past one year, or if you make changes in the methodology as it pertains to human subjects, you must submit an appropriate update form to the IRB. The forms for these cases were attached to your approval email.

Thank you for your cooperation with the IRB and we wish you well with your research project.

Sincerely,

Fernando Garzon, Psy.D.
Professor, IRB Chair
Counseling

(434) 592-4054

Liberty University | Training Champions for Christ since 1971
APPENDIX C: Change in Protocol Form

Change in Protocol Form

**Instructions:** To submit a Change in Protocol request, complete each section of this form and email it and any accompanying materials (i.e. consent forms and instruments) to ich@liberty.edu. Please cc your faculty advisor/mentor when submitting this form. Please note that we can only accept our forms in Microsoft Word format.

In addition, please submit one signed copy of page 2 of the form. This item can be submitted by email as a scanned document to ich@liberty.edu) or by fax to 434-522-0506.

Please be sure to use the grey form fields to complete this document; do not change the format of the application. Please also be sure to provide as much detail as possible, as this will facilitate the review process.

<table>
<thead>
<tr>
<th>IRB Approval Number: 1439.111412</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project Title: <strong>Voices of Young Adults with Autism and Their Perspective on Life Choices After Secondary Education</strong></td>
</tr>
<tr>
<td>Principal Investigator (PI): <strong>Susan Lynn Galler</strong></td>
</tr>
<tr>
<td>Professional Title: <strong>Inclusion Specialist/Doctoral student at Liberty University</strong></td>
</tr>
<tr>
<td>School/Department: <strong>employed by Oak Ridge Schools</strong></td>
</tr>
<tr>
<td>Mailing Address: <strong>10042 Double Tree Rd. Knoxville, TN 37933</strong></td>
</tr>
<tr>
<td>Telephone: <strong>865 384-2326</strong></td>
</tr>
<tr>
<td>LU Email: <strong><a href="mailto:sgaller@liberty.edu">sgaller@liberty.edu</a></strong></td>
</tr>
<tr>
<td>Check all that apply: <strong>Faculty</strong>  <strong>Graduate Student</strong>  <strong>Undergraduate Student</strong>  <strong>Staff</strong></td>
</tr>
<tr>
<td>This research is for: <strong>Class Project</strong>  <strong>Master's Thesis</strong>  <strong>Doctoral Dissertation</strong>  <strong>Faculty Research</strong>  <strong>Other (describe):</strong></td>
</tr>
<tr>
<td>Faculty Advisor: <strong>Dr. Anita Fauber</strong></td>
</tr>
<tr>
<td>School/Department: <strong>Education</strong></td>
</tr>
<tr>
<td>Telephone: <strong>540 448-2901</strong></td>
</tr>
<tr>
<td>LU Email: <strong><a href="mailto:afauber@liberty.edu">afauber@liberty.edu</a></strong></td>
</tr>
</tbody>
</table>

**Anticipated start and completion dates for collecting and analyzing data:** Dec. 11-January 31, 2013

1. Please provide a detailed description of the changes you wish to implement.

I would like to change the age limit of participants to 33. My former participant age range was from 18-29.

2. Please describe why these changes are necessary.

People with autism are often still in school until age 21 and have not made transitions as quickly as typical peers. I wish to include those who have been later in making transitions.
why or why not.

No additional risks. It is an advantage for the participants with autism, as they often express a desire to help others with the disorder.

**When you submit this form, please submit any supporting documents (e.g., informed consent document, recruitment materials, debriefing documents, etc.) that will be amended as a result of this Change in Protocol.**

Principal Investigator (Printed)  Principal Investigator (Signature)  Date

FOR IRB USE ONLY:

CATEGORY:  ☐ EXEMPT  ☐ EXPEDITED  ☐ FULL
ACTION TAKEN:  ☐ APPROVED  ☐ DISAPPROVED
IRB Change in Protocol Approval: IRB Approval 1439.111412: Voices of Young Adults With Autism and Their Perspective on Life Choices After Secondary Education

IRB, IRB [IRB@liberty.edu]
Sent: Monday, January 07, 2013 1:35 PM
To: Galler, Susan
Cc: IRB, IRB; Gammon, Fernando; Fauber, Anita

Good Afternoon Susan,

This email is to inform you that your request to change the age limit of participants from 29 to 33 has been approved.

Thank you for complying with the IRB requirements for making changes to your approved study. Please do not hesitate to contact us with any questions.

We wish you well as you continue with your research.

Best,

G. Michele Baker, M.A.
Institutional Review Board Coordinator
The Graduate School

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APPENDIX E: Informed Consent for Participants

LIBERTY UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Voices of Young Adults with Autism and Their Perspectives on Life Choices After Secondary Education

Investigator/Researcher: Susan L. Galler, Ed.S. Phone: 865 384-2326
Chair of Dissertation: Dr. Anita Fauber Phone: 540 448-2901
Committee Member: Dr. Bonnie S. Arnone Phone: 561 722-4233
External Committee Member: Dr. Barbara Luskin Phone: 651-647-1083

Purpose:

You are being asked to participate in a research study that is being conducted by Susan L. Galler, Ed.S. as a part of the requirement for the ED.D in Teaching and Learning at Liberty University in Lynchburg, Virginia. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

Background Information:

The purpose of this study is to understand the perspective of young adults with autism in regards to their lives after finishing high school programs.

Research Procedures:

If you agree to be in this study, you will be asked to do the following:
You will be asked to complete a demographic questionnaire and participate in two face-to-face interviews. Before the first meeting you will receive an email with the consent form, which describes the research. You will receive a phone call from the listed external committee member, Dr. Barbara Luskin. She will repeat the research procedures from the consent form and ask if you understand the information. You will wait to sign this form until the researcher is there for the first interview.

The researcher will conduct both interviews in a private setting, preferably your home. The interviews will be video-taped and audio taped in order to provide an accurate transcription of the information that you report. Each interview will last one – two hours. In the second interview you will be given an opportunity to share any information that has not been discussed and a chance to share any documents, such as written work, drawings, or anything else that you feel is important about your life. At the end of the second interview all information will be reviewed to check for accuracy.

Initial______
A professional transcription secretary will transcribe the audio tapes. The researcher will analyze all information to look for themes and then the information will be written into the dissertation format.

Confidentiality:

Your information will receive a number code and your name will not be on any of the information except for your demographic page. The page with your name and address will be kept in a separate locked facility and not with the interview notes in order to further protect your anonymity. The tapes will also be kept in a locked cabinet. All information will be locked in the researcher’s files. The transcription secretary will not have access to your identity. The tapes and written notes will be destroyed at the end of the three year required period. The results of the study will be published in the researcher’s dissertation and possibly in other research publications. However, names or identifying information will not be included in any publications.

Risks and Benefits of being in the Study:

Potential risks related to participation in the study may include emotional discomfort as you answer the questions, but the risks will not be more than encountered in everyday life. You may choose to end an interview or withdraw from the study at any time. If you have further medical concerns due to stress, you may choose to drop out of the study and contact your personal physician. Liberty University will not provide any treatment for participants in this project.

You will need to set aside one-two hours for each interview. A potential benefit in your participation is the opportunity to help others understand what life is like for you after completing a high school program. It is a hope that this information will help other people to assist high schools and colleges with transition planning and programs for young adults with Autism Spectrum Disorders.

Voluntary Nature of the Study and Compensation:

Your participation in the study is voluntary and anonymous. You are free to withdraw at any time. Your decision to participate will not affect your relationship with Liberty University. There will be no payment or compensation for this research. At the end of the second interview a gift card will be given to you as a token of appreciation for your participation.

Questions:

If you have any questions about this research study you may ask the researcher or the committee members listed on page one.

Initial________
Informed Consent:

You will be given a copy of this signed and dated consent form for your records.

I have read and understood the above information. I consent to participate in the study.

I understand that my interview will be video-taped and audio-taped.

Initial________

Signature________________________________________Date__________________

Signature of parent or guardian (if needed)___________________________________

Signature of Investigator:_________________________________________________

IRB Approval Numbers: 1439.111412

IRB Expiration Date: 11/14/13 (one year from date of approval)
APPENDIX F: Demographic Information

Registration for research project: Liberty University

Researcher: Susan L. Galler

Name: Last_________________First_________________Middle________________

____________________________________________________________________

Address________________________________________________________________

____________________________________________________________________

Birthdate____________________

Diagnosis___________________

Education: Did you complete high school? Yes No

College: How many years? ____

Vocational School? ______

Please describe your major in high school, college or vocational school.

____________________________________________________________________

When did you move out of your parent’s home? (If not living at home) Where do you live?____________________________________________________________

Current job or work program:

____________________________________________________________________
APPENDIX G: Interview Protocol

Interview Protocol

Participant Code: _____________

Date of Interview: _____________

“I want to thank you for agreeing to participate in this study” (Pause, allow for response). The purpose of this study is to describe and understand the perspective of life choices after secondary education through the eyes of young adults with autism spectrum disorder, which will be referred to as ASD. The focus will be on needs and supports through transitions related to school, work, relationships, living placement and hobbies. Do you have any questions regarding the purpose of the paper?

“I would like to remind you that your participation in this study is completely voluntary and you may withdraw at any point without penalty. If you would like to take a break at any point during the interview process, please feel free to let me know. The interview will be audiotaped and video-taped to help ensure that I represent your information accurately.” (Pause)

“Before we begin with the interview questions, I would like to review the consent form. Would you like for me to read it aloud or would you like to read it on your own? I will be glad to explain any part that you would like clarification on.” I will ask the participant if he/she understands his/her rights and if he/she is willing to sign and participate in the study. I will thank them for their time if they say no. I will ask if he/she has any questions and I will answer them before we begin. I will then ask the participant to sign the pages if he/she wishes to participate. The participant will sign two copies of the forms, one for them to keep and one copy for the researcher.

“I will turn the recorder on” (Turn the recorder on). “If you are uncomfortable answering any of the questions, please feel free to not answer and I will move on the next question. Do you have any questions at this time?” (Pause) I will be asking two questions and since there is no right or wrong answers, you are free to speak freely and openly. Please feel free to elaborate as much as you feel like. (Pause)
Interview Questions

Interview 1
(a) Tell me about what it is like to have ASD? What is a typical day like for you? (ice-breaker) The two interview questions follow.
(b) Tell me about your experience of completing high school and the transition to what you are doing now. Prompts: Work, school, spiritual or religious involvement, living arrangements, hobbies, and relationships
(c) What are the challenges and supports that you have had in regards to those experiences?
At the end of the interview, a review will be conducted for verification of information that has been given.

Interview 2
(a) How much do you think you control what happens in your life? Prompts: Who or what else controls what happens in your life?
(b) Tell me anything else that you would like to include in this interview and share any documents that you would like to share (pictures, diary, or awards).
At the end of the interview, a review will be conducted for verification of information that has been given.

Upon completion of the interview I will thank the participant for his/her participation. If the time for the second interview was set during the initial phone call, I will ask if the second interview time is still acceptable or if he/she needs to change the time. I will conclude with “If you have any questions, please feel free to call me. Thank you again for your time”. The 20.00 gift card will be given at the end of the second interview.