

6-2014

The Transition to Adulthood: Experiences of Young Adults with Asperger Syndrome

Cassandra M. Nafziger

Follow this and additional works at: <https://scholarworks.lib.csusb.edu/etd>



Part of the [Social Work Commons](#)

Recommended Citation

Nafziger, Cassandra M., "The Transition to Adulthood: Experiences of Young Adults with Asperger Syndrome" (2014). *Electronic Theses, Projects, and Dissertations*. 64.

<https://scholarworks.lib.csusb.edu/etd/64>

This Thesis is brought to you for free and open access by the Office of Graduate Studies at CSUSB ScholarWorks. It has been accepted for inclusion in Electronic Theses, Projects, and Dissertations by an authorized administrator of CSUSB ScholarWorks. For more information, please contact scholarworks@csusb.edu.

THE TRANSITION TO ADULTHOOD: EXPERIENCES
OF YOUNG ADULTS WITH ASPERGER SYNDROME

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Cassandra Marie Nafziger

June 2014

THE TRANSITION TO ADULTHOOD: EXPERIENCES
OF YOUNG ADULTS WITH ASPERGER SYNDROME

A Project
Presented to the
Faculty of
California State University,
San Bernardino

by
Cassandra Marie Nafziger

June 2014

Approved by:

Dr. Rosemary McCaslin,
Faculty Supervisor, School of Social Work

Dr. Rosemary McCaslin,
M.S.W. Research Coordinator

© 2014 Cassandra Marie Nafziger

ABSTRACT

This study sheds insight into the unique, daily struggles of individuals with Asperger Syndrome (AS) as they transition into adulthood. The majority of research available regarding individuals diagnosed with AS focuses on childhood experiences. What happens when these individuals age out of high school? What are their experiences with becoming independent, successful adults? This study elicited qualitative data concerned with individual experience from seven participants between the ages of eighteen and thirty years old. Data were collected through three face-to-face and four email interviews. Data were analyzed to identify specific challenges of adult life. All participants expressed challenges in social interaction, as well as successfully coping with stress in the areas of employment, education, and relationships. Results of this study offer a deeper understanding of the individual challenges individuals experience in young adult life.

ACKNOWLEDGMENTS

I would like to acknowledge Dr. Rosemary McCaslin for responding to all of my frantic, endless emails regarding this project. Thank you for your support, guidance, and especially your patience and encouragement. Thank you for gently pushing me toward the end of this project to find participants and gather data so I could walk at graduation with the best cohort anyone could ask for.

Special acknowledgement is due to Dr. Beth Jaworski, Director of Services to Student with Disabilities (SSD) at California State University, San Bernardino, for allowing me to reach out to CSUSB SSD students. Thank you for your interest and support in my research. Thank you for going above and beyond in providing me guidance and assistance in reaching out to students. Your help initiated the process of gathering data for this project.

Special acknowledgement goes to my husband Cory, family, friends, and colleagues who have supported and helped me through this difficult, exhausting, but highly rewarding MSW program. Thank you for your patience and understanding when I reverted to becoming a recluse the past two years of grad school!

I would not have completed this thesis project on-time, with all of my hair, without the help of my mother-in-law Adele, and my dear friend Angela. Thank you for helping me to organize my thoughts and edit my project.

Special acknowledgement is due to my best friend, Randi. Thank you for being there for me when everything seemed too overwhelming and for offering

me a place of solitude to regain my emotional and mental strength, and most importantly to focus on my assignments.

I am truly fortunate for everyone I have in my life. Words can only begin to express the debt of gratitude I owe.

DEDICATION

This project is dedicated first and foremost to my brother and the first best friend I have ever had. Jacob, you continue to amaze me in all of your endeavors. You are the most dedicated, head-strong person I know. You have been an inspiration to me and I can't wait to see where life leads you!

This project is also dedicated to individuals of all ages with Autism Spectrum Disorders. On behalf of those who shared their personal experiences for the cause of this project; life is a learning process and with time, it will get better.

TABLE OF CONTENTS

| | |
|---|-----|
| ABSTRACT | iii |
| ACKNOWLEDGMENTS | iv |
| LIST OF TABLES | x |
| CHAPTER ONE: INTRODUCTION | |
| Problem Statement | 1 |
| Purpose of the Study | 4 |
| Significance of the Project for Social Work | 6 |
| CHAPTER TWO: LITERATURE REVIEW | |
| Introduction | 8 |
| Characteristics of Asperger Syndrome | 8 |
| Employment and School | 9 |
| Relationships..... | 10 |
| Life Skills..... | 11 |
| Prevalence of Asperger Syndrome in Young Adults | 12 |
| Theories..... | 13 |
| Theories Guiding Conceptualization | 14 |
| Humanistic Perspective..... | 14 |
| Self-Efficacy Theory | 15 |
| Strengths-Based Approach | 15 |
| Summary | 16 |
| CHAPTER THREE: METHODS | |
| Introduction | 18 |
| Study Design | 18 |

| | |
|--------------------------------------|----|
| Limitations | 20 |
| Sampling..... | 21 |
| Data Collection and Instruments..... | 22 |
| Demographics..... | 22 |
| Individual Experiences | 22 |
| Procedures | 23 |
| Protection of Human Subjects | 24 |
| Data Analysis..... | 25 |
| Summary | 26 |
| CHAPTER FOUR: RESULTS | |
| Introduction | 27 |
| Presentation of the Findings | 27 |
| Demographics..... | 27 |
| State and County of Residence | 27 |
| Age and Ethnicity..... | 28 |
| School/College..... | 28 |
| Employment..... | 29 |
| Living Arrangements..... | 30 |
| Themes..... | 30 |
| Social Interactions..... | 31 |
| Employment..... | 31 |
| Education..... | 32 |
| Relationships | 33 |
| Stress and Coping Strategies..... | 34 |

| | |
|--|----|
| Stress | 34 |
| Coping Strategies | 36 |
| Suggested Improvements to Support Services | 38 |
| Meaningful Recommendations to Young Adults with Asperger Syndrome and Autism Spectrum Disorder..... | 39 |
| Summary | 40 |
| CHAPTER FIVE: DISCUSSION | |
| Introduction | 41 |
| Discussion | 41 |
| Limitations..... | 47 |
| Recommendations for Social Work Practice, Policy and Research | 48 |
| Conclusions | 50 |
| APPENDIX A: LETTER OF APPROVAL | 52 |
| APPENDIX B: DEMOGRAPHIC QUESTIONNAIRE | 54 |
| APPENDIX C: INTERVIEW QUESTIONS | 56 |
| APPENDIX D: FLYER | 58 |
| APPENDIX E: INFORMED CONSENT | 60 |
| APPENDIX F: DEBRIEFING STATEMENT..... | 63 |
| REFERENCES | 65 |

LIST OF TABLES

| | |
|-----------------------------|----|
| Table 1. Demographics | 28 |
|-----------------------------|----|

CHAPTER ONE

INTRODUCTION

Young adults with Asperger Syndrome (AS) have unique needs, varying in severity on an individual basis as they age out of secondary school and learn to become independent, contributing members of society in their transition to adulthood. Further attention and research is necessary in the field of social work in order to develop appropriate and successful services and interventions for this population.

Problem Statement

There is an abundance of research available on early diagnosis of children with Asperger Syndrome (AS) and learning outcomes, parents of children with AS, education and training for professionals working with children who have AS, and so forth. Although much of this research is new and necessary, there seems to be a lack of research or interest in the lives and needs of adults with Asperger syndrome.

The American Psychiatric Association (2000) describes diagnostic criteria for Asperger syndrome (AS), a disorder on the Autism Spectrum, as qualitative social interaction impairments manifested as deficits in the use of nonverbal communication, difficulties or inability to form peer relationships appropriate to developmental level, a lack of seeking to share interests, hobbies, and enjoyment

with others, lack of social or emotional reciprocity, and restricted repetitive and stereotyped patterns of behaviors, interests, and activities (84). According to the DSM-IV TR (2000), such impairments and behaviors cause difficulties in social, occupational and other critical areas of functioning (84).

Many adults who have Asperger Syndrome or who have never been diagnosed but experience symptoms of AS have fallen under the radar because they appear to be capable and highly intelligent individuals in many settings and areas of life; however, in other areas of intelligence or ability they may have great difficulty functioning. According to the Asperger Association of New England (AANE),(2013), many adults with AS grew up before the diagnosis of Asperger Syndrome existed in the United States and they had to teach themselves ways to survive. Those who were successful in learning to survive have worked hard to build their lives and are fearful that at any moment, everything they have accomplished could come crumbling down (AANE, 2013, p.1).

As children they were given special support and assistance in school from school personnel, parents, and other caregivers. As they grow older, they may be provided less support and eventually as they complete high school and move on to college and the world of employment, many will experience substantial difficulties in learning to live independently and to form long-lasting, supportive relationships that are beneficial to their quality of life. Adults with AS who have successfully built a life for themselves have learned tricks to compensate for atypical neurological functioning may often be denied support services because

they appear average and do not fit the eligibility criteria because they are on the “higher-functioning” end of the Autism Spectrum (AANE, 2013, p. 1).

Research on the needs of young adults with AS and their individual experiences of the transition to adulthood has become more necessary in recent years for the field of social work. It is a growing population that has flown under the radar and is in much need of support services that are tailored to the varying, individual, specific needs of adults with Asperger Syndrome. There are many organizations that provide support services for children with Asperger Syndrome and their parents including support groups and education. This study intended to generate knowledge regarding support services available and accessed in local counties. This study also intended to provide useful insight into satisfaction with available support services as well as any frustrations or barriers to accessing support services as young adults with AS.

The number of individuals diagnosed with Asperger Syndrome is increasing as the world gains awareness of and are educated to the varying characteristics of the disorder. Children who were diagnosed in the 1990s after the DSM-IV was released are now transitioning into adulthood (AANE, 2013, p.1). It is only recent that we are becoming aware of the unique struggles and needs of young adults with Asperger Syndrome.

Purpose of the Study

Macleod (1999) reports individuals with Asperger Syndrome are most often highly intelligent with average to above average IQ and are well-aware of their disability. This population yearns for the same successes as other individuals in the areas of friendship, family, and a successful career but impairments associated with AS can create barriers to achieving such successes (Autism, 1999, p. 177). Deficits or impairments characterized by AS vary from individual to individual (Higgins, Koch, Boughfman, & Vierstra, 2008, p. 291). In other words, there is no specific set of characteristics that make AS easy to diagnose. In fact, the range of impairments varies so drastically that many individuals fall under the radar and may never be diagnosed until later in life if diagnosed at all.

Individuals who experience symptoms of Asperger Syndrome on a daily basis may or may not fit the diagnostic criteria of AS at the time of diagnostic assessment in therapy thus resulting in either a misdiagnosis or no diagnosis. Symptoms of AS in adults can be subtle. For example many young adults with AS symptoms have a sophisticated sense of humor, have families of their own, may have successful careers, and can carry on reciprocal conversations; however, they have shortcomings or are not as successful in other aspects of life (AANE, 2013, p.2).

The purpose of this study was to gain insight into the daily difficulties, struggles, and barriers that are unique to individuals with Asperger Syndrome as they learn to become independent on their transition to adulthood.

Many young adults with AS remain living at home with their family of origin for as long as their family can provide for them. If they cannot continue to live at home on completion of high school and do not have the necessary life skills to live independently they may choose to live in a type of assisted or transitional living facility. Portway and Johnson (2005) report a long-term risk of Asperger Syndrome in adulthood may result in “prolonged dependency upon parents,” or caregivers (p. 78). In addition, parents who participated in their study commented that they were the only ones who understood their child’s vulnerability and often worried about their child’s future if they could no longer support them (Portway and Johnson, 2005, p. 79). If social and vocational support services were more readily available and tailored to a varying range of individual needs, young adults with AS could become better prepared for independent living.

Participants of this study consisted of young men and women of Caucasian backgrounds, between the ages of 18 and 35 years of age, who have been diagnosed with Asperger Syndrome or who identify as having Asperger Syndrome or High-Functioning Autism.

This study employed the use of a questionnaire designed to gather information regarding demographics, living arrangements, perceived strengths and challenges experienced in the areas of employment, education, and

relationships, and available support services currently accessed. The questionnaire also included a question designed to elicit suggestions regarding support services needed that are not currently available.

By surveying young adults with Asperger syndrome, this study aimed to determine the specific difficulties experienced on a daily basis while transitioning to adulthood. Simultaneously this study elicited their perceptions of support services accessed and any barriers to support services.

Significance of the Project for Social Work

There is an abundance of research on the effects of AS and learning outcomes in children as well as research conducted in the area of parenting children with AS and studies focused on successful interventions for working with children who have AS. Children and parents of children with AS seem to comprise the majority of AS research.

A literature review was able to locate only a few studies focused on working with young adults with AS. Some of these studies include research on supportive employment, interventions to assist in social support such as groups, and case studies which are relevant to the purpose of this particular study.

The majority of studies were focused on assisting in controlling anxiety and depression related to daily life stressors resulting from social impairments. As previously mentioned, impairments in social skills is one of the most common characteristics of AS. Someone with inadequate social skills may likely become

isolated, and isolation often leads to depression. The feeling of being uncomfortable around people can lead to anxiety and social withdrawal. This is especially true for victims of bullying and harassment.

There are also studies in existence that promote the importance of early diagnosis and various criteria for diagnosing in adults. All of these studies are relevant. However, studies related to interventions and support services tailored to young adults with Asperger syndrome that promote a successful transition to adulthood and eventually to living independently were sparse.

The results of this study will assist in conducting further research on the individual needs of adults with AS, the impact of available support services accessed, and possibly the development of tailored support services based on individual needs. The expectation of this study is that social service professionals working with this population will have a better understanding of the varying degree of social, occupational and behavioral impairments characterized by AS and how such impairments may impact activities of daily living. By becoming more aware and building a better understanding of such impacts, professionals can advocate for clients who actively participate in becoming independent, and who wish to become successful, contributing members of society.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Chapter Two aims to explain the characteristics of Asperger Syndrome, and the issues young adults with AS may experience on a daily basis as described in previous studies.

Characteristics of Asperger Syndrome

As mentioned in the previous chapter, Asperger Syndrome is an Autism Spectrum Disorder (ASD). Autism Spectrum disorders include Autism, Asperger Syndrome (AS), and Pervasive Developmental Disorder (PDD) (Schall & McDonough, 2010, p. 82). Asperger Syndrome is characterized by communication deficits, deficits in social skills and restricted, repetitive, stereotyped patterns of behavior, activities, and interests (Schall & McDonough, 2010, p. 82).

Reality is that although many young adults with AS perform well on the job and are fully capable of completing tasks, they experience impairments in other areas of life. For the purposes of this study, symptoms of AS are explored in three major areas of adult life including employment and school, relationships, and life skills.

Employment and School

Schall and McDonough (2010) report that individuals with AS typically have average to above average cognitive abilities and range from gifted to just mildly impaired (83). Although gifted and cognitively and physically capable, they may have difficulty in understanding emotion and implicit, unspoken directions. Portway and Johnson (2005) report common misunderstandings of individuals with AS are only recognizing literal, explicit meanings and rules (77). These misunderstandings can lead to issues in the work place with employers, coworkers, and customers. They can also lead to misunderstandings in the classroom, among peers and with instructors.

Patterns of behavior such as “intense interests to the exclusion of reciprocal interaction with others” and strict routines are characteristic of many individuals with AS in which they are most often resistant to even minor change (83). As children, individuals with AS develop a routine that helps them to function and carry out activities of daily living such as rising at a specific time every day, bathing, brushing teeth, daily meals (usually with little variation in foods), etc. The development and use of a routine helps to diminish anxiety and confusion and makes their environment more predictable (Families of Adults Affected by Asperger’s Syndrome, Inc., 2008). When the routine is thrown off, they may become agitated, and upset (Portway & Johnson, 2005, p. 76). Individuals with AS have developed and maintained such patterns of behavior and routines since they were children. With this in mind, it will likely be

uncomfortable and take a substantial amount of time and energy to adapt to changes in the classroom, impromptu assignments, working with groups, new employment, a new job position, and developing a new routine.

Relationships

Individuals with AS desire rewarding, long-lasting relationships as anyone else does. Some adults with AS learn to develop and maintain relationships, marry, and have children. Others find it difficult to initiate or contribute to conversation well-enough to begin relationships or find it difficult to relate to others. Many individuals with AS find relationships frustrating due to lack of understanding social queues, underlying emotional meanings, and unspoken expectations of others. Most often social interactions stem from special interests, thus limiting social support (Jennes-Coussens, Magill-Evans, & Koning, 2006, p. 404).

Schall and McDonough (2010) describe manifestations of five categories of characteristics associated with Asperger Syndrome including cognitive and intellectual ability, social interaction, communication, patterns of behavior, and secondary characteristics. In the arena of social skills they report deficits in all areas of social interaction and these deficits can look like problem behavior when misunderstood (83). Schall and McDonough (2010) comment that impairments in the pragmatics of language present significant challenges for individuals with AS (83). This supports the finding that deficits in reciprocal communication and understanding of nonverbal social queues are common characteristics of AS. For

example someone with AS will likely have difficulty in understanding the nonverbal nuances of communication such as body language and facial expressions. Their research suggests that although delays in language and communication skills most often improve by adolescence, “continued impairment in social communication persists in adulthood” (Schall & McDonough, 2010, p. 82).

Secondary characteristics mentioned are behaviors such as aggression, self-injury, running or wandering away, and over activity. They go on to report that many individuals with AS experience anxiety and depression disorders (Schall & McDonough, 2010, p. 83). Because characteristics of AS are not so obvious, individuals are most often misunderstood and seen as weird and odd and because of difficulties in communication and social interaction, individuals with AS may become isolated (Portway & Johnson, 2005, p. 77). Many young adults with AS have trouble building and maintaining relationships, relating to others, carrying on conversations and are vulnerable to suggestion (Schall & McDonough, 2010, p. 87).

This illustrates that depending on the severity of AS symptoms, some individuals are able to form and maintain lasting, meaningful relationships while others find relationships difficult, frustrating, and become isolated.

Life Skills

Often individuals with AS will continue to live with their parents or live in an assisted living or board and care facility as adults. Many adults with AS have

such difficulties in adjusting to responsibilities of adult life including balancing a checkbook, paying bills, working, and learning to adjust to a new routine that they must continue to depend on their families or caretakers. In a study conducted by Portway and Johnson (2005), parents of individuals with AS reported they “worried about their child’s future when they were no longer able to provide for support” (79). Their study also found that in most cases, parents wanted their growing children to gain independence but they felt there were not enough support services available (Portway & Johnson, 2005, p. 79). Young adults with AS are like any other young adult; they want to become successful, independent adults.

Individuals with Asperger Syndrome may exhibit any and all of these characteristics. However, the severity of symptoms or characteristics varies from individual to individual. Over time they learn to compensate for some, and it is possible that someone with AS may exhibit so few of the characteristics that the individual goes undiagnosed or is denied support services because they appear as if they do not qualify.

Prevalence of Asperger Syndrome in Young Adults

The prevalence of Asperger Syndrome in young adults is difficult to gauge because most studies group Autism Spectrum Disorders (ASD) into one category. Also, most diagnoses occur in childhood, which makes it difficult to account for prevalence in adulthood (Higgins et al., 2008, p. 292). According to

the Centers for Disease Control (2011), ASD may affect as many as 1 in 110 births in the United States. Graetz and Spampinato (2008) report there has been an increase in the diagnoses of children with ASD in the United States in the past twenty years (20). Many individuals diagnosed in childhood will have already compensated or learned to overcome some of the deficiencies that characterize AS and may now fall into the group of young adults who are denied support services because they appear high-functioning. However, due to the increasing number of diagnoses in children, and the fact that Asperger Syndrome is a life-long disability, professionals will most likely see an increase in young adult clients with Asperger Syndrome (Higgins et al., 2008, p. 292).

Theories

As previously mentioned, the majority of research related to Asperger Syndrome has focused primarily on diagnostic criteria, working with children on the Spectrum in the classroom, appropriate interventions for building social skills, and perspectives of parents and caregivers of children with AS. Much of this research has centered on deficits of AS, behavioral modification, and social skills training. Although highly important to working with individuals on the spectrum, these approaches and interventions are often discontinued as young adults leave high school to move on to college, the workforce, building meaningful relationships, and living independent lives. Many children diagnosed with an Autism Spectrum disorder, “70-80% will continue to demonstrate marked social

impairment in adolescence and adulthood” (VanBergeijk, Klin, & Volkmar, 2008, pg.1361). The social skills, communication skills, and coping strategies taught and learned throughout childhood and adolescence must be reinforced throughout adulthood to provide the best opportunities to live healthy, fulfilling, independent lives.

Theories Guiding Conceptualization

Theories guiding conceptualization of this study include a humanistic perspective, self-efficacy theory, and a strengths-based approach to working with young adults with Asperger Syndrome.

Humanistic Perspective

The humanistic perspective is rooted in the basic beliefs that

Each person is unique and has value, human behavior can be understood only from the vantage point of the phenomenal self—from the internal frame of the individual, human behavior is driven by a desire for growth, personal meaning, and competence, and by a need to experience a bond with others (Hutchinson, 2003, pg. 81).

In consideration of these beliefs, individuals with AS are valuable, are understood from their internal frame of reference—not as compared to others’, and that the individual with AS desires growth, personal meaning, and bonds with others. In essence, individuals with AS are to be viewed just as everyone is to be viewed.

Self-Efficacy Theory

Self-efficacy theory suggests that “the idea of personal efficacy takes center stage in explanations of how people behave in all aspects of life” (Turner, 2011, pg. 430). The concept of self-efficacy compliments the humanistic perspective by examining how the individual perceives their ability and competence; their internal frame of reference. According to Turner (2011), “if the level of perceived self-efficacy is low, a person will doubt his or her ability for success” (pg. 432). For the purposes of this study, self-efficacy theory is used to understand the individual in terms of the individual’s perceived self-efficacy in relation to the transition to adulthood; paying specific attention to perceived self-efficacy in the areas of education and employment.

Strengths-Based Approach

The use of a strengths-based approach is highly appropriate when working with this population. Individuals with AS are used to others’ viewing them as having a disorder or complex, and having deficits and challenges. Many are used to having to explain “what’s wrong” with them in hopes that others will understand their perceptions, how they see the world in relation to them, and themselves in relation to the world. According to J. D. Munro (2010), clinicians working with individuals with AS must be so optimistic; affirming the strengths, talents, and gifts of the individual, to an extent that is nearly annoying (p. 87). The affirmation of an individual’s strengths is the key to building rapport and a “positive therapeutic relationship” (Munro, 2010, pg. 87). Taking a strengths-

based approach to working with young adults with AS will help individuals realize their full potential, realize their value, and overall help them to see themselves in a positive light. For the purposes of this study, a strengths-based approach to collaborating with this population in the workforce and in college settings may help to capitalize on the strengths of individuals with AS. Thus, providing an opportunity to grow and thrive in situations and environments that might otherwise feel overwhelming and create too much anxiety. According to Turner (2011), we must “adopt a resilience attitude—that is, a belief in the client, the family, and the community—and that they can become what they hope and can move in the direction that they want to or must” (pg. 484). By focusing on strengths rather than deficits, we instill hope, facilitate courage, and can help this population to reach self-identified goals.

Summary

The majority of past research focused on diagnostic characteristics and took a deficit approach to working with individuals with AS. Most studies aimed to deliver solutions in the form of behavioral interventions, to challenges young children, parents of children on the spectrum, and professionals working with children on the spectrum face. Very few studies addressed the issue that characteristics of AS, although they diminish over time, are present throughout the lifespan. Children diagnosed with AS grow up to be adults with AS.

From a humanistic perspective, individuals with AS are viewed as valuable and by taking on this view, it is easy to see through the typical *deficits* that are normally used describe this population, and note the strengths of an individual. Lastly, by acknowledging and building on the strengths of an individual with AS, they begin to see their worth, their value, and their potential; self-efficacy theory at it's finest.

CHAPTER THREE

METHODS

Introduction

This chapter discusses the study design, how participants were elicited and selected, where and how data were collected, and how data were analyzed. Also discussed are the procedures that took place to assure participant confidentiality and anonymity.

Study Design

The purpose of this study was to explore the unique struggles young adults (ages eighteen to thirty five years old) with Asperger Syndrome (AS) face daily in their endeavors to live productive, fulfilling lives. By identifying individual struggles of each participant, this study may assist in evaluating current social and vocational support services and help to develop comprehensive services geared toward the unique needs of this population.

This study was designed to elicit individual, unique experiences and therefore best fit a qualitative, case study research approach. Support services designed for individuals with AS are typically a “one size fits all” design. That is, services are not tailored to individual needs but are geared toward generalized needs. Based on previously mentioned literature, it is understood that no two persons with AS are alike. Symptoms, characteristics, and experiences vary drastically. Knowing this, how can we generalize the needs of this population?

How can support services successfully assist this population when they are generalized?

The responses to the interview questions are based on the personal, unique experience of each individual and therefore have subjective meaning. However, underlying themes were found in common among some responses. These themes were highlighted and categorized. A qualitative approach allowed this researcher to build rapport with each individual and provide a safe environment, so that they might feel much more comfortable sharing their personal experiences. This approach also allowed each interviewee to expand on their responses and experiences.

Quantitative data were also elicited in order to provide a description of the sample population that participated in this study. To obtain a better understanding and identify specific needs, this researcher conducted individual interviews eliciting demographic information. This researcher also attempted to elicit individual perceptions of how services utilized fit participants' specific needs. Questions were designed to help in assessing the usefulness of programs and services individuals in this population are currently using.

The qualitative data collected include information regarding services accessed and individual struggles and needs experienced by participants. In-person interviews were voice-recorded to best assist in gathering pertinent information without impeding the interview process or limiting the potential

amount of information gathered. Face-to-face interviews lasted no longer than an hour.

Several participants were located out of state and could not participate in in-person interviews. These participants elected to email their responses to this researcher.

Limitations

As previously stated, no two individuals with Asperger Syndrome share the same experiences. Furthermore, individual experiences are subjective. Therefore subjectivity of experiences and perceptions present as limitations of this study. In other words, the personal experiences of the participants in this study cannot be generalized to the population of young adults with AS.

Other limitations include issues in subject or case variability and sample size. Data were collected from individuals with varied ages, gender, educational backgrounds and employment histories. However, the sample size of this study was relatively small and does not represent all young adults with AS.

Another limitation to this study was the design of the questions. Although intentionally designed to be vague in order to elicit varying, unique experiences of participants, it was evident during the first interview that some of the questions were not specific enough for this population. To clarify, one of the most common characteristics of this population is the tendency to think very literally. This was not taken into consideration when designing the questions. This researcher needed to rephrase, elaborate and give examples for several of the questions

during in-person interviews. This could not be done for interviews conducted through email. Although this researcher offered to clarify any ambiguous questions, out-of-state participants expressed no need for clarification.

Last, this study did not include questions related to activities of daily living or life skills. This study could have been more comprehensive in questions related to personal finance, paying bills, time management, obtaining a driver's license, driving a car, and daily routine. This study did not elicit individual experiences of living independently. However, this study acts as a foundation to further, more comprehensive endeavors that will help to meet the specific needs of young adults with Asperger Syndrome as they transition from adolescence to adulthood.

Sampling

Data were drawn from a purposive sample of seven young adults between the ages of eighteen and thirty-five years old, who either have an official diagnosis of Asperger Syndrome or high-functioning Autism, or identify as having Asperger Syndrome or high-functioning Autism.

Sample subjects include students registered in the Services to Students with Disabilities (SSD) program at California State University, San Bernardino (CSUSB), (Appendix A), and the general population.

Data Collection and Instruments

Face-to-face interviews and electronic, email interviews were the means of data collection for this study.

Mental health identification and demographic questions are independent variables crucial to assuring participants fit the criteria for this study and are necessary in describing the population. The unique struggles this population experiences in daily life are the dependent variables in this study.

Demographics

Demographic questions (Appendix B) were designed specifically for this study to collect independent variables such as age, ethnicity, gender, and geographic area of residence. The questionnaire also included questions regarding employment status, educational status, and living arrangements (with parents, alone, board and care, etc).

Individual Experiences

Interview questions (Appendix C) focused on the unique experiences of participants were designed to elicit responses related to how AS has impacted their transition to adulthood. Areas affected by AS on the transition to adulthood include school, employment and relationships. Participants were also asked to describe their support system, and explain how their support system has impacted their transition to adulthood.

Last, participants were asked about any services from which they receive support. If participants were receiving support services, they were asked to

comment on whether or not identified services were meeting their specific needs. Participants were also asked to comment on any improvements support services could make to better fit their specific needs or supports they wish were available.

Procedures

Data collection took place between January 2014 and April 2014. Informative flyers containing this researcher's contact information (Appendix D) and eliciting eligible participants were posted in halls around the CSUSB campus upon approval by administration, distributed through email by the CSUSB SSD Director, and were posted electronically through the use of social media.

In order to assure anonymity, the nature and purpose of the study was explained to the Director of the SSD office and permission was granted to leave informative flyers for interested students. Per request of the SSD Director, an informative email was also drafted for the Director to send out to SSD consumers who fit the criteria to participate in this study.

Face-to-face interviews were conducted either in a study room at CSUSB, or in an area chosen by the interviewee based on their location and level of comfort.

Those interested in participating in an interview through email were asked to message this researcher and were asked to read and either agree or disagree to the terms of the informed consent before questions were emailed to the participant.

Protection of Human Subjects

All subjects received written informed consent (Appendix E) assuring anonymity of participation and confidentiality of results before proceeding to participate in this study. The informed consent required participants to sign an “x” indicating they have read, understand, and agree to participate in the study. Participants were not asked their name or any other obvious identifying information on the questionnaires or in interviews. Information included in the interviews that may be considered identifying are age and gender. However, in-person participants were verbally informed that the audio-recorded interviews would be deleted at completion of the study. Individuals participating in emailed, electronic interviews were informed that their responses would be deleted from my email and printed responses would be shredded at completion of the study.

All participants were informed of their right to refuse participation and to withdraw from the study at any point in time.

All participants received a debriefing statement (Appendix F) informing them of the study and how to access results. The debriefing statement also included appropriate community resources available; San Bernardino County

211, the Psychological Counseling Center (PCC) for current CSUSB students, the Asperger Syndrome and High-functioning Autism Association (AHA), and the Global and Regional Autism Spectrum Partnership (GRASP).

Data Analysis

The quantitative procedures utilized in this study are designed to define the population sample. Participants were asked demographic questions, developed by this researcher, to better understand the independent variables that describe this population.

The qualitative procedures utilized are designed to help this researcher as well as social and vocational support providers, to formulate a better understanding of the individual experiences this population faces in their transition to becoming successful, independent adults.

All face-to-face interviews were audio-recorded and data collected was transcribed. Interviews through email were already in the form of transcription. After all transcriptions received a preliminary review, responses were grouped into categories based on topics discussed in interview questions (Appendix C) developed by this researcher. Categories include the impact of AS/ASD on adult life in the areas of employment, education, and relationships.

Responses received a second review in order to identify themes to show similarities and/or differences among responses. Themes include challenges, coping and suggestions for improving support services.

Summary

This chapter discussed the rationale of gathering both quantitative, independent variables and qualitative, dependent variables from a purposive sample consisting of seven subjects. Information about the collection of data as well as informed consent, confidentiality and anonymity of participants, and contents of the debriefing statement provided to participants was also discussed.

CHAPTER FOUR

RESULTS

Introduction

This chapter discusses the qualitative, thematic data that were collected from face-to-face and email interviews. The findings are presented in themes identified through preliminary and secondary reviews of responses collected from participants. Themes identified indicate individual challenges experienced in adult life, how participants cope with identified challenges, experiences from participation in support services, suggestions identified to improve these services, and meaningful recommendations to young adults with Asperger Syndrome and Autism Spectrum Disorder.

Presentation of the Findings

Seven individuals, between the ages of eighteen and thirty-five, shared their personal experiences as young adults with Asperger Syndrome.

Demographics

State and County of Residence. Data collected from face-to-face interviews were from four individuals residing in San Bernardino County, California. Interviewees participating in this study through email consisted of one individual residing in Tippecanoe County, Indiana, one individual residing in Powder River, Montana, and one residing in Boone County, Illinois.

Table 1. *Demographics*

| Age | Gender | Ethnicity | College Student (Y/N) | Employed (Y/N) | State/County Of Residence |
|-----|--------|--|-----------------------|----------------|------------------------------|
| 18 | 4 M | 5 self-identified as "Caucasian/White" | 4 Y | 3 Y | 4 California, San Bernardino |
| 20 | | | | | |
| 22 | 3 F | | 3 N | 4 N | |
| 23 | | 1 self-identified as "Spanish/English/Cherokee/Scotts-Irish" | | | 1 Indiana, Tippecanoe |
| 24 | | | | | |
| 25 | | | | | |
| 30 | | 1 self-identified as "Black/Korean" | | | 1 Montana, Powder River |
| | | | | | 1 Illinois, Boone County |

Age and Ethnicity. Participants in this study were required to be between the ages of eighteen and thirty-five years old. The youngest participant of this study was eighteen years of age and the oldest reported to be thirty years of age. The majority of participants fell between twenty-two and twenty-five years of age.

Participants were asked, "What is your ethnicity?" (Appendix B). As indicated in the Table 1, four participants identified as male and three identified as female. Five individuals self-identified as being of "Caucasian" or "White" ethnic background, one identified as "Spanish, English, Cherokee, and Scotts-Irish" ethnic decent, and one participant self-identified as being of "Black and Korean" ethnicity.

School/College. In order to determine whether or not participants were current students, respondents were asked, "Are you a student?" (Appendix B). Four participants identified as current college students; three participants

reported they are not currently in school. One participant reported having graduated college with a Bachelor of Science degree, is currently working on a second Bachelor of Science degree, and is planning to apply for graduate school. Three participants reported having taken college courses to pursue higher education but are not currently participating in college courses. Three participants are currently enrolled in college courses.

Employment. As indicated in Table 1, three participants reported as currently employed and four participants report as currently unemployed. Two participants in this study report having military experience. Of these two participants, one is actively pursuing a part-time military career and is employed by a government agency. Another participant who reports being employed stated, "I have a temporary, part-time (5-20 hrs a week) cleaning position at a local Broadway-style theater" (Participant 5, personal communication, 2014). One participant reported having several internship experiences through school, including a government agency, and briefly worked in retail.

One participant in this study reports never being employed but has plenty of experience with hands-on labor. This participant stated: "I'm really good with under-the-table work like mowing lawns, helping build fences, helping tear down fences, cut down trees, pulling stumps" (Participant 2, personal communication, 2014). Another participant indicated during the demographic questions that he is not employed, however during discussion about the impact of AS/ASD and employment, he stated, "I can't say I'm really unemployed; I have a slight...I can't

call it an internship, but I'm not getting paid. I'm getting work experience. I review video game hardware" (Participant 3, personal communication, 2014).

Living Arrangements. Participants were asked, "What is your current living arrangement?" (Appendix B). Five participants reported living with their parent(s) or family. One participant reported living with their spouse and children, and one participant reported living with their mother but would soon be moving to live with her significant other.

Themes

As mentioned in Chapter Three, participant responses were separated into categories describing the personal impact of AS/ASD on each individual's adult life in the areas of employment, education, and relationships. Next, responses received a second review in order to identify themes illustrating similarities and/or differences among responses. These themes are identified as challenges, coping strategies and suggestions for improving support services.

Participants were first asked at what age they received an official diagnosis of AS/ASD. Five participants received an official diagnosis, one participant was never officially diagnosed, and one participant did not disclose whether or not they had ever received an official diagnosis. Two participants reported they were diagnosed at five years old, one participant was seven years old and another was eight years old. Another participant reported being twelve years old when they received an official diagnosis. Participants were also asked

to give the age they identified as having AS/ASD if they never received an official diagnosis. The participant who never received an official diagnosis reported, “I became aware of the possibility of my diagnosis at around age sixteen” (Participant 4, personal communication, 2014). Finally, the participant that did not disclose ever receiving a diagnosis reported the age of awareness at twenty-three (Participant 5, personal communication, 2014).

Interviewees were asked to comment on how AS/ASD has impacted their adult life. Several themes became evident among responses. All seven participants expressed challenges in social interaction, and successfully dealing or coping with stress in the areas of employment, education, and personal relationships.

Social Interactions

All seven participants reported having difficulty in social interactions in more than one area of adult life.

Employment. One interviewee disclosed adverse experience in the workplace; “People call me a “bitch” a lot. I’ve gotten better with the filter though... it is very taxing trying to interact with and whatnot with people” (Participant 5, personal communication, 2014). This respondent also shared feelings that “there is no room to move up” in employment (Participant 5, personal communication, 2014). The feeling is that employers have not seen potential for this individual to grow and succeed.

Another participant reported working in customer service for a short time at a major store. This participant found it difficult being in front of people, making eye contact, and having to interact with people for an entire shift. She stated, “I didn’t feel comfortable looking at them in the eye” (Participant 1, personal communication, 2014).

One participant who described himself as technically unemployed but gaining work experience reported that the company he is reviewing video game hardware for is located overseas and he really has no interaction with them other than online (Participant 3, personal communication, 2014).

Another respondent reported not having found employment yet, but has found interviews to be challenging (Participant 7, personal communication, 2014).

Social interaction encompasses many things; it also includes understanding unwritten social rules, underlying meanings that are not blatantly stated. One participant clearly expressed a challenge in the work place with verbal instruction. She reported, “I don’t do well with verbal instructions at times. It’s helpful to have written instruction with verbal instruction” (Participant 1, personal communication, 2014). To attest to this statement, another participant reported, “The only way I can learn anything is by extreme repetition” (Participant 6, personal communication, 2014).

Education. Six out of seven of the participants disclosed having difficulty in the school setting. Two participants disclosed having difficulty in participating in

group assignments and in presentations. One participant stated, “The interaction with other students is a common problem ‘cause in college you have to learn to interact with others” (Participant 3, personal communication, 2014). The other participant reported feeling annoyed that she would usually get stuck with all of the work because she is good at it, and the rest of the class would end up doing all of the talking in presentations (Participant 1, personal communication, 2014).

Relationships. All participants reported challenges in relationships due to AS/ASD. One participant reported experiencing “trouble interacting with people” (Participant 4, personal communication, 2014) and another stated, “I make very few friends but the ones I do make I keep for long periods of time” (Participant 3, personal communication, 2014). Another participant reported, “I mean I’ve always found it a little bit hard to make friends because some people say I don’t appear interested in others or I’m kind of off in my own little world” (Participant 1, personal communication, 2014). Two participants expressed empathizing with others as challenging. One participant shared, “I find it a little bit difficult to empathize with people. I mean I find it easier to show them directions and where to go” (Participant 1, personal communication, 2014). This participant followed this comment by sharing that her instinct is to tell others the truth, the blunt truth, and feels sometimes she would rather stay silent than tell the truth. She reports she has learned this from experience growing up and the repercussions.

Social nuances also seemed to be a challenge reported by three participants. One interviewee commented, “I don’t know how to introduce myself

and get to know someone; my feelings are black and white. Either I like someone or I don't. I can't just work through the grey" (Participant 3, personal communication, 2014). Another stated, "The disorder has caused some challenge in my marriage...but my wife has learned how to help me deal with it...whenever the disorder starts to take over and my rational thinking goes away" (Participant 6, personal communication, 2014).

Several participants reported others' perceptions of them and not understanding AS/ASD and accepting them, has caused challenges. One participant shared that a friend told her, "Maybe you shouldn't tell people that you have Asperger's because they may not react to it in ways that you want" (Participant 1, personal communication, 2014).

Stress and Coping Strategies

Stress. All participants reported some type of stress and/or anxiety in relation to AS/ASD. Some participants related stress to changes or interruptions in their daily routine. One participant expressed a fear of failing that lingers in her mind (Participant 1, personal communication, 2014). Constantly, she feels she has to prove herself to others in all aspects of independent adult life. Another participant reported it takes a lot to set him off, but sometimes he has a "short fuse," "blows up," and can get "volatile" (Participant 2, personal communication, 2014). Another participant reported he feels he is now able to "get through everyday life" as long as his routine or what he is "expecting to happen that day

is not interrupted or changed too much” (Participant 6, personal communication, 2014).

Challenges in the school setting can create a great deal of stress for individuals with AS/ASD. Some participants reported challenges such as difficulty in concentration both in the classroom and in studying. Two participants reported often losing interest in class material. As one participant stated, “Very little in the way of subject matter keeps my attention for very long, and I tend to lose interest and stop caring very quickly” (Participant 6, personal communication, 2014). He went on to add, “I find it incredibly hard to focus on what is being taught to me, and generally only catch about half of what is being said” (Participant 6, personal communication, 2014). This participant also states, “School is downright infuriating for me” (Participant 6, personal communication, 2014). In tune with this statement is a response by another individual who indicated AS benefits him because he has an “accelerated thought process” and “can process a lot things a lot faster than almost anybody else” in his class (Participant 2, personal communication, 2014). Although he reports, “it also hinders me because I miss a couple of things every now and then” (Participant 2, personal communication, 2014).

Another participant reported a similar experience with college courses: “I ended up in online school since the small school did not go fast enough and I found myself losing interest and refusing to go as I was ahead on the material” (Participant 5, personal communication, 2014).

Inability to focus can also cause a great deal of stress in the school environment. According to responses regarding this topic, one participant expressed, “When I’m forcing myself to focus, there are no distractions for me... but when I have to focus on something but don’t really want to, I’ll let things distract me” (Participant 2, personal communication, 2014). Another participant reported having a study routine and when her routine is thrown off for any reason, she becomes “at edge” (Participant 1, personal communication, 2014).

Coping Strategies. All participants described some form of coping strategy they utilize to deal with stress. Two participants reported utilizing support services for students with disabilities on their college campuses where they have a quiet place, free of distraction, to complete exams. Both of these participants reported being part of some type of social support group. One is part of Narcotics Anonymous and the other participates in online forums for individuals with Asperger’s Syndrome and is part of a social group revolving around personal interests.

Others reported utilizing coping techniques to reduce stress and anxiety. These techniques included calming strategies such as “calming the mind” (Participant 2, personal communication, 2014), mindfulness, or focusing on breathing, and indulging in personal interests such as gaming, reading, physical activity, couponing, and writing.

Two participants reported reaching out to close friends and family to reduce anxiety and stress. One participant stated, “I’ve had great support with my

family. They've been super supportive and I thank them everyday for it" (Participant 3, personal communication, 2014). Another reported having long-distance friends to reach out to who know how to make her feel better (Participant 1, personal communication, 2014). One participant reported his faith, wife and daughters manage to lift him up and keep him together (Participant 6, personal communication, 2014).

All study participants engaged in some form of positive self-talk. Two participants commented, "It gets better" (Participant 3, personal communication, 2014), and "it's a learning process" (Participant 1, personal communication, 2014). One participant reported, "With a hard head, I power through it" (Participant 4, personal communication, 2014). He thought of AS/ASD as having "a different set of abilities than normal people" (Participant 4, personal communication, 2014).

One participant reported he is not involved or participating in any support services but his sister began a support group for siblings of individuals with AS/ASD and he occasionally speaks to the group about AS/ASD. He finds advocacy and informing others empowering and helpful for him (Participant 3, personal communication, 2014).

Two out of seven respondents reported participation in some type of support service. Two felt support services were unnecessary in their case; one of these respondents felt it could possibly compromise his civilian job and military

career. He also reported participation in support services having never occurred to him (Participant 6, personal communication, 2014).

The majority of the study participants were unaware of support services outside of college campuses.

Suggested Improvements to Support Services

Although the majority of respondents reported no participation in support services, some offered suggestions to improve services for young adults with AS/ASD.

One individual felt most support groups available are for family members or significant others who live with an individual with AS/ASD. This respondent suggested offering more social support for young adults on the spectrum. This individual also felt that social programs specifically catered to individuals with AS/ASD and revolving around personal interests such as gaming, theater, writing, etc. would be helpful to others like her (Participant 1, personal communication, 2014).

Another respondent felt that she would benefit from support services that would help her to better express herself and communicate effectively with others (Participant 7, personal communication, 2014). Similar to this concept, another participant felt he would benefit from support services that could help him to better handle stressful situations and feel more comfortable interacting with others (Participant 6, personal communication, 2014).

Two respondents felt that there could be more awareness of what AS/ASD entails, but more importantly they expressed the need for more acceptance by others and society as a whole. One respondent shared what has helped him the most: “People let me be who I am. Whenever someone wanted to learn more about me, I was ecstatic” (Participant 3, personal communication, 2014).

Another study participant expressed satisfaction with support services received while in primary school but wished these services could continue to help with the transition to adulthood. This participant reported, “I wish I could continue with the help in adult life. Earlier they did well with helping me make friends and whatnot, but did not do well in preparing me for adult life” (Participant 5, personal communication, 2014). This individual suggested “street counselors” to “help cope with adult challenges” (Participant 5, personal communication, 2014).

Meaningful Recommendations to Young Adults with Asperger Syndrome and Austism Spectrum Disorder

At the end of each interview, participants were asked what they would say to a young person with AS/ASD transitioning into adulthood. Three respondents shared the message, “It’s going to get better” (Participant 3, personal communication, 2014), and “It gets easier” (Participants 1 and 5, personal communication, 2014). Two respondents reported they would tell a young person with AS/ASD to “Hang-tough” (Participant 4, personal communication, 2014), and “The worst thing you can do is give up, keep moving forward” (Participant 6, personal communication, 2014). Another participant reported he would tell a young person, “Be yourself” (Participant 2, personal communication, 2014).

Summary

In summary, this chapter described the qualitative, thematic sample through demographic and narrative data collected from three face-to-face, and four email interviews. Preliminary and secondary reviews separated narrative data collected into five identified themes. Themes included individual challenges experienced in adult life, how participants cope with identified challenges, experiences from participation in support services, suggestions identified to improve these support services, and meaningful recommendations to young adults with Asperger Syndrome and Autism Spectrum Disorder.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter discusses the meaning of this study's findings, limitations to this study, and the implications for social work. The purpose of this study was to shed light on the unique experiences of individuals with Asperger Syndrome on their transition to adulthood in the areas of employment, education, and relationships. Common themes among interviewee responses are identified as challenges, coping strategies, and suggestions for improving support services.

Discussion

This was a qualitative, exploratory study that questioned individuals about the impact Asperger Syndrome or High-functioning Autism Disorder has had in the transition to adulthood in the areas of employment, education, and relationships. This study was designed to identify the unique challenges each individual faces in young adulthood and provide evidence that support services cannot be generalized to fit the needs of this population. No two individuals with AS/ASD are the same and would benefit most from services tailored to the individual.

A specific age range was set to elicit participants. This study was meant to elicit participation from individuals between the ages of eighteen and thirty-five years old. This is the range most theorists define as "young adulthood."

All but one of the participants in this study described being at a stage of transition; between dependence on family of origin and becoming independent, self-sufficient adults. Six out of seven participants were living with parent(s) or their family of origin at the time of the interview. This was expected, but could be due to factors beyond AS/ASD. These factors might include income, the state of the economy, competitive job market, limited availability of housing, and/or the individual is a full-time student with a demanding internship. Many young adults, without AS/ASD, are choosing to live with their parents until they have completed college, begun their career, and/or started a family of their own.

The oldest participant in this study was thirty years of age, married, and a father of two children. This participant had begun his career in his early twenties.

Employment presented as a significant area of challenge for participants in this study. Four out of seven participants reported as currently unemployed. One of these participants has military experience but is now a civilian and has begun to take college courses. Two participants who reported as unemployed have some work experience. One reported experience as a hands-on laborer. The other reported having technical skills.

Challenges in the area of employment were similar among all respondents. Four out of seven respondents expressed difficulty in interacting with coworkers, managers, supervisors, and customers. One respondent reported being very good at cashiering but felt it was “taxing” interacting with customers. Another participant wished others would understand that she needed

to take frequent breaks to de-stress and calm herself from constant interaction with customers. This participant reported as currently employed but commented that the work environment is highly stressful because things are often misplaced and dealing with coworkers who have very different work styles throws off routine and causes her to be anxious. She shared that past employers were not so accepting of her diagnosis. She reported her current employers take an interest in her abilities, and have placed her in an environment that is conducive to her needs which allows her to thrive.

Enrollment in college courses played a role in identifying individual challenges. Four out of seven participants identified as current college students. Two of these respondents expressed their participation and satisfaction in support services offered at their college campuses, specifically the availability of a distraction-free space for completing exams. The remaining three participants who were not currently enrolled in college courses expressed their frustrations with school. Specifically, they shared difficulty in maintaining interest in subject material. All seven participants found it difficult to maintain focus in the classroom as well as in studying. One participant openly shared that if her routine was disrupted, she became “on edge” (Participant 1, personal communication, 2014). A respondent who reported as not currently in school but has taken college courses reported doing well on schedules or routines but has found them difficult to maintain.

Six out of seven participants expressed challenges interacting with others in school. Group work in classes was a common issue for nearly all participants. This is a legitimate concern because most college courses generally incorporate teamwork in the classroom, or an involved, group project that requires group work outside of the classroom. Group projects are often difficult to coordinate with each member's schedule, but to consider the challenge of trying to understand the unwritten rules or expectations of others could probably be quite frustrating and cause a great deal of stress and anxiety for individuals with AS/ASD.

One student felt he was fairly understood by others. This participant felt that most of his instructors were aware of his strengths and challenges. However, two other participants felt more awareness and acceptance of what AS/ASD entails (the challenges, and strengths of the diagnosis), would assist them a great deal in the school environment. Both of these participants expressed their satisfaction and hopefulness in the increasing awareness of AS/ASD but felt it was still not fully understood and certainly not yet accepted by society.

Participants were asked how AS/ASD has impacted their social life and relationships. All participants expressed challenges in interacting and relating to others. One participant reported it has caused problems in his marriage but has also had a positive affect the relationship he has with his wife and daughters. He reported having "episodes," normally caused by stress in some form, which have created upsets or problems in his marriage (Participant 6, personal

communication, 2014). On a positive note, he reports his wife has been very supportive throughout the years and has taken it upon herself to research Asperger Syndrome in order to help him cope with stress. This has had a positive affect on his marriage.

Another participant expressed challenges in showing interest in others' interests (Participant 1, personal communication, 2014). Most participants reported difficulty in theory of mind, or seeing others' points of view. Several expressed enjoyment when others show interest in them, asking them about their thoughts, their rationale, and engaging with them. However, they expressed challenge in reciprocating this interest; not always because they have not learned how, but because they feel uncomfortable or do not feel the need. On the contrary, all participants expressed the desire for close, human relationships.

All respondents were asked to discuss any support services in which they participate. They were asked to discuss whether or not they felt these services met their specific needs, and how support services might be improved to fit their specific needs. Interestingly and almost expected, most participants were not participating in any support services. Only two participants reported accessing educational support services. However, the extent of the educational services accessed only encompassed exam taking. One out of seven respondents reported participation in individual therapy, a social group revolving around personal interest, and seeking social support through online forums for peers with AS. One out of seven respondents reported educating others about AS/ASD

has helped him to build self-esteem while spreading awareness and encouraging acceptance. Two participants reported no need for support services and expressed the perception that support services enable “coddling” and should encourage more self-reliance. However, all but one participant was aware of any support services outside of educational support.

Three out of seven participants felt they did not need further support services. Two participants expressed a desire to learn more about available support services for young adults with AS/ASD. Two participants suggested improvements to services for young adults with AS/ASD. One of these participants suggested more support groups specifically catering to transition-aged youth and young adults with AS/ASD to help them adjust to changes, and build social support. The other suggested continued support services from primary education through college education to assist in building social support, and assisting in a smooth transition from dependence to independence. This participant used the term “street counselors” to suggest individual assistance in challenges related to adult life. I believe she was implying “street counselors” could assist in problem-solving, decision-making, and coping with stressful situations.

All challenges expressed by participants in this study were related to social interaction, coping strategies, and awareness and acceptance by others and society.

Limitations

Several limitations became evident as this study was conducted. First, this study recruited a small sample of seven interview participants of various backgrounds. The findings of this study cannot be generalized to all individuals with Asperger Syndrome or High-functioning Autism transitioning into adulthood.

Second, this researcher had difficulty in recruiting participants for reasons that can only be speculated. This population may be difficult to reach based on the methods of recruitment and data collection. This study was designed for face-to-face interviews. This population can be described as introverted. They may find face-to-face interviews with a complete stranger suspicious and/or uncomfortable.

Third, the interview questions were designed to be general so that each participant could interpret, expand questions, and elaborate on their personal experiences as they saw fit. However, a common characteristic of AS/ASD is literal interpretation. Most often individuals with AS/ASD will take things for face value. This was not a terrible issue in face-to-face interviews because the researcher had the ability to elaborate on questions or make them more specific. This researcher was not able to do this for electronic, email interviews. This is a significant limitation considering the majority of interviews were conducted through email.

Recommendations for Social Work Practice, Policy and Research

The purpose of this study was to collect personal perspectives as an individual with Asperger Syndrome or High-functioning Autism, transitioning into young adulthood. By asking individuals what their unique experiences have been, this researcher has gained perspective about what this population feels would specifically meet their needs to assist them in becoming successful, independent adults.

A common problem this population experiences in locating and accessing services is they are not “severe enough” to qualify for support services. Social workers, with knowledge and experience in working with this population, could assist individuals to better communicate their specific needs and how these needs could be met.

Social workers could work with employers, college campuses, instructors, and social service providers to educate others about AS/ASD, the challenges, and the strengths individuals with AS/ASD experience in these settings. Social workers can educate others as to how to work best with, and accommodate this population in a way that builds self-esteem, and encourages independence and growth.

Also, all participants reported their immediate family as their primary support system. Often adults on the spectrum, become dependent on their primary support system for various reasons. Society has yet to accept the challenges this often marginalized population experiences as significant. Yes,

these individuals are highly intelligent, high-functioning, and capable of leading successful, fulfilling, independent, adult lives. However, there are many if not most that would benefit from even the slightest support outside of the primary support system. Often, the primary support system may not have the resources to provide adequate support to assist their family member in becoming independent adults. Social workers are best equipped to assist families with transition-aged individuals with AS/ASD to find and access support services that could help them to help themselves in this significant and highly important developmental phase of life.

A significant concern in regard to this population has to do with the current changes to Autism Spectrum Disorder (ASD) in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, or DSM-5 (2013). According to the DSM-5 (2013), persons who were diagnosed as having Autistic disorder, Asperger Syndrome, Childhood Disintegrative disorder, or Pervasive Developmental Disorder are lumped under the “umbrella” of Autism Spectrum Disorder spectrum (American Psychiatric Association, 2013). The rationale is that having “a single umbrella disorder will improve the diagnosis of ASD,” “allowing clinicians to account for the variations in symptoms and behaviors from person to person” (*DSM-5: Autism Spectrum Disorder Fact Sheet*, pg. 1, 2013). This change is geared to encompass the diagnosis of adults, who may not have been diagnosed in childhood. However, there is still uncertainty as to how individuals who have already received an official diagnosis of Asperger Syndrome, and

strongly identify with this diagnosis, will react or adjust to having been fit under the “umbrella” of ASD. One participant commented that Asperger Syndrome is very different from Autism, and others who do not understand the difference may view her disorder as Autism. If we are moving toward increased awareness and acceptance, this may cause challenges for individuals when disclosing their diagnosis. They may feel the need to defend their diagnosis and separate it from others under the spectrum.

Considering the DSM-5 (2013) change, there is also uncertainty as to how this change in diagnosis will affect access to support services for individuals on the higher end of the spectrum. Specifically, will individuals such as the participants in this study, now meet criteria for services that have been denied in the past? More research is needed in these areas.

Conclusions

This study concludes that no two individuals with Asperger Syndrome or High-functioning Autism transitioning into adulthood are the same. Therefore, support services must be catered to the specific needs and future goals of the individual, and encourage independence and growth, in order for them to benefit.

As this study was conducted, it became clear that many individuals are not aware of the support services available to them or to anyone with AS/ASD. This conclusion indicates a gap in service and lack of outreach to this growing population.

This study also concludes that there is still insufficient awareness and most importantly, acceptance of Asperger Syndrome and high-functioning Autism by society.

APPENDIX A
LETTER OF APPROVAL



Student Affairs
Services to Students with Disabilities

MEMORANDUM

TO: Rosemary McCaslin, Ph.D.
FROM: Beth Jaworski, Ph.D.
RE: Letter of Support
DATE: January 23, 2014

Please accept this memo as support for Cassandra Nafziger to recruit participants for her IRB-approved MSW study through Services to Students with Disabilities.

909.537.5238 • fax: 909.537.7090 • TTY: 909.537.7230 • <http://ssd.csusb.edu>
5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

The California State University • Bakersfield • Channel Islands • Chico • Dominguez Hills • East Bay • Fresno • Fullerton • Humboldt • Long Beach • Los Angeles
Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

APPENDIX B
DEMOGRAPHIC QUESTIONNAIRE

DEMOGRAPHIC QUESTIONNAIRE

1. What is your age?
2. What is your ethnicity?
3. What is your gender?
4. What state do you live in?
5. What county do you live in?
6. What is your current living arrangement?
7. Are you a student?
8. Are you currently employed?

Nafziger, C. (2013). *Demographic questionnaire*.

APPENDIX C
INTERVIEW QUESTIONS

Interview Questions

1. How old were you when you were diagnosed with Asperger Syndrome/an Autism Spectrum Disorder? If you weren't officially diagnosed, at what age did you identify with having the disorder?
2. In what areas of your everyday life (work, social life, school, personal relationships) do you feel Asperger Syndrome/Autism Spectrum Disorder has made a significant impact?
3. If you are a student, in what ways has Asperger Syndrome/Autism Spectrum Disorder affected your college experience?
4. If you are employed, in what ways has your Asperger Syndrome/Autism Spectrum Disorder affected your employment experience(s)?
5. In what ways has Asperger Syndrome/Autism Spectrum Disorder affected your personal relationships (family, friendships, romantic relationships)?
6. How do you handle or cope with any challenges/obstacles that Asperger Syndrome/Autism Spectrum Disorder presents in everyday life?
7. Do you participate in any social support service programs specifically designed for individuals with a diagnosis of Asperger Syndrome/Autism Spectrum Disorder? If so, please describe these programs/services.
8. Do you feel that these support services meet your individual, specific needs?
9. If not, what areas do you feel could be improved to better fit your needs?
10. What suggestions do you have for improving support services?
11. Describe your support system (those individuals, programs, services you feel make a significant impact on your daily life).
12. What advice would you give an adolescent with Asperger Syndrome who is preparing for young adulthood (graduating high school, transitioning from dependence to independence)?
13. Any additional comments, suggestions, thoughts you feel are necessary to consider for the purpose of this study?

Nafziger, C. (2013). *Interview questions*.

APPENDIX D

FLYER

MSW Student Seeking Study Participants Who

- **Are 18-35 years old**
- **Have An Autism Spectrum Disorder (ASD)**
(Formerly known as Asperger Syndrome (AS)
Or High-Functioning Autism)

Seeking individuals interested in participating in an interview concentrated on sharing your individual experiences of the transition to adulthood as a young adult diagnosed with an Autism Spectrum Disorder.



Participants will receive a reusable Starbucks travel mug and will be entered into an opportunity drawing for a chance To win a Starbucks Gift Card!

Interviews are confidential and voice-recorded.

If interested in participating,
Please contact Cassandra Nafziger at
nafzige@coyote.csusb.edu for more information
and to sign-up for an interview.

Autism Spectrum Study
Cassandra Nafziger
nafzige@coyote.csusb.edu

APPENDIX E
INFORMED CONSENT



California State University, San Bernardino
 Social Work Institutional Review Board Committee
 College of Social and Behavioral Sciences
 Department of Social Work
 APPROVED 2/18/14 VOID DATE 2/18/15
 IRB# 2013-038 CHAIR [Signature]

Informed Consent

The study in which you are being asked to participate is designed to explore the unique needs of individuals diagnosed with Asperger Syndrome as they transition into adulthood. This study is being conducted by Cassandra Marie Nafziger, MSW student, under the supervision of Dr. Rosemary McCaslin, Professor of Social Work at California State University, San Bernardino. This study has been approved by the School of Social Work Subcommittee of the Institutional Review Board at California State University, San Bernardino.

Purpose: To explore the unique needs of young adults between the ages of 18 and 35 years of age who have a diagnosis of an Autism Spectrum Disorder (ASD) (formerly known as Asperger Syndrome (AS)).

Description: Study consists of an audio-recorded interview. Participants will be asked demographic questions such as age, gender, ethnicity, etc. The interview will also consist of questions regarding personal experiences as young people diagnosed with an Autism Spectrum Disorder (formerly known as Asperger Syndrome) transitioning into adulthood.

Participation: Participation in this study is completely voluntary, you may choose not answer any questions you do not wish to answer. If at any point during the questionnaire or interview you wish to withdraw, you may.

Confidentiality: Information collected during interviews will be kept confidential. Identifying information will not be attached to responses provided during the interview. Audio recordings will be destroyed after information is transcribed and research is submitted.

Duration: Interviews should last between 15-20 minutes and no longer than 25 minutes.

909.537.5501
 5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

The California State University • Bakersfield • Channel Islands • Chico • Dominguez Hills • East Bay • Fresno • Fullerton • Humboldt • Long Beach • Los Angeles
 Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

Risks: A possible risk to participating in the focus group may be slight discomfort sharing personal experiences. Considering this risk, a debriefing statement explaining this study in more detail will be provided at the end of the focus group.

Benefits: Potential benefits to individuals and society would be that this study helps to raise awareness of the unique, individual needs of this population, and will assist in developing more tailored, comprehensive support services for young adults with an Autism Spectrum Disorder (formerly known as Asperger Syndrome).

Contact: If you have questions regarding this study please contact Dr. Rosemary McCaslin, Professor of Social Work, at (909)527-5507, rmccasli@csusb.edu.

Results: The results of this study can be viewed after September 2014. Results will be available at the John M. Pfau Library on the California State University, San Bernardino campus.

Audio Recording: I understand my interview will be audio recorded ____ Yes ____ No

Signature: By marking an "x" on the line below, you are indicating that you have read the information provided above and are consenting to participate in this study.

Mark: _____ Date: _____

California State University, San Bernardino
Social Work Institutional Review Board Sub-Committee
APPROVED 2/18/14 VOID AFTER 2/18/15
IRB# 201338 CHAIR 

APPENDIX F
DEBRIEFING STATEMENT

Debriefing Statement

Thank you for your participation in this study. This study was designed by Cassandra M. Nafziger to explore the unique needs of individuals diagnosed with Asperger Syndrome as they transition into adulthood. Your contributions to this study will assist researchers in understanding the specific struggles and individual needs of those diagnosed with Asperger Syndrome on their journey to independent, successful adults. Data from this study may also assist in evaluating local support services currently provided to this population. If you have any questions about this study, please feel free to contact Dr. Rosemary McCaslin, Professor of Social Work, at (909) 537-5507.

If any questions during the interview created any feelings that you would like to discuss further with a counselor or therapist, please contact resources provided below. If you would like to view the results of this study, they will be available at the John M. Pfau Library on the California State University, San Bernardino campus after September 2014.

The Asperger Syndrome & High-Functioning Autism Association (AHA)

AHA serves individuals on the autism spectrum, their families, and the professionals who work with them, providing crucial resources and support as they face challenges, build on their strengths and fulfill their potential. AHA helps families and individuals become informed self-advocates. Our programs encourage awareness and acceptance. www.ahany.org/index.htm.

The Global and Regional Autism Spectrum Partnership (GRASP)

GRASP's mission is to improve and enrich the lives of adolescents and adults on the autism spectrum, and their families through, community advocacy & outreach, education, peer supports, programming and services, at no cost to its members. Contact GRASP by calling **1(888)474-7277** or visit <http://grasp.org/main>.

The Psychological Counseling Center (PCC) at CSUSB

The counseling staff at the PCC is available to serve CURRENTLY ENROLLED CSUSB STUDENTS Monday through Friday with evening hours offered on Tuesdays and Wednesdays. The PCC is not open weekends or holidays, but if you need to talk with a counselor anytime of the day or night, call **(909)-537-5040**.

211 San Bernardino County. An information and referral service to help you connect with health and social services. By dialing **2-1-1** (or **888-435-7565**) in San Bernardino County, you will be assisted 24 hours a day, 7 days a week by bilingual staff (Spanish). If you need assistance in another language, 211 utilizes a translation line, available to communicate in over 150 languages. You may also access the 211 website at <http://www.211sb.org>.

REFERENCES

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- American Psychiatric Association. (2013). *DSM-5: Autism Spectrum Disorder Fact Sheet*. Retrieved from <http://www.dsm5.org/>.
- Asperger's Association of New England(AANE). (2013). *Living with Asperger's syndrome-adults*. Retrieved from <http://aane.org>.
- FAAS, Inc. Families of Adults with Affected by Asperger's Syndrome. (2008). *Adults with Asperger's syndrome*. Retrieved from <http://www.faaas.org>.
- Graetz, J. E., & Spampinato, K. (2008). Asperger syndrome and the voyage through high school: Not the final frontier. *Journal of College Admission, Winter*, 19-24.
- Higgins, K. K., Koch, L. C., Boughfman, E. M., & Vierstra, C. (2008). School-to-work transition and Asperger syndrome. *Work* 31, 291-298.
- Hutchinson, E. D. (2003). *Dimensions of human behavior* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome. *Autism* 10(4). 403-414. doi: 10.1177/1362361306064432.
- Macleod, A. (1999). The Birmingham community support scheme for adults with Asperger syndrome. *Autism* 3(2), 177-192.
- Munro, J. D. (2010). An integrated model of psychotherapy for teens and adults with Asperger syndrome. *Journal of Systemic Therapies* 29(2), 82-96.
- Portway, S. M., & Johnson, B. (March 2005). Do you know I have Asperger syndrome? Risks of a non-obvious disability. *Health, Risk & Society* 7(1), 73-83. doi: 10.1080/09500830500042086.
- Schall, C. M., & McDonough, J. T. (2010). Autism spectrum disorders in adolescence and early adulthood: characteristics and issues. *Journal of Vocational Rehabilitation* 32, 81-88. doi: 10.3233/JVR-2010-0503.

VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the Autism spectrum: College and beyond. *Journal of Autism & Developmental Disorders* 38, 1359-1370. doi: 10.1007/s108003-007-0524-8.