

2015

Goal Achievement in Young Adults with Asperger Syndrome and High Functioning Autism

Melissa Racobaldo

University of South Carolina - Columbia

Follow this and additional works at: <http://scholarcommons.sc.edu/etd>

Recommended Citation

Racobaldo, M. (2015). *Goal Achievement in Young Adults with Asperger Syndrome and High Functioning Autism*. (Master's thesis). Retrieved from <http://scholarcommons.sc.edu/etd/3110>

This Open Access Thesis is brought to you for free and open access by Scholar Commons. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of Scholar Commons. For more information, please contact SCHOLARC@mailbox.sc.edu.

Goal Achievement in Young Adults with Asperger Syndrome
and High Functioning Autism

by

Melissa Racobaldo

Bachelor of Science
Clemson University, 2011

Bachelor of Science
Clemson University, 2012

Submitted in Partial Fulfillment of the Requirements

For the Degree of Master of Science in

Genetic Counseling

School of Medicine

University of South Carolina

2015

Accepted by:

Crystal Hill-Chapman, Director of Thesis

Suzanne McDermott, Reader

Sarah Ravan, Reader

Lacy Ford, Vice Provost and Dean of Graduate Studies

© Copyright by Melissa Racobaldo, 2015
All Rights Reserved.

Dedication

For my family, for supporting me since Day 1 and for allowing me to understand what unconditional love truly is. And for my nieces and nephews, my inspiration to be the best aunt and role model I can.

Acknowledgements

I would like to thank the USC Genetic Counseling Program, where I was provided with every opportunity and support to grow into the Genetic Counselor I am today. To my classmates, with whom I have made the happiest (and most stressful) memories over the past two years, to Janice, our leader and provider of endless motivation, and to Peggy, who has continuously provided us with support over the past two years.

I would like to thank Crystal, Dr. McDermott, and Sarah, who stuck with me on this thesis topic even in the most stressful and desperate of times. I would also like to thank the many individuals I contacted to help spread the word on my thesis. Although there was not as much uptake as we would have hoped for, I know a fantastic community supported us. Last but certainly not least, I would like to thank the participants in my study, and not just because they were the reason for its completion. It takes a lot of strength to be able to discuss times in your life that were difficult, and I have truly benefited from learning the persistence and perseverance required for these individuals to overcome some of the obstacles they have faced.

“And now these three remain: faith, hope, and love, but the greatest of these, is love.”

1 Corinthians 13:13

Abstract

Purpose: This study aimed to evaluate perspectives of young adults with Asperger syndrome (AS) and High Functioning Autism (HFA) regarding supports and services, future goals, and confidence in their success. The goal of this study was to identify valuable supports and areas in which this support was lacking. Identifying areas of support for young adults with AS/HFA transitioning into adulthood aids in providing consistent services for successful goal achievement. The study has value among genetic counselors as the discovery of genetic etiologies of autism has led to referral of families with ASD to the genetics clinic. **Methods:** Young adults with AS/HFA were invited to participate through an online questionnaire or telephone or in-person interview. Invitation letters were sent via email to local and national support groups and colleges in South Carolina, as well as on social media sites. The online questionnaire and interviews included questions regarding receiving a diagnosis, education, supports and services, future goals, feelings regarding the DSM-5, and demographics. **Results:** Of the total respondents, ($N=12$), eight met the inclusion criteria, four completed the online questionnaire, two completed a telephone interview, and two completed an in-person interview. Participants felt their diagnoses provided a source of identity and explanation for their differences, which were not always viewed as positive. A family member, teacher, or peer who understood the diagnosis or shared a likeness with the participant was identified as the greatest source of support. Current services were minimal, and participants lacked confidence in achieving future goals and felt they could benefit from

help in social skills or goal planning. Participants with AS did not favor the new DSM-5 change because of their identification with the diagnosis. None of the participants reported meeting with a genetic counselor. **Conclusions:** Young adults with AS/HFA are lacking in support during their transition to adulthood and pursuit of their future goals, particularly in the area of social communication. The findings of this study allow genetic counselors to be better prepared in identifying these areas of need and directing families to the appropriate resources when they present in the genetics clinic.

Table of Contents

Dedication.....	iii
Acknowledgements.....	iv
Abstract.....	v
List of Abbreviations	xi
Chapter 1: Background	1
Chapter 2: Goal Achievement in Young Adults with Asperger Syndrome and High Functioning Autism	14
2.1 Abstract	15
2.2 Introduction	16
2.3 Materials and Methods	21
2.4 Results	23
2.5 Discussion	31
2.6 Conclusions	38
Chapter 3: Conclusions.....	40
References.....	42
Appendix A – Participant Invitation Letter: Online Questionnaire	45
Appendix B – Online Questionnaire.....	47
Appendix C – Participant Invitation Letter: Interview	53
Appendix D – Interview Questions.....	55
Appendix E – Interview Transcriptions.....	57

List of Abbreviations

AD	Autistic Disorder
APA	American Psychiatric Association
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
CNV	Copy Number Variant
DSM	Diagnostic and Statistical Manual of Mental Disorders
GC	Genetic Counselor
HFA	High Functioning Autism
NT	Neurotypical
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
REM	Reciprocal Engagement Model
SCD	Social Communication Disorder
SST	Social Skills Training
TC	Transition to Community
VR	Vocational Rehabilitation
VR-SCT	Virtual Reality Social Cognition Training

Chapter 1. Background

1.1 The History of Asperger Syndrome (AS)

Hans Asperger, a Viennese pediatrician, first defined Asperger syndrome in 1944 after close observation of young children in his clinic. He termed the condition ‘autistic psychopathy’, and described the features of the group of children he presented as having a variety of impairments in learning, attention, behavior, emotions, and instincts, particularly when in the context of social interactions. It was noted that none of the children who shared these features had either impaired intellectual capabilities nor delayed language development, and that there were overlaps of his clinical picture with conditions such as schizophrenic psychoses. During his observations, he found that it was possible for his group of subjects to form relationships and maintain a stable personality over time, differences owing for this separate diagnosis to be recognized (Hippler & Klicpera, 2003).

Lorna Wing, an English psychiatrist, followed Asperger’s works and observed individuals in her own clinic who fit the picture of this ‘autistic psychopathy’ (1981). She suggested the use of a diagnosis of Asperger syndrome (AS) instead, due to the negative connotations associated with the word “psychopathy”. She agreed that the features of this disorder did overlap with features of autism. However, some features were lacking in several key areas that made the clinical picture deserving of its own diagnosis. AS shares with autism the impairments in communication and social interactions and behaviors that exemplify resistance to change, repetition of activities,

and restricted interests. Major differences noted by both Asperger and Wing were that the majority of individuals did not have a delay in the development of speech and that they were of normal to high intelligence. The accounts mentioned that individuals with this condition were able to form relationships and hold jobs, although not without experiencing difficulties (Wing, 1981).

The Diagnostic and Statistical Manual of Mental Health (DSM) first adopted this newly termed condition, AS, in 1994 into the fourth edition (DSM-IV). Criteria outlined in the DSM-IV included an impairment in social interaction and repetitive and stereotyped patterns of behaviors similar to autism without clinically significant delay in language, cognitive development, or age-appropriate self-help skills, and curiosity with their surroundings (APA, 1994). In the years following this addition, there was great difficulty in providing a consistent diagnosis of AS among individuals, as this diagnosis was subject to change (APA, 2013) and created confusion among physicians and other healthcare professionals.

1.2 AS, High Functioning Autism (HFA), and Evolution of the DSM

The DSM is dynamic and has been undergoing such adaptations since the first published edition in 1952. It is used for providing a diagnosis following the criteria that can be communicated among health professionals. A diagnosis can help drive the future management and care of the individual according the specific symptoms of the individual. Diagnostic inconsistency is one reason the DSM has frequent revisions, as it is a current review of diagnostic criteria. Thus, researchers and work groups work hard at developing DSM criteria for specific diagnoses, which has been the case for the evolution of AS.

Wing (1981) mentioned the interchangeable nature of the condition AS and another autism spectrum disorder (ASD) known as high functioning autism (HFA). HFA did not appear as a diagnosis with the inclusion of ASD in the DSM-III (1980). However, it became a widely recognizable condition in which individuals who received the diagnosis were noted to have the diagnostic features of ASD but an IQ in the range above 70 (Ghaziuddin & MountainKimchi, 2004). The main characteristic for differentiating the diagnosis of one over the other was to determine if a language delay was present (HFA) or not (AS), leading to a distinction that can be problematic when trying to determine what clinical presentation qualifies as a delay. Sanders (2009) reviewed the history of AS and HFA in an attempt to determine whether there was a clear-cut distinction between the two, and it was apparent to the researcher that there was not. He felt strongly enough to say that “up to now, there seems to be little consistent evidence of significant differences in symptomology, or social, emotional, or psychiatric problems between AD and HFA” (p. 1565), where AD means Asperger Disorder.

The release of the most recent version of the DSM in May of 2013, the DSM-5, brought the change from four separate pervasive developmental disorders (PDD) to a solitary named spectrum of disorders, Autism Spectrum Disorders (ASD). Instead of individuals receiving a diagnosis of Autistic Disorder, Asperger Syndrome, Childhood Disintegrative Disorder, or PDD-NOS (not otherwise specified), the umbrella ASD diagnosis will be given. The ASD diagnosis is ranked according to severity of symptoms in the two main categories of social communication impairments and restricted repetitive patterns of behavior. The Neurodevelopmental Work Group saw the need for this diagnostic adjustment because of the previously mentioned inconsistencies that spanned

across not only AS and HFA, but also across the four separate diagnoses in individuals across different centers and clinics. The work group felt that having this continuum where symptoms are ranked from mild to severe has more potential to allow for earlier diagnosis (APA, 2013). A study by Huerta, Bishop, Duncan, Hus, & Lord (2012) determined that the DSM-5 identified 91% of 4,453 children who currently had a clinical diagnosis of one of the four PDD categories and 690 children with non-PDD diagnosis (such as language disorder) by the DSM-IV. There remains a lack of literature on what actual impact this change has had on receiving a diagnosis, and it is therefore important to continue tracking the impact this change may have.

1.3 Reactions to the DSM-5 from the “Aspie Culture” and Perceived Outcomes

Since the development and recognition of AS, a strong identity and community has formed, and an “Aspie culture” has been growing for over the past 20 years. Those who identify as “Aspies” have expressed concerns about the removal of the AS diagnosis from the DSM-5. Spillers, Sensul, & Linton (2014) evaluated online discussion boards frequented by Aspie individuals. The main themes they found in these discussions were potential losses of their identity and community, an unfavorable trend towards the “cure movement”, and the potential loss of services they had received.

The “neurodiversity” movement began in the 1990s and was spearheaded by Judy Singer, a sociologist whom herself had a diagnosis of AS. This movement highlights the concept that each individual has a varying degree of neurological abilities, and therefore receiving a diagnosis of a specific neurological or neurodevelopmental disorder is just a variant of normal (Jaarsma & Welin, 2011). One of the key points of the neurodiversity movement is that the condition, this variant of normal, is a part of what makes a person

who they are. This would lead individuals to refer to themselves as an autistic person rather than a person with autism, as the latter would refer to an individual who is trapped underneath a diagnosis, a contradiction to the person-first language that is taught to be preferred in the public.

Spillers et al. (2014) found a collective acknowledgement in online message boards and threads that the public, policy makers, and medical professionals had little grasp on the issues that affected the neurodiverse AS individuals. One excerpt they retrieved from a message board said, “We should clarify exactly which characteristics of AS are disabling in NT world. Issues where we need support to function as contributing members of society” (p. 255), where NT stands for neurotypical. These individuals were broadly concerned that they may no longer qualify for services they had received, and that the generalized services would not be tailored to their particular needs. The majority of individuals said that they developed the ability to mimic social behaviors that would allow them to cope and function in society, but still felt the pressure of the concept of a “cure movement”. They do not want to be cured. The author stated that they have a “style of neurological processing that couldn’t possibly go away, although social skills might improve” (p. 254).

To convolute the situation a bit more, a new diagnostic category referred to as social communication disorder (SCD) has been added to the DSM-5 and is considered to be a potential future diagnosis for an individual who may have had AS or PDD-NOS (Coury, 2013). This diagnosis could pose the greatest risk for loss of services, even though individuals diagnosed with SCD will most likely receive therapies for speech and language domains.

1.4 Connecting with the Features of AS: Impact on Individuals Diagnosed

Receiving a diagnosis of AS can help individuals feel empowered and find an explanation for why they previously felt isolated or different when compared to their peers. As far back as Wing's case studies reported in 1981, documentation exists that some form of depression or anxiety related to difficulties in making social connections and understanding social language exists, and missed opportunities to connect with peers are one outcome of these difficulties. Nearly all individuals with AS experience difficulties interpreting social cues and relating to peers which can, at least in part, be attributed to an inappropriate use of nonverbal behaviors and lack of social or emotional reciprocity (Giarelli & Fisher, 2013). Muller, Shuler, & Yates (2008) investigated the communication challenges that affect social interactions and found that participants in their study "dreaded having to engage in 'chit-chat' with colleagues, schoolmates, or peers, because such conversation can be bewildering in that it doesn't appear to follow a predictable set of rules" (p. 279). When the social language does not follow a predictable set of rules that these participants were referring to, it emphasizes the nature of an AS individual's resistance to change. This resistance to change can also display itself in a form of repetitive or restricted behaviors, the meticulously following of a set rules, and arrangement of objects in a certain way.

Punshon, Skirrow, & Murphy (2009) found that participants in their study sought out support services that they had not yet received prior to a diagnosis. The individuals found great value in having access to these supports, including "meeting other people with AS, making friends, and feeling as though they 'fit in' with a group of people" (p. 277). They also were able to identify the core features of AS that they themselves had

and made an effort to compensate for this, particularly through trying to learn appropriate social skills. The majority of participants in the Muller et al. (2008) study also described ongoing efforts to compensate for the effects...by developing greater social/self-awareness...[the diagnosis] helped participants identify and address areas of weakness such as reading body language, or using pitch and intonation to communicate affect...Most reported social understanding improved with time and effort. (p.180)

Receiving a diagnosis can lead to receiving recommended management of the condition. Early language and nonverbal skills are considered to predict positive outcomes in adaptive behavior, communication, and socialization for individuals with AS and ASDs (Szatmari, Bryson, Boyle, Streiner, & Duku, 2003), which emphasizes the importance of early intervention through social skills training (SST). SST “involves teaching specific skills (e.g., maintaining eye contact, initiating conversation) through behavioral and social learning techniques” (White, Keonig, & Scahill, 2006, p. 1859) and can be of benefit to prevent social dysfunction. Individuals with AS or HFA are at a higher risk than those of the general public for unemployment and less satisfying personal relationships, so they rely on SST to learn how to navigate their social environment (Rao, Beidel, & Murray, 2008). The environment after secondary education becomes less predictable as social contexts are continuously changing, making this time occasionally overwhelming (Giarelli, Ruttenberg, & Segal, 2013). Thus, it is not uncommon for neuroatypical individuals to feel challenged, and the struggles for these individuals at this time are vast (Giarelli & Fisher,

2013). Previous studies have shown that the process of transitioning to the community takes on an entirely new complexity for individuals with AS due to the condition's core features.

1.5 Transition to Community (TC) for Individuals with AS

The transition from childhood to adulthood is a natural process that occurs as individuals develop and take on different roles in their community. As children grow into adulthood they gain independence over their future in social, vocational and educational realms (Giarelli & Fisher, 2013; Giarelli et al., 2013). For some it means taking responsibility for their health, forming romantic relationships, beginning their own family, getting a college degree, and supporting themselves by obtaining a job. The transition represents a collection of different social systems that individuals must choose to become a part of, such as a specific work force or a group among their peers. A large part of their success during this transition depends upon “content and process of communication of others in the social system” (Giarelli et al., 2013, p. 564). This communication and processing content refers to both expressive and reciprocal interaction between the individual and those with whom they interact. Often times, achievable goals are set prior to this transition in order for individuals to identify the future steps they need to make to reach these successes.

Certain features that make individuals with AS highly qualified candidates for jobs or various community roles are their intellectual capacities and organizational skills (Giarelli et al., 2013). A need for organization or abiding by an explicit set of rules can make individuals successful in an environment that requires regulation or quality assurance (Giarelli & Fisher, 2013). Skills that were once considered to be disruptive to

a task can become a valuable tool when channeled into the right role. Roux et al. (2013) found that a little more than half of a population of individuals with ASD that they studied had held jobs. They also found that “young adults with an ASD who had higher functional skills” and “better conversational abilities” (p. 936) were the most likely of the group to achieve employment.

The imbalance between intellectual strengths and lack of social skills can also make it difficult for employers and individuals in the community to understand individuals with AS. Individuals in the study by Giarelli et al. (2013) expressed that extrinsic barriers were much harder to manipulate. These barriers were identified as the inflexibility of a work, school, or living environment; coworker or community negativity; and just the general misunderstanding of AS. Participants in the Griffith, Totsika, Nash, & Hastings (2012) study felt that the medical professionals who were supposed to be advocating for them and helping to get their support needs met showed a misunderstanding of the content of AS and how it affected the individual. All reported, “attempts at accessing formal support were generally unsuccessful...due to lack of knowledge about AS among health and social service professionals” (p. 541).

There are a few sources of employment support that can be identified to help correct for this perceived lack of knowledge. Informal and formal instruction to increase autism awareness in the community, particularly with employers and coworkers, and job coaches, in addition to using SST adjusted to the workplace (Griffith et al., 2012) are possible interventions.

In 2013, Giarelli et al. interviewed adolescents with AS and found that they considered their features as both barriers and bridges to successful transition to

adulthood. The authors reported that the awareness of an AS diagnosis provided insight to the individuals about intrinsic barriers which included social difficulties, restricted interests, repetitive behaviors, and associated features of AS including limited attention span and focus, difficulties in motor control, and low self-image. These perceived barriers were considered to be under the individuals' control, and participants felt that it would be easier to adapt themselves to accommodate for these barriers, rather than to expect that their surroundings would adapt to accommodate them, such as coworkers, employers, and community members.

1.6 Identifying and Achieving Future Goals

Resistance to change and social impairment are some of the largest obstacles that individuals with AS need to overcome in order for them to transition to the community successfully (Giarelli & Fisher 2013; Giarelli et al., 2013). In addition, it is important to determine what individuals actually consider a successful transition to community. The Giarelli & Fisher study (2013) found that all of their participants considered achieving some level of independence to be their main goals. Benchmarks of independence included living alone or with a friend, attending college, gaining employment, finding a partner, marrying, and raising a family.

Identifying desires and goals plays an important initial step in transition. Perhaps the pathway to success lies in finding and clearly defining the intermediate steps that are needed. For example, participants in the study by Muller et al. (2008) expressed that they longed for “greater emotional intimacy” (p. 179), which included romantic and other relationships. The combination of social support for individuals with AS and the education of individuals close to them about what AS really means could be the first step

to developing desired relationships. Muller et al. (2008) also found that their participants wanted to be advocates for others affected with AS in any way they could, including organizing support and advocacy groups, volunteering at events, and sharing their stories at conferences or teacher preparation classes. This particular group of individuals is highly motivated to give back to their communities in order to prepare the younger generation and community so that transition success may be achieved.

1.7 Services Utilized in the Transition Process

SST for individuals with ASDs can arguably be considered the prime component in their successful transition process. Punshon et al. (2009) explained that the transition “should be considered not a single event, but as a process that may span months/years” (p. 281). Most individuals from the study proposed that development of more social support networks would be of significant benefit to other individuals with AS. Vocational rehabilitation (VR) is also another avenue that has been increasingly utilized amongst transition-aged individuals with ASDs, yet there is an incomplete understanding of why individuals who undergo VR still show variability in employment outcomes (Burgess & Cimera, 2014).

In 2013, Kandalafi, Didehbani, Krawczyk, Allen, & Chapman released a research study analyzing the results of a Virtual Reality Social Cognition Training (VR-SCT) intervention in young adults with ASD. Eight individuals with high-functioning autism between the ages of 18-26 completed ten sessions of the VR-SCT over a period of five weeks. Pre- and post-training evaluation showed participants’ increase in social skills, including social cognition and social functioning related to emotion recognition and occupational functioning. The authors projected that the social difficulties experienced

during the transition to adulthood of individuals with ASD would be mitigated if they participated in VR-SCT interventions.

1.8 Autism Spectrum Disorders (ASDs) and the Role of Genetics

The prevalence of ASD has increased from 1 in 150 children in 2000 to 1 in 68 since 2010 (CDC, 2014). There have been many theories as to the cause of ASD, and over the years it has been discovered just how complex this condition is. Not only is there clinical heterogeneity for ASD as made evident with the new diagnostic continuum of features, but also it is genetically complex. There are many different underlying loci with reduced and variable penetrance, syndromic forms, and monogenic forms that can be used to explain the presentation of ASD. With the advancement of technology and genetic testing techniques, researchers have identified copy number variants (CNVs) and point mutations that range from full penetrance to polygenic forms with not yet described gene-gene and gene-environment interactions (Persico & Napolini, 2013). There are numerous environmental agents that have been identified that interact with genetic and epigenetic factors that result in ASD and AS. As of today, what we can summarize is that most causes of ASD remain unknown, however, a genetic cause can be identified in up to 25% of diagnosed cases (Huguet, Ey, & Bourgeron, 2013). Families may be referred to a genetics specialist to determine if the cause of the ASD lies in this 25%, or to assign a recurrence risk (Carter & Scherer, 2013) based on empiric evidence.

Many adults continue to depend on family for support, which may in part be due to the lack of understanding and effective advocates for AS. There is still a gaping hole of information for young adults with AS about the skills needed for a successful transition to community life. With the new DSM-5 change, it is likely that individuals

with AS or HFA will receive a diagnosis of ASD, which would give them the option of meeting with a geneticist and genetic counselor. Although genetic counselors usually interact with families during the early years of diagnostic testing, adolescents and young adults with AS may return to genetic counselors around this time of transition.

Genetic counselors provide a balance of medical knowledge and psychosocial support to the families they see through use of the Reciprocal Engagement Model (REM). The REM is based on five tenets that make up genetic counseling, which reflect the education aspects, individual attributes, and relationship aspects of the session. These tenets are “genetic information is key,” “patient autonomy must be supported,” “patients are resilient,” “patients emotions matter,” and “relationship is integral to genetic counseling” (Veatch, Bartels, & LeRoy, 2007, p.724). “The most important and impactful outcomes of genetic counseling from clients’ perspectives are often of a psychosocial nature” (Austin, Semaka, & Hadjipavlou, 2014, p. 905). If genetic counselors and other advocates were aware of the struggles that these individuals face with regards to transition into adulthood and achieving their future goals, the focus of the counseling session could be shifted to address these challenges and gather resources and referrals necessary for future success. The best way to determine how to overcome this potentially difficult transition process is to identify the future goals of the individual

Chapter 2: Manuscript

Goal Achievement of Young Adults with Asperger Syndrome and High Functioning Autism¹

¹ Racobaldo, M., Hill-Chapman, C., McDermott, S., & Ravan, S. To be submitted to *Journal of Autism and Developmental Disabilities*

2.1 Abstract

Purpose: This study aimed to evaluate perspectives of young adults with Asperger syndrome (AS) and High Functioning Autism (HFA) regarding supports and services, future goals, and confidence in their success. The goal of this study was to identify valuable supports and areas in which this support was lacking. Identifying areas of support for young adults with AS/HFA transitioning into adulthood aids in providing consistent services for successful goal achievement. The study has value among genetic counselors as the discovery of genetic etiologies of autism has led to referral of families with ASD to the genetics clinic. **Methods:** Young adults with AS/HFA were invited to participate through an online questionnaire or telephone or in-person interview. Invitation letters were sent via email to local and national support groups and colleges in South Carolina, as well as on social media sites. The online questionnaire and interviews included questions regarding receiving a diagnosis, education, supports and services, future goals, feelings regarding the DSM-5, and demographics. **Results:** Of the total respondents, ($N=12$), eight met the inclusion criteria, four completed the online questionnaire, two completed a telephone interview, and two completed an in-person interview. Participants felt their diagnoses provided a source of identity and explanation for their differences, which were not always viewed as positive. A family member, teacher, or peer who understood the diagnosis or shared a likeness with the participant was identified as the greatest source of support. Current services were minimal, and participants lacked confidence in achieving future goals and felt they could benefit from help in social skills or goal planning. Participants with AS did not favor the new DSM-5 change because of their identification with the diagnosis. None of the participants

reported meeting with a genetic counselor. **Conclusions:** Young adults with AS/HFA are lacking in support during their transition to adulthood and pursuit of their future goals, particularly in the area of social communication. The findings of this study allows genetic counselors to be better prepared in identifying these areas of need and directing families to the appropriate resources when they present in the genetics clinic.

2.2 Introduction

2.2.1 The History of Asperger Syndrome (AS). The first clinical description of Asperger syndrome (AS) was made in 1944 by a pediatrician named Hans Asperger and was referred to as an ‘autistic psychopathy’. While the condition he described shared the features of autism spectrum disorders (ASDs) in impairments in learning, attention, behavior, emotions, and instincts, his subjects maintained stable personalities, formed relationships, and had neither impaired intellectual disability nor delayed language development (Hippler & Klicpera, 2003). Lorna Wing brought worldwide attention to this condition and gave it a new name of Asperger syndrome (AS), as she felt that psychopathy presented too negative of a connotation for the condition (Wing, 1981). In 1994, AS was adopted into the fourth edition of the Diagnostic and Statistical Manual of Mental Health (DSM) as a separate diagnosis from ASD. Criteria for AS included impairments in social interaction and repetitive and stereotyped patterns of behaviors similar to autism without intense preoccupation with surroundings or clinically significant delay in language, cognitive development, or age-appropriate self-help skills (APA, 1994).

Since the DSM-IV, there have been dilemmas and inconsistencies with individuals being diagnosed with AS (APA, 2013). There has been confusion about the

distinction between AS and High Functioning Autism (HFA), where individuals meet all the criteria for ASD but have an IQ above 70 (Ghaziuddin & MountainKimchi, 2004). Wing noted the interchangeable nature of AS and HFA (1981), but felt a language delay was the key to deciphering between the two. Sanders (2009) concluded that in his review of the history of AS and HFA, “there seems to be little consistent evidence of significant differences in symptomology, or social, emotional, or psychiatric problems between AD (Asperger Disorder) and HFA” (p. 1565).

It was hoped that the release of the DSM-5 in May 2013 would help clear up the long-standing confusion, since the umbrella term of Autism Spectrum Disorder (ASD) was used. The once categorized pervasive developmental disorders (PDD) of autistic disorder, AS, Childhood Disintegrative Disorder, and PDD-NOS (not-otherwise specified) became a continuum where symptoms are ranked from mild to severe (APA, 2013). Using clinical data on 4,453 children with a diagnosis of one of the four PDD categories and 690 with non-PDD diagnoses, Huerta, Bishop, Duncan, Hus, & Lord (2012) determined that 91% of those individuals would meet the DSM-5 diagnostic criteria.

2.2.2 Self-perception of AS. The concern for this change comes most strongly from the “Aspies,” or those diagnosed with AS themselves who have spent the past 20 years growing what they refer to as an “Aspie culture.” They fear for a loss of identity, community, and services received, as well as foresee an unfavorable trend towards the “cure movement” (Spillers, Sensul, & Linton, 2014). Since the 1990s, the “Aspies” have followed the lead of Judy Singer to support the “neurodiversity” movement, which highlights the concept that each individual has a varying degree of neurological ability.

Receiving a diagnosis of a specific neurological or neurodevelopmental disorder such as AS is just a variant of normal (Jaarsma & Welin, 2011). The greatest risk for loss of services outside of speech and language domains comes with the new diagnostic category of social communication disorder, a potential diagnosis rather than AS (Coury, 2013).

For many individuals, their AS diagnosis meant empowerment and helped explain why they felt isolated or different from their peers. There was an explanation for their difficulty interpreting social cues and nonverbal behavior, along with their lack of social or emotional reciprocity (Giarelli & Fisher, 2013). In 2008, Muller, Shuler, & Yates (2008) found that many individuals with AS “dreaded having to engage in ‘chit-chat’ with colleagues, schoolmates, or peers, because such conversation can be bewildering in that it doesn’t appear to follow a predictable set of rules” (p. 279). Having a diagnosis allows individuals to seek out support services, meet other people with AS, and have a sense of “feeling as though they ‘fit in’ with a group of people” (Punshon, Skirrow, & Murphy, 2009, p. 277). In identifying the core features of AS in themselves, individuals can find ways to compensate by learning social skills. This was evident in the self-reports in Muller et al., where “most reported social understanding improved with time and effort” (2008, p. 180).

Early language and nonverbal skill therapy predicts positive outcomes in behavior, communication, and socialization for individuals with AS (Szatmari, Bryson, Boyle, Streiner, & Duku, 2003). Social skills training (SST) involves teaching skills such as initiating conversation and maintaining eye contact through behavioral and social coaching (White, Keonig, & Scahill, 2006).

2.2.3 Transition to Community (TC) for Young Adults with AS. SST also predicts success after secondary education, as individuals with AS or HFA are at a high risk for unemployment and less satisfying personal relationships than their NT peers (Rao, Biedel, & Murray, 2008). The transition to community introduces a new environment that is much less predictable as social contexts are continuously changing, and it can be overwhelming and challenging for both NT and neuroatypical individuals (Giarelli, Ruttenberg, & Segal 2013; Giarelli & Fisher, 2013). Transitioning to community means gaining independence over future social, vocational, and educational realms including taking responsibility for health, relationships, continuing education, and becoming employed (Giarelli & Fisher, 2013; Giarelli et al., 2013). Individuals with AS can be qualified candidates for some jobs or community roles because of their intellectual capability and organizational skills (Giarelli & Fisher, 2013; Giarelli et al., 2013).

Still, only a little over half of the ASD population that includes AS actually goes on to sustained employment. While the greatest correlation of this employment was the ability to communicate, individuals with AS are still struggling to obtain and maintain jobs (Roux et al., 2013). This might be attributed to the general lack of understanding of AS by employers and community members. The AS community themselves feel that their main advocates, the health and social service professionals, misunderstood the competencies of people with AS and therefore do not effectively work to get their support needs met. Increasing awareness among employers, coworkers, and job coaches possibly increases the potential for this change (Griffith, Totsika, Nash, & Hastings, 2012).

Just like any other individual in the community, individuals with AS want to achieve some level of independence (Giarelli & Fisher, 2013) through advanced

education, employment, or in their social life. Some long for greater intimacy, both in the platonic and romantic sense (Muller et al., 2008), and others see themselves as advocating for AS (Muller et al., 2008). Transition is a longitudinal process and “should be considered not a single event, but as a process that may span months/years” (Punshon et al., 2009, p. 281). As the prevalence of ASD has increased from 1 in 150 children in 2000 to the current prevalence of 1 in 68 children (CDC, 2014), more adolescents with AS are going through transition to adulthood.

2.2.4 The Role of the Genetics in ASD. Often, families are referred to genetic specialists to determine if the cause of ASD is genetic. While this study is not focused on the cause of ASD, the complexity in the clinical presentation is recognized in the newest edition DSM-5. There has also been recent identification of genetic components to autism with the advancement of technology and genetic testing techniques (Persico & Napolini, 2013). While the majority of cases of ASD have an unknown cause, a known genetic cause can be identified in up to 25% (Huguet, Ey, & Bourgeron, 2013). Individuals can pursue an evaluation by genetics to see if this cause can be identified. This can then be translated into a more accurate recurrence risk for family members than the typical empiric risk provided with ASD of unknown etiology (Carter & Scherer, 2013). Since the DSM-5 will likely result in AS being diagnosed as an ASD, individuals usually meet with genetic specialists, among them genetic counselors. Genetic counselors (GCs) provide education and psychosocial support to the families, using the Reciprocal Engagement Model (REM) based on the tenets that “genetic information is key,” “patient autonomy must be supported,” “patients are resilient,” “patients emotions

matter,” and “relationship is integral to genetic counseling” (Veach, Bartels, & LeRoy, 2007, p. 724).

While one of the primary roles of GCs is to educate families on genetics, they also assume the role as advocates for their patients, and therefore will likely advocate for their patients with AS/ASD. “The most important and impactful outcomes of genetic counseling from clients’ perspectives are often of a psychosocial nature” (Austin, Semaka, & Hadjipavlou, 2014, p. 905). In order to address the issues and provide beneficence to their families, GCs should be made aware of the struggles that are faced concerning transition into adulthood and achieving future goals. Speaking to these individuals directly to discover their goals and the steps they are currently taking to achieve them might help overcome the difficulties of the transition process. In assessing their confidence and finding out what areas are lacking, the genetic counselor can address challenges, gather resources, and make referrals to improve the likelihood for success.

2.3 Materials and Methods

2.3.1 Participants. The target participants were young adults between the ages of 18 and 25 with a diagnosis of AS or HFA. Study notifications and participant invitation letters were sent to support group leaders of local and national support groups, social media outreach, local colleges, and personal referrals from interested individuals. A link was included in the participant invitation letter to direct interested individuals to an online questionnaire, and another participant invitation letter was sent out that included contact information for the principle investigator to complete a telephone or in-person interview. Inclusion criteria for the questionnaire and interview included young adults with a current or former diagnosis of AS or HFA according to the DSM-IV criteria. The

participant also must have completed or is expecting to complete high school. Exclusion criteria included individuals with a physical disability. This study was approved by the Institutional Review Board, Office of Research Compliance, of the University of South Carolina, Columbia, SC in November, 2014.

2.3.2 Online Questionnaire and Interview Information. The online questionnaire was designed using Survey Monkey and included 35 questions. A copy of the participant invitation letter and the online questionnaire can be found in Appendix A and B, respectively. The questionnaire was available between November, 2014, and April, 2015.

These questions were also used as an outline for the semi-structured interview performed with individuals who were interested in participating in a telephone or in-person interview. A copy of the interview participant invitation letter and semi-structured question outline can be found in Appendix C and D, respectively. The eligible interview participants were contacted directly by the principal investigator after receiving notification of interest in participation through email or telephone. At this time, the interviewee and principal investigator decided on a time to conduct the full, semi-structured interview over the phone or in person, which was estimated to take approximately 30 minutes. The interview was conducted using the guided list of questions and the participant had the option to not answer a question or discontinue the interview at any point. The interviews were conducted in March and April, 2015.

In order to protect the confidentiality of the participants, any identifiers including email addresses and phone numbers were kept anonymous and were destroyed after

completion of the survey. No identifying factors were left in the analysis that could trace the participant's answers back to their identity.

2.3.3 Statistical Analysis. Data from SurveyMonkey.com was collected and organized for analysis. Frequency, counts, and percentages were used to review categorical data.

2.3.4 Qualitative Analysis. The interviews were recorded and transcribed verbatim to produce qualitative, categorical data that the principle investigator used to code into emerging themes that were validated by another reader. This was also the case for the open-ended question responses collected from the online questionnaire.

2.4 Results

2.4.1 Online Questionnaire Results. A total of eight participants completed the online questionnaire. However, only four surveys were used in the analysis due to the incompleteness of the remaining four surveys which did not meet the inclusion criteria. All four survey respondents were female with an average age of 22 years and had a diagnosis of AS. All participants lived with a family member, including a parent(s) ($n = 3$) and/or sibling(s) ($n = 2$) or their spouse ($n = 1$).

2.4.1.1 Receiving the Diagnosis. The average age at diagnosis was 19 years old and was achieved by a psychiatrist ($n = 2$), mental health care worker ($n = 1$), or self ($n = 1$). Table 2.1 shows the selections participants made when asked, "What do you see in yourself that matches this diagnosis?" and the number of respondents who agreed with the statements.

Table 2.1:

Self-Identification with the AS Diagnosis

Difficulty with social relationships	3 (75%)
Difficulty with communication, such as beginning or maintaining a conversation	4 (100%)
Difficulty picking up on social cues, such as body language	3 (75%)
Difficulty adjusting to changes in routine activities	4 (100%)
Difficulty recognizing subtle changes in speech, such as tone, pitch, and accent	3 (75%)
Avoidance of eye contact with others	3 (75%)
Preoccupation and increased knowledge in one or few interests	4 (100%)
Heightened sensitivity or overstimulation by loud noises, lights, or strong tastes or textures	4 (100%)

2.4.1.2 Education and Employment Information. The highest level of education completed by the participants was some college ($n = 2$), high school graduation ($n = 1$), and some high school ($n = 1$). The respondent that was still in high school is anticipating graduating within the year. The three remaining respondents reported being currently enrolled in college courses, employment through a contractor, and being a full-time housewife. All four indicated that they were mainstreamed in regular education classes, and the classes they excelled in were English ($n = 3$), Science ($n = 2$), Math ($n = 2$), and Art ($n = 1$).

2.4.1.3 Therapies, Support Services, and Genetic Counseling. Previous therapies received by the respondents included mental health services ($n = 4$), occupational therapy ($n = 1$), speech therapy ($n = 1$), and physical therapy ($n = 1$). All respondents indicated that they were not currently receiving any services, and that they had never met with a genetic counselor.

2.4.2 Interview Results. Two individuals completed a telephone interview and two completed an in-person interview. Three respondents were male and the remaining respondent was female with an average age of 21 years old. Three respondents reported AS and one reported HFA. Participants are either living with their parents ($n = 1$), in a dorm on campus by themselves ($n = 1$), in a condominium with a roommate ($n = 1$), or with their partner ($n = 1$). The average length of the four interviews was 21 minutes and 56 seconds.

2.4.2.1 Receiving the Diagnosis of AS or HFA. Not all respondents were certain as to when their diagnosis was made, but three were able to give an estimation of junior or sophomore year of high school, fourth grade, and at 23 years of age. The respondents also could not identify who it was that provided that diagnosis for them.

2.4.2.2 Education and Employment Information. One respondent was currently in high school anticipating graduation, two had completed high school and were pursuing their bachelor's degree, and one had received her/his bachelor's degree and was pursuing a master's degree. Three respondents reported that they mostly received mainstream education with few resource classes and the remaining respondent reported having mostly self-contained classes with a few mainstream courses. Courses that the respondents indicated excelling in were art ($n = 1$), math ($n = 1$), computer sciences ($n = 1$), history ($n = 2$), and science ($n = 1$).

2.4.2.3 Therapies, Support Services, and Genetic Counseling. The respondents were asked about current and previous therapies and support services they had received relating to their diagnosis. One reported previously having had mental health services and is currently receiving them on an as-needed basis. This participant is also a member

of a local support group geared towards young adults with AS. Another respondent reported previously having had speech therapy that stopped at some point in high school. Another respondent reported that he or she did not receive any types of therapies or support services. The final respondent could not recall any specific therapies or support services he or she received besides a job coach, but believes that there may have been social skills therapy at one point. None of the participants reported having attended a genetic counseling appointment.

2.4.3 Thematic Analysis. All eight participants from the online questionnaire ($n = 4$), telephone interview ($n = 2$), and in-person interview ($n = 2$) gave free responses to questions regarding the broad topics of how they feel about their individual diagnosis, their experiences with previous services or supports and education, future goal achievement, and the change in the DSM-5. Themes were derived from these responses and analyzed for frequency. Full transcriptions of the four interviews can be found in Appendix E.

2.4.3.1 Positives and Negatives of Having a Diagnosis. All respondents were asked to share what they thought were the positive and negative aspects of having a diagnosis. Only one respondent did not provide an answer for these questions. Understanding that a diagnosis provided an explanation for why they had differences was a positive aspect, as identified by the respondents:

- *Knowing that I'm not abnormal, and knowing that I need to change my way of doing things to maintain a successful and balanced life for my family and myself*
- *To know why I could never fit in at school, clubs, etc.*
- *I just wanted to know the answer to ...why I was experiencing life the way I was ...I always got the feeling that there was something sort of off about myself...and I couldn't place my finger on what it was*

They also identified features of the diagnosis that benefited them, such as being able to focus their special interests into career opportunities, having a good memory, and being able to creatively think about things differently. One respondent noted the negatives that could come included “struggle with sensory overload, and social situations can leave me physically exhausted. I sometimes act strange, and that makes me a target for bullies and other unsavory people. My special interests can quickly become addictions”.

Having a reason for why the respondents felt different from others was not always identified as a positive thing. This was partially attributed to the stigma that may come from receiving a diagnosis. Some quotes provided by the respondents included:

- *It's difficult knowing you process information differently and can't do anything about it.*
- *People look at you differently, people treat you differently, just because its got a name now.*
- *At first...it explained a lot of things for me, but after a while...my old feelings came back and I still felt that I am not right. Just because I have an answer for why I am doesn't mean that I'm okay with it...I'd just rather not have it.*
- *I feel like everybody knows each other on a level that I can't really see...it's just frustrating being blind to those kinds of things.*
- *I felt like I was just completely different from everybody...it was just really rough on me.*

2.4.3.2 Support from Family Members, Teachers, and Peers. Seven out of eight respondents felt that it was a family member ($n = 5$) and/or teacher ($n = 3$) and/or peer ($n = 2$) that provided them with the most support. Family members identified included a parent ($n = 5$), grandparent ($n = 1$), and brother ($n = 1$). The respondents felt the greatest support when there was an understanding or likeness between themselves and their

support person. The following statements are quotes that were taken directly from the open-ended and interview questions that illustrate this level of support:

- *I do better in groups with people who kind of relate to me and kind of share my experiences and maybe get a little hint here and there from them...The reason I like groups more is because there's more dialogue going on, especially when they're in your, your own sort of 'neck of the woods' so to speak.*
- *They kinda like understood that I had Asperger's and a lot of my teammates also had ADHD and all these other things like different disabilities.*
- *They listened and took me seriously when I told them why I behave in certain ways.*
- *Some teachers recognized I was gifted.*

However, teachers and peers were also identified as a source of struggle or difficulties for the respondents. This is observed in the following statements taken directly from the interviews and online responses:

- *I've actually had teachers tell me in the middle of class, in front of everybody, that I was faking it, or that Asperger's wasn't real. Yeah, that was definitely tough*
- *Kids would make fun of me and they didn't know what Asperger's was and I got called a bunch of names like "retard" and stuff like that*

2.4.3.3. Achieving Independence Requires More Work. The majority of the respondents wanted to achieve some level of independence either through employment ($n = 6$) and/or completion of college in order to feel successful ($n = 3$). The following are direct statements that respondents provided when asked about what their most important goal was:

- *I just want to establish a good enough, stable income and a good enough life for myself.*
- *I would want to have a job and just, just have my own, my own living space.*

The respondents recognized that they would benefit from extra help, particularly in social skills and goal planning, in order to be successful. Up until this point, the majority of respondents had received this help through family members or worked on it themselves. Respondents who have felt more success with their social encounters provided a source of adjustment of their social realms to cover their previous difficulties. The following statements are direct quotes regarding this topic:

- *Eye contact, that's another thing that I was really, my mom really helped me out on eye contact...I think it's going to help a lot because when I'm going to get a job I want to be able to look somebody in the eye.*
- *I can kinda display myself well enough...I've been told that I can articulate myself very well...I learned some things, just trying to act on other people and such.*
- *I identified what I may need help with at university and where I can get help.*
- *There is no special education program in my school, but my mother works with the teachers...I am working to overcome this by asking questions and researching social skills, joining online Asperger's support groups, and keeping a card with the crisis center hotline on hand at all times in case I need it.*

Some respondents still lacked the confidence that their future goals would be achieved, even if they had received previous therapies or support services. Respondents expressed feelings of inadequacy in some areas they felt were important for being successful in adulthood, along with way that they might overcome this. Direct statements regarding the reasons as to why they may lack confidence in achieving their goals were as follows:

- *Getting through an interview is my biggest problem, because just associating with another person, especially in a kind of professional environment where they're really examining my personality and stuff...it's really going to be difficult for me to put on a, put on a different cloak of like, normalcy. Try to cover myself up to make sure they take me seriously.*
- *I feel a bit intimidated by the idea of finding a job and a place to live, since most entry-level jobs require more social skills than I currently have.*

- *Sometimes goals can be overwhelming and it is difficult to identify the steps needed to achieve it.*
- *My lack of social skills, especially my tendency to not look at people when they're talking and behave like a convicted criminal when I'm nervous.*
- *The transition between childhood and adulthood can be difficult for everyone, but especially for people on the autism spectrum. I can get overwhelmed when looking at the big picture, and it would help if someone reminded me to take small steps.*
- *I think it would be helpful to have someone who can help me pick the right education and job, because I can't do it for myself.*
- *I haven't received very good education in social skills and what to expect.*

2.4.3.4 Apprehensive Feelings Towards the DSM-5 Release. The seven respondents with a diagnosis of AS were asked to express their feelings regarding the AS diagnosis removal from the DSM-5. Only one respondent did not feel affected by this change, and responded, "I was told I was on the spectrum, and that if the old rules still applied it would be Asperger's." This respondent indicated that they received their diagnosis in November, 2014. Three respondents indicated a concern for the effects this would have on the types of help and services individuals with AS would receive due to their perceived differences between AS and ASD. Respondents also acknowledged that AS is another label they use to provide themselves an identity different from that provided by ASD. The following statements are direct quotes provided on this topic:

- *People with Asperger's Syndrome have different problems and need different services than people with other types of Autism Spectrum Disorders.*
- *People with Asperger's diagnosis may not have access to help.*
- *When one hears Autism, they immediately associate it with a person that will never be able to function without the assistance of another person. Asperger's individuals can take care of themselves through training and guidance. As long as we are given the proper way to perform we can navigate just fine.*

- *It's just another label, but labels do kind of change what people think.*
- *I understand that like Asperger's kind of falls under autism, with autism as like a wide spectrum, but Asperger's is like, sort of a narrow, specific area of that spectrum...getting rid of that name kind of leaves ambiguity.*
- *It's kind of not the same thing...I had some friends that had autism...and I just don't see us on the same line, or same page...I put up with a lot of difficulties but they put up with a lot more...I feel like people won't really know that Asperger's is like a real thing...I know a lot of people don't know what Asperger's is and they've just been like 'wow, you're making this up'.*

2.5 Discussion

2.5.1 The Diagnosis of AS Provides Individuals with an Identity. The average age at diagnosis was 19 years old among the participants of the online questionnaire, and while an exact average could not be ascertained from the interviews, the earliest age at diagnosis reported was in the fourth grade. The CDC provides a median diagnostic age for AS at 74 months, or six years and two months of age, and a median diagnostic age for ASD at 50 months, or four years and 2 months of age (2014). While the respondents in this study were diagnosed older than the average six years of age, the older age at diagnosis was not surprising.

Each respondent provided an awareness and self-identification of the features of AS that they saw in themselves. All of the features are consistent with the DSM-IV (1994) criteria of impairments in social communication and restrictive and repetitive behavioral stereotypes. Psychiatrists and mental health workers were identified as providing a diagnosis for three respondents, while the other five had a “self” diagnosis or were unsure who provided it. Three of the respondents who were unaware of who made the diagnosis could vaguely recall

the process of receiving the diagnosis. AS is a lifelong condition, so receiving a diagnosis was similar to receiving a description or label for the described differences the participants were experiencing. These results were similar to those found in the study by Punshon et al. (2009) of individuals with AS who felt their diagnosis provided them with an identity. This self-identification with AS could also provide an explanation for why our participants did not find the DSM-5 change as a favorable one.

2.5.2 An Explanation for Differences is Both Positive and Negative. A diagnosis of AS brought about both positive and negative feelings for our participants. Positive outcomes that were identified related to having an explanation for their feelings and utilizing their features in a productive way, which is consistent with how individuals in previous studies could benefit from identifying the careers that would align with certain features such as organizational skills (Giarelli & Fisher, 2013; Giarelli et al., 2013). Our participants explained that while having a diagnosis may have provided initial relief in terms of having a reason for their difficulties, the stigma, and the persistent feeling of being different was not mitigated by this label. Another participant acknowledged that while special interests can be beneficial, they also pose a threat of “quickly becoming addictions.” Two of the participants in this study also specifically mentioned feelings of depression. Simonoff et al. (2008) estimated up to a 70% incidence of comorbidity of psychiatric disorders with ASD. These findings are significant for a need to provide consistent and continuous resources for individuals with ASD.

2.5.3 Supports are Lacking Outside of Family Members, Teachers, &

Peers. Our participants expressed that their sources of support understood the challenges and needs for improvement. The most consistent support received was mental health services, and other therapies received were occupational therapy, speech therapy, physical therapy, and social skills therapy. Of note, our participants did not report receiving many therapies or support services outside of what they received from their family members, teachers, and peers. The lack of services can in part be explained by the older age at diagnosis of our participants. A later diagnosis means missed opportunities for the participants to be brought to the attention of appropriate therapists and support services to benefit them.

Our participants also reported that they would benefit from extra help, particularly in improving their social communication skills. Lack of typical communication skills is a difficulty expressed in nearly all individuals with AS (Giarelli & Fisher, 2013; Muller et al., 2008) so it was expected that our participants would feel intimidated by the social contexts that are to ahead of them in their adult future. Previous studies note that almost half of the population of individuals with ASD held jobs, and conversational skills were a positive predictor of this success (Roux et al., 2013), which emphasizes the importance of a development of comfort in conversation for these individuals. The majority of participants for our study had spent time developing their social skills with family members, teachers, and peers, or by working on it themselves.

2.5.4 Independence is the Ultimate Goal. Our participants identified goals that they wished to achieve in transitioning into adulthood, and each goal

identified related back to the theme of independence. Independence may mean losing that intimate connection and reliance on the supports of the family members, teachers, and peers that were found to be most beneficial at younger ages. This was the case for one of our participants whom expressed difficulties in his college courses, commenting on how he wished he had the same teachers who understood him and were helpful to him in high school. Individuals expressed how helpful it would be, or would have been, if they had someone that was able to help them plan out the future steps necessary to achieve their goals. One participant suggested having a job-focused session in his monthly support group meetings as a way for overcoming his feeling of inadequacy in interviewing skills. The concerns presented in these times of transitions are not new concerns to even NT young adults, and there still remains a need for how to accommodate the needs for all young adults in this area of transition to full adulthood.

2.5.5 Value to Genetic Counselors. Regardless of the consensus of negative attitudes towards the new DSM-5 change in our participants and those in previous studies (Spillers et al., 2014), referrals will be made for individuals with a diagnosis of ASD that perhaps may have once been diagnosed as AS. Due to the removal of AS from the new DSM-5 (APA, 2013), it is likely that individuals who would have previously received a diagnosis of AS will now receive a diagnosis along the autism spectrum (Huerta et al., 2012). The increasing prevalence of ASD to 1 in 68 (CDC, 2014) was paralleled by the identification of a variety of genetic causes of ASD (Persico & Napolini, 2013) in about 25% of cases (Huguet et al., 2013). Children with ASD are being referred to genetics clinics to determine this cause or to estimate a recurrence risk (Carter & Scherer, 2013), and to get

information on appropriate resources to help with the management of their ASD. It is likely that none of the participants have been to see a genetic counselor because the fluidity of AS and ASD, or HFA, had not yet been established at the time of diagnosis. There is a dearth of evidence as to the exact support genetic counselors provide to ASD families, or any families they see in general, and

there is a long-standing perception of genetic counselor bias among many in the disability community. This perception may be difficult for many to accept, because it challenges a goal of genetic counseling – to advocate for the needs of clients affected with disabilities (Madeo, Biesecker, Brasington, Erby, & Peters, 2011, p. 1783).

While this study is not focused on the genetic counselor relationship with individuals with AS, there is much value to be gained from the results of this study. Exploring first-hand the misconceptions that individuals with AS face, what supports and services they receive to aid in their symptoms, and their thoughts about future goal achievement, we can envision incorporation of genetic counselors to provide resources to aid in this transition process.

With the tendency of the AS diagnosis to come later in an individual's life, it is important for genetic counselors to be aware of the specific needs of these individuals and the possible referrals and services that could be beneficial in their management even without the identification of a genetic cause. Taylor, Edwards, & Ku (2006) suggested that adult patients check in with their genetics providers, which could be more efficient if the community were more aware of the value of a genetic counselor. An evaluation of preparedness of the transition surrounding

genetic conditions from childhood to adulthood was performed by Taylor et al. (2006). The authors acknowledged the lack of research regarding this topic, along with the lack of medical literature regarding “long-term prognosis, management of concomitant adult-onset disorders, and behavioral/psychological management of adults” (p. 298).

One way to bring about more awareness and to reconcile this uncertainty is for genetic counselors to “pursue opportunities and collaboration with disability communities” (2011, p. 1782) as suggested by Madeo et al. In performing qualitative studies such as this one, genetic counselors and other individuals in the community can be made aware of the struggles faced by young adults with ASD, and therefore will be better prepared in how to best counsel individuals with ASD/HFA whom they might see in the pediatric or adult clinic.

2.5.6 Future Direction. Additional research needs to be performed on the recent changes made to the DSM-5 in regards to the removal of AS and its suspected new diagnosis on the less severe end of ASD, or HFA. We have made speculations in this paper as to how individuals with a diagnosis of ASD who may have been considered AS will be referred to the genetics clinics. Research efforts need to determine if the level of severity of ASD has any influence on the referral patterns of these individuals to genetics. Continued research among young adults with a diagnosis of AS to confirm results from previous studies and to answer new research questions raised by studies such as this one needs to be ongoing. .

Another area for future research would be to perform a collaborative study with schools and genetic counselors to determine the utility that meeting

with genetic counselors could have for individuals during this transition phase. Individuals who receive a diagnosis of ASD at a later age may be referred to the genetics clinic around the same time that they would be discussing plans for their future.

2.5.7 Limitations. The small sample size of eight participants was a limitation of this study. However, findings were consistent with previous studies that performed interviews in this population (Giarelli & Fisher, 2013; Giarelli et al., 2013; Punshon et al., 2009). The nature of the AS or HFA diagnosis could be a contributing factor to this, and the sharing of information with a stranger could have made the task of completing an online survey or talking over the phone or in-person an unfavorable one. We recall from the study by Muller et al. that participants “dreaded having to engage in ‘chit-chat’ with colleagues, schoolmates, or peers, because such conversation can be bewildering in that it doesn’t appear to follow a predictable set of rules” (2008, p. 279). Interviewing and questioning individuals directly is also relying on complete recall of experiences that occurred in the past, which is not always consistent or accurate with actual events. For example, our participant’s parents may have more knowledge regarding the specific details of types of support and services received.

Another limitation is that colleges are not aware of all of the students with a diagnosis of AS or HFA unless these students are brought to their attention. We used the disability services of local colleges to help identify individuals who would qualify for the survey, as we thought that these services had a more

intimate relationship with the individuals and would provide more incentive to participate.

Another limitation of the study is that we do not know the equivalence between the survey and the interview. We based the semi-structured interview on the same questions asked on the online questionnaire, but due to the small sample size we were unable to compute statistics to determine the interview and questionnaire's reliability and validity.

2.6 Conclusions

This study further adds to results collected from young adults with AS and HFA about their overall feelings on the transition into adulthood. The participants had an average age of diagnosis in their early adulthood, so many of the individuals felt that having a diagnosis gave them an explanation for the differences they have been experiencing since their childhood. Participants could identify the social communication difficulties associated with the diagnosis and felt that it was one of the biggest hurdles to overcome in order to achieve their future goals of obtaining some level of independence in their future. Family members, teachers, and peers were found to be the most helpful supports throughout the individual's life, and careful attention has been paid to developing better skills in daily communication that NT individuals take for granted. The most common service received in the participants was mental health services, although it was not reported to be a consistent service. Few participants reported any other type of support outside of their family members, teachers, and peers. The consistency of supports and services is necessary for young adults with AS or HFA gaining independence through attending college, becoming employed, and living on their own, as they are at an

increased risk for psychiatric disorders and still feel ill-prepared for pursuing their goals. The DSM-5 change will likely provide individuals who would have received a diagnosis of AS with a diagnosis of ASD. Genetic counselors can be a source for identifying the necessary referrals and resources needed for this group as individuals with ASD are increasingly referred to the genetics clinic. This study provides personal perspectives articulated by these young adults with AS which genetic counselors can use to identify areas of need for this group, to advocate for their resources, and to provide appropriate referrals for management, especially during the complex and often difficult transition process into full adulthood.

Chapter 3: Conclusions

This study further adds to results collected from young adults with AS and HFA about their overall feelings on the transition into adulthood. The participants had an average age of diagnosis in their early adulthood, so many of the individuals felt that having a diagnosis gave them an explanation for the differences they have been experiencing since their childhood. Participants could identify the social communication difficulties associated with the diagnosis and felt that it was one of the biggest hurdles to overcome in order to achieve their future goals of obtaining some level of independence in their future. Family members, teachers, and peers were found to be the most helpful supports throughout the individual's life, and careful attention has been paid to developing better skills in daily communication that NT individuals take for granted. The most common service received in the participants was mental health services, although it was not reported to be a consistent service. Few participants reported any other type of support outside of their family members, teachers, and peers. The consistency of supports and services is necessary for young adults with AS or HFA gaining independence through attending college, becoming employed, and living on their own, as they are at an increased risk for psychiatric disorders and still feel ill-prepared for pursuing their goals. The DSM-5 change will likely provide individuals who would have received a diagnosis of AS with a diagnosis of ASD. Genetic counselors can be a source for identifying the necessary referrals and resources needed for this group as individuals with ASD are increasingly referred to the genetics clinic. This study provides personal

perspectives articulated by these young adults with AS which genetic counselors can use to identify areas of need for this group, to advocate for their resources, and to provide appropriate referrals for management, especially during the complex and often difficult transition process into full adulthood.

References

- American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders*. Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Austin, J., Semaka, A., & Hadjipavlou, G. (2014). Conceptualizing Genetic Counseling as Psychotherapy in the Era of Genomic Medicine. *Journal of Genetic Counseling*, 23, 903-909.
- Burgess, S. & Cimera, R. E. (2013). Employment Outcomes of Transition-Aged Adults With Autism Spectrum Disorders: A State of the States Report. *American Journal on Intellectual and Developmental Disabilities*, 119,(1): 64-83.
- Carter, M. T. & Scherer, S. W. (2013). Autism spectrum disorder in the genetics clinic: a review. *Clinical Genetics*, 83, 399-407.
- Centers for Disease Control. (28 March, 2014). *Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2010*. Retrieved from:
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w
- Coury, D. L. (2013). DSM-5 and Autism Spectrum Disorder: Implications for Families and Clinicians. *Journal of Developmental and Behavioral Pediatrics*, 34(7), 494-496.
- Ghaziuddin, M., & MountainKimchi, K. (2004). Defining the intellectual profile of Asperger syndrome: Comparison with high-functioning autism. *Journal of Autism and Developmental Disorders*, 34(3), 279-284.
- Giarelli, E & Fisher, K. (2013). Transition to community by adolescents with Asperger syndrome: Staying afloat in a sea of change. *Disability and Health Journal*, 6(3), 227-235.

- Giarelli, E., Ruttenberg, J., & Segal, A. (2013). Bridges and Barriers to Successful Transitioning as Perceived by Adolescents and Young Adults With Asperger Syndrome. *Journal of Pediatric Nursing*, 28, 563-574.
- Griffith, E. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). I just don't fit anywhere: support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, 16(5), 532-546.
- Hippler, K. & Klicpera, C. 2003. A retrospective analysis of the clinical case records of 'autistic psychopaths' diagnosed by Hans Asperger and his team at the University Children's Hospital, Vienna. *Philosophical Transactions of The Royal Society of London, Series B: Biological Sciences* 358(1430), 291-301.
- Huerta, M., Bishop, S. L., Duncan, A., Hus, V., & Lord, C. 2012. Application of DSM-5 criteria for autism spectrum disorder to three samples of children with DSM-IV diagnoses of pervasive developmental disorders. *American Journal of Psychiatry*, 169(10), 1056-1064.
- Huguet, G., Ey, E., & Bourgeron, T. (2013). The genetic landscapes of autism spectrum disorders. *The Annual Review of Genomics and Human Genetics*, 14, 191-213.
- Jaarsma, P. & Welin, S. (2011). Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement. *Health Care Analysis*, 20, 20-30.
- Kandalaf, M. R., Didehbani, N., Krawczyk, D. C., Allen, T. T., & Chapman, S. B. (2013). Virtual Reality Social Cognition Training for Young Adults with High-Functioning Autism. *Journal of Autism and Developmental Disorders*, 43, 34-44.
- Madeo, A. C., Biesecker, B. B., Brasington, C., Erby, L. H., & Peters, K. F. (2011). The Relationship Between the Genetic Counseling Profession and the Disability Community: A Commentary. *American Journal of Medical Genetics, Part A*, 155, 1777-1785.
- Muller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, 12(2), 173-190.
- Nieboer, A. P., Cramme, J. M., Sonneveld, H. M., Roebroek, M. E., van Staa, A. L., & Strating, M. MH. (2014). Reducing bottlenecks: professionals' and adolescents' experiences with transitional care delivery. *BMC Health Services Research*, 14, 47.
- Persico, A. M. & Napolini, V. (2013). Autism Genetics. *Behavioural Brain Research*, 251, 95-112.

- Punshon, C., Skirrow, P., and Murphy, G. (2009). The ‘not guilty verdict’: Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism, 13*(3), 265-283.
- Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social Skills Interventions for Children with Asperger’s Syndrome or High Functioning Autism: A Review and Recommendations. *Journal of Autism and Developmental Disorders, 38*, 353-361.
- Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary Employment Experiences Among Young Adults with an Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(9): 931-939.
- Sanders, J. L. (2009). Qualitative or Quantitative Differences Between Asperger’s Disorder or Autism? Historical Considerations. *Journal of Autism and Developmental Disorders, 39*, 1560-1567.
- Simonoff, S., Pickles, A., Charman, T. Chandler, S., Loucas, T., & Baird, G. (2008) Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929.
- Spillers, J. L. H., Sensul, L. M., & Linton, K. F. (2014) Concerns About Identity and Services Among People with Autism and Asperger’s Regarding *DSM-5* Changes. *Journal of Social Work in Disability & Rehabilitation, 13*(3), 247-260.
- Szatmari, P., Bryson, S. E., Boyle, M. H., Streiner, D. L., & Duku, E. (2003). Predictors of outcome among high functioning children with autism and Asperger syndrome. *Journal of Child Psychology and Psychiatry, 44*(4), 520-528.
- Taylor, M. R. G., Edwards, J. G., & Ku, L. (2006). Lost in transition: Challenges in the expanding field of adult genetics. *American Journal of Medical Genetics, Part C (Seminars in Medical Genetics), 142C*, 294-303.
- Veach, P., Bartels, D. M., & LeRoy, B. S. (2007). Coming full circle: a reciprocal-engagement model of genetic counseling practice. *Journal of Genetic Counseling, 16*(6), 713-728.
- White, S. W., Keonig, K. & Scahill, L. (2006). Social Skills Development in Children with Autism Spectrum Disorder: A Review of the Intervention Research.” *Journal of Autism and Developmental Disorders, 37*, 1858-1868.
- Wing, L. (1981). Asperger’s syndrome: A clinical account. *Psychological Medicine, 11*(1), 115-129.

Appendix A – Participant Invitation Letter: Online Questionnaire

University of South Carolina School of Medicine USC Genetic Counseling Program

Dear Potential Participant:

You are invited to take part in a graduate research study focusing on young adults with Asperger syndrome (AS). I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research looks at what services and supports individuals with AS have received or are currently receiving that they find to be the most beneficial to helping them pursue their future goals, and which services they wish they had. The research involves taking a questionnaire that can be found at the URL below:

<https://www.surveymonkey.com/s/valuable-support-for-AS>.

The questionnaire proposes a number of questions regarding your opinion about the services, and the supports you received, what your future goals are, and what you are doing now. If you do not wish to answer a certain question, please skip that question and continue with the rest of the questionnaire.

All responses will be kept anonymous and confidential. We only ask for your name and phone number in the event that you are interested in providing more information at a later date over the phone. It is not necessary that you provide this information. The results of this study might be published or presented at scientific meetings; however, your answers will never be identified in any way. The survey should take about 15-20 minutes to complete.

Your participation in this research is voluntary. By completing the questionnaire, you are consenting that you have read and understand this information. At any time, you may withdraw from the study by not completing the questionnaire.

Thank you for your time and consideration for taking part in this study. Your answers may help implement future transition planning for individuals with AS or higher functioning Autism Spectrum Disorder. This will also allow Genetic Counselors to make appropriate referrals when they see an individual with an ASD. If you have any questions about this research, you may contact either me or my advisor, Crystal Hill-Chapman, PhD, using the contact information below. If you have any questions about

your rights as a research member, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

Sincerely,

Melissa Racobaldo
Master of Science Candidate
University of South Carolina School of
Medicine
USC Genetic Counseling Program
Two Medical Park, Suite 208
Columbia, SC 29203
Melissa.Racobaldo@uscmed.sc.edu
(609) 417-7307

Crystal Hill-Chapman, Ph.D.
Associate Chair of Psychology
Coordinator of Graduate Psychology
Programs
Associate Professor of Psychology
Francis Marion College
Clinical Assistant Professor of Obstetrics
& Gynecology
University of South Carolina School of
Medicine
USC Genetic Counseling Program

Appendix B – Online Questionnaire

Receiving the Diagnosis of Asperger Syndrome

1. How old were you when you were diagnosed with Asperger Syndrome (AS)?

2. Who made the diagnosis?

3. What do you see in yourself that matches this diagnosis?

- Difficulty with social relationships
- Difficulty with communication, such as beginning or maintaining a conversation
- Difficulty picking up on social cues, such as body language
- Difficulty adjusting to changes in routine activities
- Difficulty recognizing subtle changes in speech, such as tone, pitch, and accent
- Avoidance of eye contact with others
- Preoccupation and increased knowledge in one or few interests
- Heightened sensitivity or overstimulation by loud noises, lights, or strong tastes or textures

Other (please specify)

4. What do you feel are the positive aspects to being diagnosed with AS?

5. Are there negative aspects to having this diagnosis? If so, what are they?

Educational Settings and Related Services

6. What types of education did you receive when you were younger? (Choose all that apply)

- Mainstreamed (i.e. regular education classes)
- Resource classes (i.e. "pull-out" or special instruction classes)
- Self-contained (i.e. special education class)
- Other (please specify)

7. What subject(s) did you excel in?

8. Who did you find most helpful to you in regards to your educational success? In what ways were they helpful?

9. In what year did you graduate from high school? If you are currently in high school, please put in your expected graduation year.

10. Have you previously received any of the following services? (Please select all that apply)

- Occupational Therapy
- Speech Therapy
- Physical Therapy
- Applied Behavioral Therapies
- Social Skills Training
- Mental Health Services
- Other (please specify)

11. Are you currently receiving any services or support? Please explain below.

12. What previous service did you find to be the most helpful to you and why?

13. Did/do you feel prepared to pursue your future goals after completing high school? Why or why not?

14. Who was the most helpful in directing you to these services?

15. In what areas did you feel your preparation for the future are or were most lacking (for example, handling social situations, what to expect, educational aspects)? How are you working to overcome this?

16. Have you ever participated in a transition planning program?

Yes

No

Goal Setting

17. What is the most important goal for you to achieve in the next 5 years?

18. How confident are you that this goal will be reached?

Very confident

Confident

Unsure

A little pessimistic

Very Pessimistic

19. What are you doing to achieve these goals?

20. Is there anything that you think might keep you from achieving these goals? If so, what is it?

21. Have you ever had a mentor or advocate help you in planning for the future? What was their exact role?

22. Do you think it would be beneficial to have advocates or mentors aid individuals in identifying their future goals to create plans for taking the steps needed towards achieving their goals? Why or why not?

Genetic Counseling Experience

23. Have you ever met with a genetic counselor? If "Yes", please complete the next series of questions. If "No" or "Don't Know", you may skip to the next section.

- Yes
- No
- Don't Know

24. How old were you when you first met with a genetic counselor?

25. What was discussed during the genetic counseling session?

26. What were you expecting to get out of the session? Was this achieved?

Demographics

27. What is your age?

28. What is your sex?

- Male
 Female

29. With whom do you currently live? (Please choose all that apply)

- Parent(s)
 Siblings
 Other relatives
 Friend(s)
 Roommate (assigned to you, i.e. in a college dormitory or through an apartment complex)
 Significant other
 Alone
 Other (please specify)

30. In which city do you currently live?

31. What is your highest level of education completed?

- Some high school
 High school graduation
 Some college
 Technical college
 Other (please specify)

32. Please list if you are employed, in school (include type of schooling), or unemployed and not in school.

Asperger syndrome and the DSM-V

The new edition of the Diagnostic and Statistic Manual of Mental Disorders, the DSM V, no longer has the diagnosis of Asperger syndrome. It is likely that individuals who would have previously received the diagnosis of Asperger syndrome will now receive a diagnosis along the Autism Spectrum.

33. Does the label of Asperger syndrome versus Autism Spectrum Disorder matter to you? Why or why not?

34. How do you feel about the removal of a diagnosis of AS from the new DSM V?

Participant comments

35. Is there anything you have been thinking about since completing this questionnaire that you wish to comment on?

Survey Completion

The questionnaire is complete. Your participation in this study is greatly appreciated. Should you wish to discuss something further, please feel free to contact me at Melissa.Racobaldo@uscmed.sc.edu.

Thank you

Appendix C - Participant Invitation Letter: Interview

University of South Carolina School of Medicine USC Genetic Counseling Program

Dear Potential Participant:

You are invited to take part in a graduate research study focusing on young adults with Asperger syndrome (AS) and high functioning autism (HFA). I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research looks at what services and supports individuals with AS or HFA have received or are currently receiving that they find to be the most beneficial to helping them pursue their future goals, and which services they wish they had. The research involves a telephone or in-person interview that should take an estimated 30-45 minutes.

The interview will involve a number of questions regarding your opinion about the services and supports you received, what your future goals are, and what you are doing now. You always have the option to pass on a question should you choose to not answer.

All responses will be kept anonymous and confidential. Your responses will not be associated with your contact information, and your contact information will be destroyed upon completion of the research project. The results of this study might be published or presented at scientific meetings; however, your specific answers will never be identified in any way.

Your participation in this research is voluntary. By completing the interview you are consenting that you have read and understand this information. At any time, you may withdraw from the study by asking to end the interview. Please use my phone contact information of (609) 417-7307 or email Melissa.Racobaldo@uscmcd.sc.edu in order to schedule a convenient time for the interview.

Thank you for your time and consideration for taking part in this study. Your answers may help implement future transition planning for individuals with AS or HFA. This will also allow Genetic Counselors to make appropriate referrals when they see an individual with an ASD. If you have any questions about this research, you may contact either me or my advisor, Crystal Hill-Chapman, PhD, using the contact information below. If you have any questions about your rights as a research member, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

Sincerely,

Melissa Racobaldo
Master of Science Candidate
University of South Carolina School of
Medicine
USC Genetic Counseling Program
Two Medical Park, Suite 208
Columbia, SC 29203
Melissa.Racobaldo@uscmed.sc.edu
(609) 417-7307

Crystal Hill-Chapman, Ph.D.
Associate Chair of Psychology
Coordinator of Graduate Psychology
Programs
Associate Professor of Psychology
Francis Marion College
Clinical Assistant Professor of Obstetrics
& Gynecology
University of South Carolina School of
Medicine
USC Genetic Counseling Program

Appendix D – Interview Questions

The following list of questions was used as an outline for the telephone interview questions. Where appropriate, the interviewees were asked to expand upon their answers.

- 1) How old are you?
- 2) In what state do you live?
- 3) With whom do you currently live?
- 4) Have you graduated from high school? If so, in what year did you graduate?
- 5) What is your highest level of education completed? Are you currently attending college?
- 6) What type of education did you receive? (main-stream, resource classes, etc)
- 7) What subjects did you excel in?
- 8) Who or what did you find most helpful to you in regards to your educational success? In what ways were they helpful?
- 9) How old were you when you received your diagnosis of AS?
- 10) Who made this diagnosis?
- 11) What are the positive aspects to having this diagnosis?
- 12) Do you feel there are any negative aspects to having the diagnosis? If so, what are they?
- 13) Have you previously received any type of therapies or support services related to your diagnosis of AS?
- 14) Did you find any of these particularly helpful? What made them helpful?
- 15) Are there any support services you wish you had received? Why?
- 16) Are you currently receiving any services or support below?
- 17) Who was the most helpful in directing you to these services?

- 18) What is the most important goal for you to achieve in the next five years?
- 19) How confident are you that this goal will be reached and in what ways are you working to achieve this goal?
- 20) In what ways do you feel unprepared to reach this goal and how are you working to overcome this?
- 21) Have you ever had a mentor or advocate help you in planning your future goals? Did you find them helpful?
- 22) Have you ever met with a genetic counselor? If yes, how old were you when you met with them? What was discussed during the session? Did your expectations for the session meet what you got out of the session?

The new edition of the Diagnostic and Statistic Manual of Mental Disorders, the DSM-5, no longer has the diagnosis of Asperger syndrome. It is likely that individuals who would have previously received the diagnosis of Asperger syndrome will now receive a diagnosis along the Autism Spectrum (ASD).

- 23) Where you aware of this change?
- 24) Does the label of AS versus ASD matter to you? Why or why not?
- 25) How do you feel about the removal of AS from the new DSM-5?
- 26) Is there anything else you wanted to mention since starting this phone interview?

Appendix E – Interview Transcriptions

Participant 1

Gender: Female

Method: In-person

Total time: 9 minutes and 24 seconds

How old are you?

I'm 20

In what state do you live in?

South Carolina

With whom do you currently live?

What?

Who do you live with right now?

My, uh, parents

And you haven't graduated from high school yet, is that correct?

No, I did graduate last year. But I went back this year.

Are you going to be done after this year?

Yes. I will.

What type of classes were you in?

Um, I'm in, like, self-contained classes right now, but I do, like, regular classes too for some of them.

For what classes do you do self-contained?

Like math, but math and everything else like that I go out...

Which is nice, because I get freedom

What subjects did you excel in?

What's that?

What's your favorite subject?

Art.

What do you like about art?

Because I like to draw stuff and color. And like, make stuff. I made that pot up there (referring to a pot on a ledge in the house), that vase pot.

Oh really?

It's pretty. My mom added that hairy stuff.

That's really pretty. And that was just through a class in school that you made that?

Yeah

Who or what did you find most helpful to you in school? In succeeding in school and in doing well in school.

My parents, probably

In what ways were they helpful?

They just got, they just helped me out when I needed help.

Was that with doing homework?

I don't really have homework. My teacher doesn't assign it. Which is kind of weird. But it was nice.

So you mean your parents were more helpful in getting you through school, just navigating through school?

(shakes head)

And what is your diagnosis? Is it high functioning autism?

Mhmm. It's not that bad, though. It's not like everybody else's. This one kid in my neighborhood...he's, he is just crazy. I don't say that about him though whenever I'm around him.

How old were you when you received your diagnosed?

I don't know

Do you know who made the diagnosis?

No

What are the positive aspects to having this diagnosis?

I really don't know

Have you previously had any type of therapies or support services related to your diagnosis?

No, not really

Nothing like occupation therapy, speech therapy...?

I don't think so

Social skills therapy?

Yeah, but I'm not sure when that was.

Did you find any of them particularly helpful?

No, not really

Are there any support services you wish you had received?

Not really

Are you currently receiving any services?

Right now my mom's actually looking for like, umm, I'm not sure if it's like, a care person or someone that would be driving me around so I can do stuff and go places and not be home all day. And they'll get paid during it too. So it's a person to pay them

Do you have your license?

No, and it's much easier. And actually they'll help cook because my parents when they cook, but I can cook for them when they come home for the day, so I can, so they can come and dinner will be ready.

Is that something you wish you were able to do? Having dinner ready for them?

I don't care. I don't use the stove now, I don't care for it. I don't like fire. It's a gas stove, I just don't like, like the flames coming out of it. Yeah and it scares me, so I'm like, no I won't cook, thank you.

So tell me about what you are trying to achieve in the next five years?

I want to get a job hopefully

And do you have a job coach or someone helping you?

Yeah I have a job coach right now. I'm trying to, hopefully get into this program that I've applied and interviewed for this week. Hopefully I can get into it.

What is the program?

It's "Project Search". It's like run by different jobs through a hospital. It's like going to school but it's not going to school. You're actually working. You're being physical instead of being sitting down all day.

So learning the jobs that the hospital would have?

Mhmm.

How long is the program?

I don't know. I really don't

Did your job coach find this program?

No, my parents found it. I think my parents found it. I don't know, can't ask me.

Well, it sounds exciting.

It will be. And that way I won't have to be home all next year.

Do you live where Project Search is located?

No, no. They take me there and then get me back home.

It must be close to home then.

I think it's a hospital somewhere. I think it's close. It's at the new heart hospital, I think. Or whatever it is, the hospital near the hospital they just built.

So would that care giver, or person you mentioned before that would drive you around, would they be the ones to take you to your job?

I think so.

And you just had your interviews for this, right? Do you think it went well?

What? Yeah. All I did was one, that's all. I hope so, they're supposed to send me a letter this week. I hope I get in.

After the program is done, will a job come out of it?

Hopefully, they might give me a job there, but I don't have to accept it, if they can find me a job somewhere else.

Would that other job be in the hospital-related field?

No, I don't want to work in the hospital. I want to work with dogs, probably. Well, I don't know yet what I want to do. Right now my passion is dogs. But it might change, I don't know. It might be a vet, I don't know. Whatever's available, I guess.

Are you working with dogs now?

I'm volunteering

Where are you volunteering at?

Palmetto Lifeline

How often do you do that?

I think it's two days a week during the school week.

So it's after school you would go there?

No I go in the morning, and then I think my, and then I go to school for two hours. And then I'm done. Which is kind of ridiculous, but, oh well.

The two hours of school?

Yeah, because, well it's one class and I just...it doesn't make sense.

What class is it?

It's on A days, I think it's career prep which is kind of ridiculous because we do nothing .

You don't feel like it's helpful?

No, it's not. Except for my volunteering.

What is your responsibility with the dogs?

We play with them, and walk them, and, um, and then put, then sometimes we do play groups with the dogs outside. And then that's usually about it. That's all I can do right now. But I sometimes do laundry. Or whatever, whatever they need help doing, I do it. I can't really wash the carriage because that's what they do, if the people work there, they do that.

You sound very helpful, and like you do a good job. Is that a place that you would like to work in the future? Somewhere like you're volunteering?

Yes. Hopefully. I don't know yet.

Besides your job coach helping you through the process of Project Search, has there been anyone else who has been helpful to you? You also mentioned your parents.

That's all

Have you ever met with a genetic counselor?

No

Is there anything else you wanted to mention since we've been talking?

Not really

Participant 2

Gender: Male

Method: Telephone

Total Time: 21 minutes and 51 seconds

How old are you?

I'm 19, I'll be 20 in about a month.

Do you live in South Carolina?

I do

With whom do you currently live? Who do you live with?

I live on campus.

So you've graduated from high school?

Yes ma'am

What year did you graduate?

Uh, '13.

So you're in college now?

Yes ma'am

What year are you in college?

Uh, freshman year. This is actually my, uh, third semester. I didn't do as well the first two. Then I went to, um, the air force, but I got medically discharged, so now I'm back here.

You said the Air Force you went into?

Yes ma'am.

How long was that for?

I was in the reserves. So I went to [three general meetings] so I was in there for about four months. And I went to basic training, I was there for four weeks. To which was air force training. Then I went to ...

Did you enjoy your time there?

I, I learned a lot. I wouldn't say I regret it. I'm saying that I wouldn't say that I regret it

What drew your interest to the Air Force?

Well, basically I wanted to kinda like, a launching pad, to you know, get a hold of my life, and it worked well cause I was, wanting to do well and in college but I kinda messed up for a time. And I'm doing, I'm doing better this semester, so hopefully I'll be able to stay in.

What do you think the difference is between this semester and the other semesters?

Or what change are you trying to make?

I'm trying to, I'm tryna have some more conviction

Did you receive any types of support in school or therapies, like occupational therapies, social skills training, or things like that?

Just, uh, speech therapy. But that stopped about freshman or sophomore year in high school.

When did you get your diagnosis of Asperger's?

I think it was junior year or sophomore year, probably junior year.

Who made this diagnosis?

It was, um, I believe it was, um, someone, someone me and my mom went to. Actually afterwards I didn't even think about it, but. Hmm. I don't remember it all that well, but, um, I remember being told and I didn't think that much of it. But I was like, huh, ohh ok...

It made you think a little bit more?

I mean I didn't try to think much of it, I mean it still is like, it is something that they're like, oh, well, it's a thing now.

Did you think there were any positive aspects to having the diagnosis after?

Not really. I mean, I don't like, I don't think of it as a positive or negatives of it, it's basically there.

So going through school, were you able to do well? Were you in general classes?

Well that's kind of the interesting part of it, like, basically when I was in elementary school and middle school I was actually in a lot of um gifted programs and like, gifted programs are what I knew, like what our school had. I usually, I did pretty well. Then a lot of high school, somewhere around middle school I kind of, I kind of fell off. I was still taking honors classes and was doing ok, but it just kind of felt like I, it just kind of felt like it sort of stayed on the same level. Like I never really got smarter.

Was it something that you felt you had more difficulties learning or kind of the change in atmosphere?

I think it was the, I think it was just kind of a harder time adjusting, really. Maybe not in the atmosphere but the work itself.

Did you excel in any one subject or did you favor any one subject over the others?

I did. It was um, science and history. I wouldn't major in history now because it's a lot of writing to do but I like classes like science and history because I feel, I feel like, and this is subjective, I feel like it matters a bit more and I'm learning a lot more and there's things that we learn that pertain to basically us in general but a little bit more...that's why I'm a psychology major now.

What do you want to do with your psychology major?

I just, I just want to talk to people, honesty, I just want to, after, after my change, my old major was business and then being in the military, I just felt like, I just wanted to help people and talk to them. And it may not be that good of a career choice, but I still want to get into it.

Was there anyone in particular you found helpful in regards to your schooling or outside of school? I know you said the transition in middle school was difficult, was there anyone that really stuck out to you?

Oh yeah, that's when I met my best friend actually. In 6th grade. And we're actually still keeping in touch. I just had someone to talk to, and I still do. Basically. We shared and still share what our interests are.

What's your biggest interest now?

Still video games, probably.

Do you live in a dorm on campus?

Yes I do

Do you have a roommate?

I do not

Well that's nice to have a room to yourself.

Yeah, it's great

Are there any support services you wish you had received up until now? Why?

Not really. I mean what I have now is pretty nice, but, I don't really feel like it's made too much of a difference. That's all.

What do you have now?

I think it's a 504, it's called....A 504 plan, something like that.

Can you explain what it is a little bit more to me?

I'm honestly not too sure what it does. I should probably start asking more questions.

Do you feel like that would be helpful?

I do. The 504 plan is with the college

Do you have someone at the college who is helping direct you with the services?

Uh, Dr. Lawson, actually.

What is the most important goal for you to achieve in the next five years?

The next five years. The next five years, uh, I would want to have a job and just, just have my own, my own living space.

Do you feel confident that you are going to be able to reach those goals?

Yes I do. Yes ma'am.

What would you say are the steps you are taking now to achieve this goal?

I'm going to try to, um, basically the, um, the whole conviction thing I was talking about earlier. I don't push myself enough, like, basically all it's been is other people pushing me at this point. So I could be more proactive.

I can't believe January was three months ago. It does not feel like it.

Why does January stick out to you? Start of the year?

Mhmm

Do you think there is something that is going to hold you back from getting a job and living on your own?

No I do not, the only thing I really have is, like, socially, I can kinda, I can kinda, display myself well enough to come off as...I've been told that I can articulate myself very well. But, but beyond that, it's just like I can make friends, I can figure out who kinda share, who I can talk to about things that I like, basically. I can figure that out. And it gets a lot easier from there.

Do you think that's a skill that you've picked up over the years?

I would, actually, like, like growing up I did get, uh, ... (floored?) a little bit. And I'm kinda glad I did. I learned some things. Just trying to act on other people and such.

Participant 3

Gender: Male

Method: Telephone

Total Time: 32 minutes and 22 seconds

How old are you now?

Um actually I'm 20 but I'm about to be 21

When do you turn 21?

The 21st

Do you have any plans for then?

I plan on going back to Indiana. And hang out with friends

Where are you now?

Uh Florida, about an hour away from Tampa

Are you going to school in Florida?

Yeah I actually do online classes through a school in Orlando this year because my Grandma and Grandpa, my Grandpa's been diagnosed with leukemia, so I've been helping them out

So do you live with your Grandma and Grandpa in Florida then?

No, I live with my girlfriend

Is it a girlfriend you met in Indiana or someone from Florida?

Indiana

So she moved down with you?

Yeah

That's good that you have someone with you

Yeah

What year did you graduate from high school?

2013

And what year are you now in college?

Uh in college? I'm actually doing, I'm going for my bachelor's degree but it's actually a two year program and uh, yeah, so, I guess you could say the point I'm at right now, sophomore?

So kind of like halfway through then?

Yeah

What are you getting your bachelors in?

Video game design

What is it?

Video game design. It's a lot of fun. It's hard, but it's fun

Have you always been interested in the video game and designing?

Honestly, yeah, I mean I don't think I would be, I don't think I would be where I am today without video games

What do you mean by that?

Well when I was younger, I had a really hard time fitting in, like at school and stuff, so I used to go home and sit in my room all day and play video games and that was my, that was like my way to get away from everything. And I had a rough time in school, so

What made school rough for you?

Well, um, I didn't get diagnosed with Asperger's til um, like the end of 4th grade, around there. But, like, before that, um, and after that, I had a rough time, the, like, kids would make fun of me and they didn't know what Asperger's was and I got called a bunch of names like "retard" and stuff like that. And I had, my brother was the same grade as me, so the kids, he protected me. But, um, video games, that was kind of like my way of getting away from everything.

I'm so sorry that you had kids that treated you that way

Oh, it's ok, I mean, high school was a lot better to me

What made high school better?

Um, well, okay, in junior high I started playing football, and when I got to high school I kept on playing football. And I think my teams were a lot, like, better with me. I mean they kinda like understood that I had Asperger's and a lot of my teammates also had ADHD and all these other things like different like disabilities, so I think that kind of helped me because all of them had that stuff, like different things too and it kind of made it easier because they helped me out in school. Yeah

Was it sort of like they could relate a little bit more?

Yeah. I mean cause when I went off to, like, when I was in grade school and when I was in junior high, I don't know, our school was really small. There weren't a lot of kids that, a bunch of the kids didn't have like disabilities, so not many of them like, could relate to me. So after that I went to a high school that was a typical high school, a regular public school, but they had a huge department that focused on, like, kids with learning disabilities and actually had teachers that would sit down and help and, yeah so that definitely helped out a lot.

And you said it was around 4th grade when you got an official diagnosis?

Um yeah I mean my mom noticed. She said she definitely noticed I had something because I mean I was just everywhere and, um, I actually didn't even speak until I was about 4 years old. Yeah I mean so she knew I had something but the doctors didn't seem like they could diagnose it until I was a little bit older around 4th grade, yeah, I was diagnosed.

Do you remember who it was that made the diagnosis?

Um, I don't remember, but I do remember, I can describe basically um what I had to do and stuff. Basically I flew out to California and I had, I spent three days of being in this doctor's office and from what I remember, basically tests and stuff, and had me play all these games and stuff, and then they diagnosed it. But my mom would be the one that would know who the doctor was.

How did you feel after you got the diagnosis? Did you think there any positive or negative things that came from it?

Um, to be honest, um, I didn't really know, like, what I was doing, at the doctor's office. Like I didn't know I was being, or uh they were going to diagnose me with, something at all. I just thought I was there to have fun. My mom never told me why I was there. And afterwards she found out I was diagnosed, she waited, uh, a couple of months or whatever and, she uh, sat me down and talked to me. At first I think I was a little confused about like what Asperger's was and then um, I think, I kind of went through a little bit of a phase where I was depressed. Because I felt like, well it probably lasted for a couple of years, but I felt like I was just completely different from everybody, and, I don't know, it was just really rough on me.

When did you begin feeling better about the diagnosis?

I think I started feeling better around 6th, 7th, or 8th grade, I started feeling a little bit better but I still got bullied, a lot um, but, uh, like with that things felt like they were getting so much better. I was finally starting to make some friends. I mean I had a few friends back in grade school and middle school, but when I got out of grade school it

seemed like it got a lot better and I was just friends with a bunch of different people and high school really treated me well.

Did you have any resource classes or any pull-out classes or were you mainstreamed?

Um, okay well my freshman year I went to Plymouth High School and they really, they had like a resource group class, but my mom wanted to try me in the mainstream and that didn't go over so well. It ended up getting me kicked out of that school cause I got in trouble and I ended up getting sent away for 3 1/2 months. And that was the worst three 1/2 months of my life. Um, but then after that I went to a new school. This school had like the best program, like they, I mean, the principal, he specialized in Asperger syndrome. So, and yeah, that was kind of nice, when you have people that like specialize in it, because like, I've actually had teachers tell me in the middle of the class, in front of everybody, that I was faking it. Or that Asperger's wasn't real. Yeah that was definitely tough because there were multiple times where my mom had to go in and like actually sit down and talk with like these teachers because they didn't believe me.

I'm glad you finally got to a place that was better for you.

I mean for the most part, I was mainstreamed. I mean, back in high school, the actual school I graduated from, I was, all my classes were mainstream, except for like, like independent work, we'd have 30 minutes at the end of the class to do work. I would go to the resource room and we'd have kids that would like, all there together and we would all get our homework done there. And then we'd have uh, usually I'd have one to two study halls in the resource room every day, so that definitely helped too because the teachers there weren't like just teachers, they were like, they kind of just treated us like people. It was nice because there were kids in school that like said that we didn't deserve the extra help and ...

So what was your favorite subject?

Oh definitely history. I mean I would just sit there, and I would study the book, like I would memorize the facts and so when I would come back to the class I would surprise everyone

What do you like the most about history?

Um, I've read a lot of the book... but like, the military side of history, like the battles and stuff, old ways, all that stuff. Yeah

So there was a specific person or group of people that you found to be the most helpful? In terms of being so successful in school?

You mean like other students? Or Teachers?

It could be either, if that's who you felt was helpful

Honestly, the person that helped me the most through, like, my mom used to sit down and help me and uh work with me all the time with Asperger's and I was really, really bad and I'm so much better. But I probably wouldn't have graduated high school if it wasn't for my mom. And I had a few teachers that were, like, amazing, just like help me and be around me a lot. I also had a few teachers that, they would purposely get me mad so I would not be in their class. Yeah, so, I mean, my buddies on the football team really helped me. I mean if it wasn't for that in high school it would have been like grade school.

What types of things did your mom and the group of teachers help you work on?

Um, well my mom, I mean, she helped me with everything, I mean. I was never really a strong reader, and she used to sit down and read with me and she definitely helped a lot because in 8th grade my reading level was like a 2nd grade. So she helped me a lot with that, and work up to 6th grade or whatever. But she used to always explain to me that the, she used to kind of help me when kids would bully me and stuff. She would talk to me about it and stuff. And I think she kinda, uh, helped me a lot with that, but um, my speech...I think my speech is probably the biggest thing she helped me with. I used to not be able to say certain words and stuff and she used to help with that.

Did you ever have to have speech therapy? Or any other types of therapies like occupational, physical, etc?

That's actually the funny thing, um, when I was younger, and when I first started to talk, nobody could understand me, and it was just a bunch of gibberish. Well um the doctors told my mom, they said there's no way that he's going to be able to speak normally and he needs speech therapy. Well she sat down and worked with me for a couple months and sort of proved me not needing speech therapy. She was kind of my speech therapist. She set me down, taught me how to say words, and, yeah.

Do you participate in any support services now? Or have you ever done anything before?

Um, actually, I've done like a charity thing and I know that that doesn't sound like it's a difficult or anything, but I did a video game charity thing, and basically, for this charity, I got donations and stuff and built up my donations, and um, you play 25 hours of video games straight. And if you can do it, all your money will go to wherever, like, charity you want it to go to. So I've done that, but, that's all I've done because I've been so busy with school and stuff.

Woah, 25 hours? Video games seem like a lot of fun.

Oh, yeah, they are fun. And I'm also learning a lot, like, the thing with video games, like, why they helped me so much, I think, is because they tell me a little bit about life. And like, at least video games never judge me, just playing video games, they taught me, like, a lot. They teach me about doing things, and like just life.

So your ultimate goal, is that to be a video game creator? Are you pretty set?

Um yeah, I actually want to work in the industry for about 10 years, 15 years, and then develop my own company. My company would be like Olympic games, where the younger kids are interested now. And it's going to help me out with my Asperger's.

So they're pretty life-like games then?

Um, yeah.

Are they ones like you would create an avatar and be in real world settings?

Yeah. It's like a RGP (?) role-playing

What would an average scenario or role-playing scene be like?

Well, um, I play a lot of role-playing games but I'd have to say that the ones I play the most are World of Warcraft, Skyem (?), all these different ones. And I played them with a younger kid, these games, and I took a college psychology class that included video games and stuff and we learned why certain people play certain video games and, well I have Asperger's, and I played those games because they made me feel better about myself, about my Asperger's. Makes me feel more in control of my life.

Do you think that sort of relates to doing online courses?

That's kind of a 50-50 because with online I can make my own schedule, which really helps, because I don't like to be rushed to do stuff and being rushed in class, all that stuff. And it's kind of nice because I can like schedule, and I do play a lot of video games so that's like where I excel. But then again, there are some subjects like math that I have trouble with and need teachers, so that's a subject where like, I wish I had the teacher in front of me. I do miss having teachers like high school because they did help a lot, with like my school stuff. And I think, that's one disadvantage of resource rooms. You get so used to having somebody there

Is there anyone you've tried to reach out to now when you're having troubles with school work?

Um, well we can contact the teachers, but, um, it does help, but it's not like having a teacher that's right there in front of you showing you how to do stuff.

Do you think there's anything that may hold you back from reaching your future goals of being in the industry and eventually running your own company?

The biggest thing that I've always had, or see, when it comes to being social, I guess it's something that I've always had, so being in the industry, that means being around people, being able to have, like, people feel comfortable with me being around them. I wish, I mean I've had, people not become comfortable, and I think the reason is because I'm not like, sometimes I don't know how to like respond to certain things and like, don't know how to act. I think that's going to be the biggest thing, but, I've really worked on it. And like, eye contact, that's another thing that I was really, my mom really helped me out on, was eye contact, like how to look at people in the eye for a little bit. It's a huge thing and I think it's going to help a lot because when I'm going to get a job I want to be able to look at somebody in the eye.

So your mom worked on you with eye contact?

Yeah, that's another big thing she worked on me with. She worked on, or told me that I had to wait for a couple seconds. When I was younger, when I used to look at people in the eye, they would look at me funny because I used to force myself to do it. I think I scared people a little bit.

Well that's great that you've made improvement and you're working on things

In your psychology classes, did you learn anything about the DSM?

No I don't think I did

It's criteria they use to diagnose things like Asperger syndrome and Autism Spectrum Disorders. So in May of 2013, they removed the diagnosis of Asperger syndrome and made Autism Spectrum Disorder a broader diagnosis in the hopes that individuals who would have received a diagnosis of Asperger's would now be on the Autism Spectrum in the higher functioning end. You would keep your diagnosis, but I was wondering if the labels of Asperger's and Autism made a difference to you?

I mean, that's something I've been thinking about for a while now. Um, I actually just, I was talking to my girlfriend about it because we've been watching this show that has a

couple people with Asperger syndrome and it's kind of teaching me a lot of like, Asperger and kids with how we are different. And I have asked myself that question. And, um, yeah I think it's very important to me and I don't, I don't think it should be on the same spectrum as autism. It's kind of not the same thing. I mean, I had some friends that had autism, like different forms of autism, and I just didn't see like, us on the same line, or same page, you know? I think it should be separate. I know a lot of the like autistic crowd and stuff, they probably don't want us to be on their spectrum, and a lot, I mean, I've heard people say that, and I'm not saying all people say it, but I have heard people say that Asperger's compared to autism. Well, I mean, I put up with a lot of difficulties but they put up with a lot more, so, I don't agree with this change. I mean, I've never met anyone else with autism-I mean Asperger syndrome, I'm the only person that I've ever known that has had Asperger syndrome and I know it seems, that it's like, rare, because I guess I just don't know how rare it is. I will say it would be kind of cool to meet somebody, but I don't know how our personalities would match up.

Do you feel like you can't relate to the autistic people you've met before?

Yeah, I mean, I've always, ever since I was little I've felt like, just different than everybody, like, uh, in my mind I always thought that everybody else was a completely different race and there's like the human race, and then there's like, my...me, you know? It's, I don't know, sometimes I feel like I just, don't fit in, or used to think that.

It sounds like you really have come a long way, and it's good to hear how well you're doing now

I think probably what, probably what I think my biggest achievement in life is just that I've been enjoying school since high school so far and I honestly felt like I wouldn't get this enjoyment

Going back to the autism spectrum and stuff, um, I guess what I think also, that all this means now, with Asperger's maybe being on the same spectrum, is that, um, it wasn't on it and now people are just like, I feel like people won't really know that Asperger's is like a real thing, people are just going to like, you know, I'm just worried that people won't really believe. I know a lot of people don't know what Asperger's is and they've just been like 'wow, you're making this up'

Yeah, some people don't understand

Probably just like the hardest thing is like, my girlfriend, she's like great and she read books, great about it. She's getting better because at first she didn't really understand what Asperger's was, but she definitely awesome.

Thank you for asking me these questions, not a whole lot of people like, recognize Asperger's and it means a lot that somebody wants to ask me these questions and I've never really had anybody sit down and ask me my thoughts, never really had a stranger ask me about my Asperger's

Participant 4

Gender: Male

Method: In-person

Total time: 24 minutes and 5 seconds

How old are you now?

I am 25, I just turned 25 last month

Oh wow I just turned 25 last month!

Oh cool, so we both have March birthdays

Do you live in South Carolina?

Yeah, I, my parents live down in Charleston. We've been here for about, going on 7 years now

Where did you live before?

We lived in Greenville before that for 2 years and before then it was kind of a hodge-podge because my dad used to be in the Air Force so we moved around a bunch of different locations but I spent most of my time in Ohio in the Dayton area.

Oh I have some friends in Ohio, not in the Dayton area, though

Where at, like, Cleveland?

Toledo, have you ever heard of it?

Yeah it's near Michigan

When did you graduate from high school?

I graduated in 08, that's the same year we moved from Greenville to Charleston

Okay, so you went to high school in Greenville?

Yeah

Who do you currently live with?

Here in Columbia I have my own, I live in a condo with another roommate. But my mom owns the condo

Is your roommate a friend of yours, someone you knew before?

I never knew him before, but, he's a nice person to live with anyway. I've had a couple of bad roommates in Tennessee

You lived in Tennessee before?

I went to MTSU, Middle Tennessee State University

So did you transfer to USC?

Actually, I'm in graduate school, just like you, so I graduated from MTSU and then came here for grad school

What are you doing in grad school?

I'm studying Aerospace engineering. Yeah they had a really good aerospace program at MTSU but they, they didn't have it at the time here in South Carolina and they still don't have an undergrad one as far as I know. So I had what's called an Academic Common Market Place, which is kind of, I think it offers you in-state tuition in another state if you can find a program that isn't in your state of residence and if you're studying full time so that's what I did.

Oh I think they had something like that for the genetic counseling program I'm doing, but unfortunately South Carolina didn't participate in it.

I think it's a regional thing.

Gotcha. Well I went to Clemson, I feel like that should have counted for something!

Yeah, I know like, a couple of people from Clemson, I think there is one from a couple of the retreats, like one Awakening and another state-wide one

What type of classes did you have in high school? Were they general classes, or did you have any resource classes?

I'm not entirely sure, what do you mean by resource classes?

Maybe any classes where you had one-to-one experiences with the teacher, or you were pulled-out for a smaller group setting?

Like a tutoring thing? Or something like that? I only had, as far as I can remember, I only had one class that was even remotely like that. But it was more of a study hall. I can't remember the name of it, but, it was that my first two years of high school and I actually lived in Ohio at the time, so there was like a handful of us in there, and uh, we, we could just study and do whatever we wanted. It was like a quite time for me.

And so you didn't have that after you moved to Greenville?

No

Well what was your favorite subject?

I did pretty good in math, I was ahead of a lot of the other kids in math. My teacher, like, emailed my mother saying a bunch of stuff about me. That and, uh, computer science, I took a couple AP courses in high school.

Judging by your grad school studies I should have guessed those subjects were what you did really well in.

Was there someone or something that you used to help you excel in school?

Like any special, um, I was on something called the 504 plan. Which I heard my mother mention a couple of times, I don't really know the details of what it is, like I don't really remember any particular components to it. That's probably a thing you could look up.

I will. Did you feel like you struggled in any one area of school?

Uh, it was mostly, it was mostly socially. I don't remember having, I don't remember getting really bad grades that much. Aside from a couple of times, a few bad marks here and there on math early on. But, I kinda got spun up on it, got picked up, and then did well

When did you get your diagnosis?

I got my diagnosis when I was living in Tennessee, hmm, from this counseling center in Nashville called Athena Counseling. It was about, a little over 2 years ago at the end of 2012.

Oh so it was a pretty recent diagnosis?

Yeah I went up to the like, this uh, evaluation center somewhere in Murphysborough and they did a whole bunch of tests on me, like a computer clicky, some computer thing that was like kinda determining how your brain works, IQ tests, and like, uh, scenario things

Did you seek out the testing yourself?

My mother suggested it to me and I made my own appointment for it

What made you both think that the testing was needed?

Well it was just, uh, I just, wanted the answer to why, uh, why I was experiencing life the way I was because it was like, this was kind of, I always got the feeling that there was something sort of off about myself, like in my life, and I couldn't really place my finger on what it was. I suspected Asperger's but had never gotten an official diagnosis then, but there was a lot of, I had a couple of difficulties with my professors at MTSU, sort of

personal ones that just convinced me that I kind of needed to get to the bottom of this. As well as some of my friends.

So did you ever read up on Asperger's beforehand?

I've heard my mom talking about it once. Like she tried to get me diagnosed with it when I was younger, she took me somewhere, I forgot where it was, but they ended up not diagnosing me cause I think cause this was back in an ear where they didn't really completely understand it. And I just, I think it was one of those things where they had it in their heads that you had to have every trait or symptom of it and like not having one trait will rule you out

But you still felt convinced that it was a possibility?

Yeah, definitely

So what was the biggest thing that made you think about it?

A lot of social encounters in general that I had, um, just the way people were reacting to me in general, like, they kind of could sense it, after a while, that there was something, you know, off about me.

What do you think is different about the way you handle social situations?

I suppose I really just, sometimes I, didn't really, don't really know how to react to a certain situation, or I kind of suspect that I should do something but at the same time I'm just doing a lot of guesswork, where like I could do this, but then they could do this, this, this, this, and this, or open up a whole different can of worms, you know?

After the official diagnosis, how did it make you feel?

At first it, um, it explained a lot of things for me, but after a while I just still, I uh, my old feelings came back and I still felt that I still am not right. Just because I have an answer for why I am doesn't mean that I'm okay with it. I kinda, I just, felt like, uh, even though, I did, even though I knew it, I'd just rather not have it.

What makes you feel not right?... (long pause) Remember it's completely okay if you don't want to answer

No, I'm just trying to think of something specific, like as specific as possible, but it's just...I feel like everybody kind of knows each other on a level that I can't really see. And that's why, they can see things in each other and in me that I can't. And it's just frustrating being blind to those kinds of things

So up until this point had you any types of therapies or supports, like speech therapy, social skills training...

I've had counseling, uh, I can't remember therapies, I know I probably had some sort of therapy sessions when I was younger, but, I didn't really have counseling until I got into college and I started experiencing depression, and stuff like that.

Was college the first time you'd been on your own?

Yeah, I actually had like, um, I actually wasn't on my own until I went to MTSU. I first went to College of Charleston, since my parents lived in Charleston already, it was kind of a moot point to be living away from them

What made you make the move out to MTSU?

Well at the time at College of Charleston I was studying computer science because I had done so well in high school, but, it was a huge jump in proficiency level that they were expecting of me in college. The professors were, I feel like there was like a breakdown of communication between like the professors and me as a student. And probably there were some students in there, that like, I literally just couldn't go on there trying to get

that degree. And I had been sort of more interested in aviation anyway so I found that degree and ended up going there.

So counseling started at MTSU. Are you still getting counseling now?

I was seeing a counselor for a couple of months here at USC until recently, because he was trying to do some cognitive behavioral therapy with me, but his philosophy didn't, I just didn't agree with his philosophy, it didn't make sense to me at all what he was, the things he was trying to tell me, so I eventually found this, um, this South Carolina Autism group. And it's like somewhere I was going to in Tennessee called GRASP, which is sort of a more, national thing with different chapters. But I finally, I just said I do better in groups with people who kind of relate to me and kind of share my experiences and maybe get a little hint here and there from them. And they can bridge some gaps

It's good that you were asking questions. Did you seek out GRASP right after your diagnosis?

I think my mother also suggested that to me, because, and I did start going there after my diagnosis, up until a little bit before I graduated from MTSU. The reason I like groups more is because there's more dialogue going on, especially when they're in your, your own sort of "neck of the woods" so to speak.

Do you graduate this May?

No, actually I have two more classes after this semester so I graduate in December

What comes next after graduation?

I'm gonna try and get a job somewhere. Hopefully my chances will be better with a Master's degree.

What's the biggest goal you're trying to achieve after graduation?

I just want to establish a good enough, stable income and a good enough life for myself.

Do you know where you want to live?

Anywhere I get a job, really

Are you pretty confident that you'll be able to reach your goal of employment?

Not really because I haven't had any success so far. I've been attempting, I've been trying to get internships for the last, at least, two years or so, like even when I was at MTSU, but I still couldn't get anything

Anywhere I've looked, mostly with companies like Boeing, Lockheed Martin.

Boeing, is that in Greenville?

No that's in Charleston, they moved, they opened up there about 5 years or so ago. I know there's some, I know there's Fluor there. Maybe that's what you're thinking of

Maybe! Is there anything you think that would be holding you back from getting a job after graduation?

I think, getting through an interview is my biggest problem, because just associating with another person, especially in a kind of professional environment where they're really examining my personality and stuff, it's really hard to, it's really going to be difficult for me to put on a, put on a different cloak of, like normalcy. Try to cover myself up to make sure they take me seriously.

Is there anyone that you're talking to now or that you plan on talking to that will help you prepare for the interview process?

I'm going to try and see if, uh, if I can't get that group to do something like that, like open up a little dialogue about job hunting and stuff like that or jobs in general. Because I'm sure a lot of "Aspies" struggle with the interviews

That sounds like a really great idea. Is most of the group around your age?

There's a handful of people that are the same age as me. I actually think most of them might be. There are some that are younger than me, and most are college aged. But there are some that are more middle-aged adults there also

Well I think it's a very good idea that you have, because interviews can be tough.

Have you brought this up with the group?

I did on our last meeting on Tuesday. And he said he'd maybe consider it, that it might be our next topic.

Has anyone been helping you plan your action steps for continuing the job pursuit?

Probably my mom, she's kind of been nagging me about it, and like to do some searches for me. She's sent me a lot of jobs that I've applied for and I've applied for some myself that I've found.

Have you ever heard of the DSM, or the DSM-5?

No, what is that?

So, the DSM is what has the criteria for how you diagnosis Asperger's and how you diagnosis Autism. They just updated it in May of 2013, and the new one no longer has Asperger's as a diagnosis

Oh really?

Correct. So what they did was broaden the spectrum of autism

Oh, so they don't consider Asperger's as like, a thing anymore?

Everyone who has a diagnosis will keep there diagnosis and it will continue to be recognized, but the thought is that maybe individuals who would have received a diagnosis of Asperger's will now receive a diagnosis along the autism spectrum

Ok. I don't imagine why they'd do that

I can tell you were having a reaction to that.

Oh, I just, I am confused, I mean I'm trying to like consider why they'd, why that's necessary, you know?

So you think the difference between Asperger's and autism is big for you?

I mean I understand that like Asperger's kind of falls under autism, with autism as like a wide spectrum, but Asperger's is like, sort of a narrow, specific area of that spectrum.

And kind of getting, kind of getting rid of that name kind of leaves ambiguity. I don't know. Unless they're coming out with some sort of new name for it. It is baffling.