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A QUALITATIVE STUDY OF MALE ASPERGER'S SYNDROME

STUDENTS: TRANSITION FROM

HIGH SCHOOL TO COLLEGE

By Jon Alan Lyman

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Submitted in Partial Fulfillment of the Requirements of the Degree of

Doctor of Psychology

July 2008

PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by ___Jon Alan Lyman___

on the __22nd__ day of _____May_____ , 20_08_ , in partial fulfillment of the

requirements for the degree of Doctor of Psychology, has been examined and is

acceptable in both scholarship and literary quality.

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This dissertation is dedicated to my parents who have always supported my directions in life. Both have passed on wisdom that I tap daily. Thank you for your strength and lifelong support.

I thank my student participants who readily agreed to help me. I wish all of you success in school and in your future.

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Abstract

This study examines the narrative statements of individuals with Asperger's Syndrome concerning their recollections of the transition from high school to college. Nine male college students are led, via interviews, starting with their experiences in high school, to the initial stages of preparing for college life, and ending with current experiences in college. Analysis of the data focuses on the factors that have impact on this transition. The study is intended to contribute to the development of qualitative data about Asperger's Syndrome, informing students with Asperger's Syndrome who intend to apply to college, and providing recommendations for parents, and professionals who are supporting transition goals. This study is designed to add to the body of information available about students with Asperger's Syndrome

For the most part we humans live with the false

impression of security and a feeling of being at home

in a seemingly trustworthy physical and human

environment. But when the expected course of

everyday life is interrupted, we are like shipwrecked

people on a miserable plank in the open sea, having

forgotten where they came from and not knowing

whither they are drifting. But once we fully accept this,

life becomes easier and there is no longer any

disappointment.

Albert Einstein

Letter (26 April 1945); as quoted in *Albert Einstein, The Human Side: New Glimpses From His Archives* (1981) edited by Helen Dukas and Banesh Hoffman

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Chapter 1

Statement of the Problem and its Context.

The numbers of individuals being diagnosed with an autism spectrum disorder (ASD) has dramatically increased within the last decade. It is estimated that there are over 1.5 million individuals diagnosed with ASD and that over 100,000 of these individuals are school children ages 6 through 21. This represents a 500% increase in the past 10 years. (United States Government Accountability Office, 2005).

There is a great deal of information regarding educational intervention for children with ASD but little information is available regarding young adults, particularly those at the higher functioning end of the spectrum. Many of the high functioning students in the autism spectrum are diagnosed with Asperger Syndrome (AS). Because of the dramatic increase in research and the information available for the education of children in the autistic spectrum, more supports and help have been applied to their education. Children identified with AS are succeeding in increasing numbers in the lower grades and in high school and are going on to college. Students with AS are arriving in college because many display academic strengths despite varying deficits in communication and social skills. Knowledgeable

clinicians in the field have published recommendations for interventions in support of individuals with AS in school, based on anecdotal information from field work. However there is little information available for the parents, professionals and the students themselves about the transition from high school to college.

Socially, individuals with AS are often isolated from others. This is not due to shyness, attention span, aggressive behavior, or lack of experience. It is primarily due to the difficulties involved in being unable to adapt their behavior to the changing demands of the environment. Cognitively, verbal expression and receptive ability to register and interpret non-verbal meanings is not an automatic task for an individual with AS. This places them at risk in the complex social environment of college. They are often literal in their understanding of words and do not easily understand the verbal cues for communicating emphasis such as tone, pausing between words, and louder versus softer. Verbal communication is a way for individuals with AS to ask for or to relate information about things, but it is not used easily as a means for enhancing social contact. In a social context, individuals with AS have difficulty grasping the intentions or the motives of others. They often have the ability to accumulate large amounts of information concerning highly specialized subjects such as weather, geography, geology, modes of transportation, etc. These subjects tend to fit into categories of non-living objects and mechanical systems. For example, the AS student might be

interested in joining school clubs primarily as a way to add to their

knowledge bases and secondarily to be involved with peers socially. The

student with AS wants to be a part of the social world around him or her but

often lacks the skills to do so.

When Lorna Wing (1981) commented initially on the work of Hans

Asperger who wrote in German, the syndrome was virtually unknown in the

English speaking world. In the intervening years many studies have resulted

in the development of a phenotype of Asperger Syndrome that qualitatively

and quantitatively has expanded the original diagnosis placed in the

Diagnostic and Statistical Manual of Mental Disorders- Fourth Edition

(DSM-IV) in 1994. In a recent journal article, Wing (2005) looked back at

the consequences of bringing to light this condition first described by Hans

Asperger in 1943. She notes that describing and naming the syndrome has

had positive results for individuals with AS and that although there has been

a growth of support services, more services are needed.

Researchers who have studied the transition of adults with AS into

the world of work (Gerhardt, 2003; Miller Schuler, Burton, & Yates, 2003,

Hurlbutt & Chalmers, 2004) make recommendations for ways to assist the

individual with AS in his or her search for employment but note the need for

more research. Despite the skills and strengths that students with AS possess,

many face difficulties maintaining themselves in an educational setting and

experience lifelong difficulties in finding and maintaining jobs. These students pose a challenge to the higher education system because their deficits, such as their lack of social understanding, result in barriers to success.

There are numerous college programs for Learning Disabled high school students transitioning to college. There are very few analogous programs for AS students.

Purpose of this Study

This study examined the transition of AS students from high school into college, using a qualitative case study design. Nine college students with AS were asked to discuss their experiences concerning the initial stages of preparing to go to college and the actual transitions to college. The role of this researcher was to chronicle their stories, elaborate on common themes found and relate the themes to the educational needs of these nine individuals during the transition period.

Specific aims of this inquiry are as follows:

1   To describe the transition to college via semi-structured interview of nine college students with Asperger Syndrome.

2   To interpret these interviews via grounded theory and to describe the emerging

themes of transition from high school to college.

3   To interpret the data collected in order to make informed clinical statements about a) what interventions would be most likely to help AS students through the transition period, and b) best practices for professionals striving to meet the needs of transitioning students with AS.

Chapter 2

Literature Review

Asperger Syndrome (AS) is a neurocognitive, social and communication disorder that is in the higher functioning range of the Autism Spectrum (Coplan, 2003). It was named for a physician, Dr. Hans Asperger who wrote a thesis regarding his findings about a set of related behaviors and symptoms for a small group of boys that he was treating. Wing (1981) was the first to translate and publish his work. In 1944, Asperger wrote about and identified a unique thread of common behavior and personality in several of his patients. He was treating young boys who had common impairments in social relationships, verbal and non-verbal communication, and restricted repetitive patterns of interest in activities or hobbies. His work was buried within the context of World War II until Wing published on the subject in 1981. In 1994, the diagnostic criteria for AS was added to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV, APA, 1994).

The DSM-IV identifies AS as a Pervasive Developmental Disorder, noting that the hallmarks of this condition are markedly impaired social interactions and restricted, repetitive patterns of behavior, interests and activities. Since the nearly 10 years that this diagnosis was first described in the DSM-IV, researchers have added other behaviors that help to define AS; these include marked difficulties in reading the non-verbal language or prosody of communication (Shriberg, Paul, McSweeny, Klin, 2001) and the limited ability to take the perspectives of others as well as the difficulty in verbalizing their own perspectives/insights (Rutherford, Baron-Cohen, & Wheelwright, 2002). Examination of the literature from the past three years indicates that the most recent research has focused on findings that individuals with AS appear to have deficits in the ability to self-reference, to display empathy, and to infer the emotions/thoughts of others. These researchers (Rutherford, et al., 2002) call their line of inquiry Theory of Mind (ToM) research, and have attempted to differentiate AS from other Pervasive Developmental Disorders via comparison with High Functioning Autistic and AS populations.

Discussion of AS and its differentiation from Autism is part of the scientific debate in which researchers have attempted to place the data from studies into a neatly conforming theory that relates brain structure to behavior. However, determination of the relationship between development or lack of development of structures in the brain that correlate with AS or

Autism is not a simple question. Researchers suggest differences will be found but have not yet found those differences (Lotspeich, Kwon, Schuman, Fryer, Goodlin-James, Buonocore, Lammers, Amaral, & Reiss, 2004). Some neurological (Lotspeich, et al., 2004) and behavioral (Szartmari, Archer, Fisman, Streiner, & Wilson, 1995) investigators suggest that Autism and AS are distinctly different constructs. However, the majority of the clinicians in the field have expanded the definition of AS to be included as part of the Autism Spectrum Disorder (ASD).

Regardless of one's perspective on whether or not AS is a distinctive disorder or one best described as part of a spectrum, the qualitative differences suggested in the literature are informing how researchers attempt to describe the differences and also informing to the clinicians in the field who work with school-aged children who have been diagnosed with AS. Review of the diagnostic criteria from the DSM-IV (American Psychiatric Association, 1994) for AS versus Autism reveals common criteria that open the door for questioning whether or not there truly is a difference between the two conditions. In a study of 157 children (Mayes, Calhoun, & Crites, 2001) previously diagnosed with autism and AS, there was 100% diagnostic agreement by a psychologist and child psychiatrist with no knowledge of the previous diagnosis, that all of the children met the DSM-IV criteria for Autism. This result was achieved despite the fact that 47 of the children had IQ's of 80 or above. Authors of this study question whether or not there is

any clinical distinction between AS and Autism (Mayes, 2001). A

comprehensive study of the speech characteristics of adolescents and adults

with AS and High Functioning Autism (Shriberg, Paul, McSweeny, & Klin,

2001) described the speech profiles for these two populations. The findings

were that there were few significant differences between the two groups; the

exception is that subjects with AS tended to use more words, a characteristic

which the researchers termed volubility. Prosody, the added information that

affects the meaning of spoken words, was an area in which both groups

showed deficits.

Clinicians in the field hold to the belief that qualitative

differences that impact individual students needs do exist, and they argue for

making the distinction between autism and AS, not as categorically defined

differences but as qualitative differences. Qualitative distinctions between AS

and Autism place them, functionally, on a continuum because of the core

related features of significant difficulties in communication and socialization.

The Educator's Viewpoint on AS

How do educators define AS? What are educators doing to

help students with AS? Children and adolescents diagnosed with Asperger

Syndrome (AS) present a challenge to educators. Educators have had to come

up with interventions to help AS students in the school setting. Examining the

recommended interventions in the literature gives a picture of what

professionals believe are the problems of educating school-aged individuals

with AS. It also provides information about the interventions ascribed to

those problems and by extension adds to the knowledge base of the definition

of AS. Williams (2001) identifies seven general characteristics of children

with AS: insistence on sameness, impairment of social interaction, restricted

range of interests, poor concentration, poor motor control, academic

difficulties, and emotional vulnerability. Needs that require intervention are

also identified; these include the transition from elementary grades into

middle school (Adreon & Stella, 2001), over-literal interpretation of language

(Shriberg et al., 2001), poor motor skills (Szartmari, Archer, Fisman,

Streiner, & Wilson, 1995), difficulty with abstract information such as

metaphors and idioms (Church, Alisanki, & Amanullah, 2000), and co-

morbid conditions of depression and attention deficits (Ghaziuddin, 2002).

Theory of Mind (ToM) researchers have discovered that students and

adults with AS do not display reciprocity of thought; that is, in a social

situation they often assume that the persons with whom they are talking know

what they know. This has disastrous results in the social arena. The theory of

joint attention (Meyer & Minshew, 2002) suggests that in social settings

students with AS cannot share attention between people and objects, a

capacity that normally develops within the first year of development.

Therefore, they do not capture facial expressions, tone of voice, and gestures

and are unable to use these to enhance understanding within the social

setting. Educators and researchers have documented the results of teaching

social skills as an intervention (Myles & Simpson, 2002; Gutstein & Whitney, 2002).

Recent research (Griswold, Barnhill, Myles, Hagiwara, & Simpson, 2002) on AS and academic achievement has concluded that students tested showed a wide range of academic achievement scores from significantly below average to significantly above average. The study also reveals that knowing that the student carries the diagnosis of AS is of very little value when developing IEP goals and objectives for the student. Scores without specific interpretations based on observation and accompanying qualitative information are of little value to teachers dealing with the needs of the student with AS. Individual analysis of skills and deficits within each subtest would be helpful. Furthermore, the clinician should provide a synthesis of the cognitive abilities and academic skill development for such areas as memory, visuospatial ability, attention/executive functioning, ability to integrate pattern/detail, and speed of processing.

Review of the literature for the definition of AS reveals that the definition has expanded since its inclusion in the DSM-IV. This expansion of the definition seems due to the increase in awareness of AS. Clinicians in the field have responded to the needs of students with AS by explaining the nature of AS, widening the definition and providing concomitant interventions directed to specific areas of deficit for individuals with AS.

Diagnosis of AS

In a review of the literature, cases were found that display the inadequacy of diagnosis of the spectrum of Autism Disorder (AD), High Functioning Autism (HFA), and Asperger Syndrome (AS). A life span approach emphasizes the dynamics of the growth of an individual throughout his or her life, providing a theoretical construct for the rate, progression, stages, and unique characteristics of a developmental disorder as it relates to the chronological age of the subject. Because many individuals had reached adulthood before the addition of the AS diagnosis in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994), many individuals who fit that criteria may benefit from re-examinations of their diagnoses, with an eye towards development of supports that will benefit each specific individual. Some adults who were labeled with childhood schizophrenia or with schizophrenia are actually adults with AS (Perlman 2002). In re-examining clinical diagnoses, one should evaluate whether or not the patient ever had the ability to see events from the perspectives of others. Theory of Mind (ToM) proponents (Kinderman, Dunbar, Bentall, 1998; Rutherford, Baron-Cohen, & Wheelwright, 2002) describe the AS individual as one who has never been able to process information regarding the mental states of others. Persons in a psychotic state, or schizophrenics, are hypothesized as having had at one time, the ability to gauge the emotional states of others, even though they

have lost that ability because of their current mental conditions. Thus there is

an important distinction between AS and other mental disorders, reflecting

lack of ToM that is specific to the developmental timeline of emergence of

ToM problems.

Attempts to describe those elements that make someone diagnosable

with AS have led to several studies expanding the definition beyond the

DSM-IV criteria for diagnosis. As the definition in the literature expands so

does the diagnosis of AS and Autism Spectrum Disorders (ASD). In general,

there have been fewer polarizing differences revealed and more similarities

noted along a continuum. Research into ASD and AS has not provided a

differential diagnosis that supports AS as a separate entity. In a recent study,

Macintosh, Dissanayake (2004), reviewing the empirical evidence for

differences between those diagnosed with High Functioning Autism (HFA)

versus AS, insufficient evidence was found to establish the validity of AS as

a syndrome distinct from HFA. Thus these findings are consistent with the

view that AS belongs on an autism spectrum. The authors also concluded that

the research does not support the fact that there are qualitative differences

between HFA and AS. This finding may be more specifically the result of the

fact that there has been very little qualitative research done with individuals

who have AS. The expanded definitions of AS offered in the professional

literature describe qualitative differences as shown in the previous section on

the definition of AS.

Firth (2004), a researcher from University College London (UCL) who has researched Autism and Asperger Syndrome, has edited and authored several books on the subject. Firth notes that there are more questions than answers surrounding diagnosis of AS. Autism, High Functioning Autism (HFA), Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder Not Otherwise Specified (PDD/NOS) and AS have been mixed together in the popular literature and also mixed together in diagnosis by professionals. Individuals are labeled with AS because this tacitly hints at superior intelligence. Cases of HFA, PDD, and PDD/NOS contain a range of individuals who have varying IQ scores and functional capabilities. There is a heterogeneity within these groups that includes individuals who have very poor social skills with low IQ and individuals with good social skills with high IQ scores. Firth notes that the most workable differential method of diagnosis providing a distinction between Autism and AS is that early language and cognitive levels should not have been delayed in AS. The AS diagnosis should be supported by evidence that single words were spoken by age 2 and communicative phases spoken by age three. Firth cites three problems related to development that are associated with this method of diagnosis. First, the evidence supplied is retrospective; recall could be inaccurate. Second, vocabulary of children later diagnosed with AS tends in early stages to be precocious, containing adult-like phrases that are not normally used by children. Third, the phrases used by children to

communicate do not necessarily indicate language understanding because they may be imitative. Firth notes that current information on verbal ability might be more helpful in determining a diagnosis than retrospective information from childhood and that the revision of the DSM-IV will most likely need to provide guidelines for diagnosis that encompass the perspective of AS as part of a spectrum of disorders of Autism.

Coplan (2003) proposes a conceptual model of Autistic Spectrum Disorder (ASD) that includes, for diagnostic purposes, the age, the severity, the developmental levels, and the cognitive abilities. Current measures, such as the Childhood Autism Rating Scale (Schopler, Riechler, Renner, 1988), the Gilham Autism Rating Scale (Gilham, 1995), and the Autism Diagnostic Observation Schedule (Lord, Rutter, and DiLavore, 1998) are often given only once. Yet because this is a developmental disorder, an individual could be reassessed, based on age related norms and not meet the criteria for diagnosis. The three scales mentioned above describe severity of functioning based on level of atypicality. The term atypical denotes developmental and behavioral features that differ from the expected, given normal development or in children with uncomplicated developmental delay. Coplan, (2003) sees ASD as composed of overlapping concepts of Autism, PDD, and AS. What differentiates them is the place where one would place them in terms of the level of atypicality (x- axis) from severe to moderate to mild, and the accompanying level of intelligence (y-axis), ranging from Profound Mental

Retardation to Genius IQ. This creates four quadrants in which the far upper right quadrant contains primarily AS and PDD individuals, the far upper left quadrant contains primarily HFA individuals; the individuals with Autism and Mental Retardation fall in the lower left quadrant, and the last quadrant, the lower right contains individuals with PDD, MR, who display atypical features. Coplan adds one more dimension to his model that provides support for the idea of a spectrum-based model, age. In his model, age is represented on the Z axis. The addition of age as a dimension helps to conceptualize the place where an individual falls on the Autism spectrum. It theoretically provides for a way to represent the heterogeneity of the spectrum while at the same time aiding in understanding the differences between the components of Autism, PDD, PDD/NOS, HFA and AS. Although this model does not answer questions of etiology, it may help in conceptualizing the big picture of the clinical observations made by professionals who are treating these individuals in the field and may also assist in guiding further research, especially for AS individuals who, because of their high levels of cognitive ability and subtle or mild atypical features, have gone undiagnosed and untreated well into adulthood.

Prevalence

The prevalence of AS is not known (Firth, 2004). One of the reasons for this is the fact that the current guidelines for diagnosis do not encompass the wider definition of AS described by clinicians in the field; also, as stated

previously, the terms AS, PDD, and PDD/NOS are often used

interchangeably (Kusch & Peterman, 1995, Volkmar, 1997). There are

however, prevalence rates available for Autism Spectrum Disorders (ASD)

which encompasses all of the disorders of the spectrum including AS.

Current researchers of prevalence rates for Autism (Yeargin-Allsopp,

Rice, Karapurkar, Doernberg, Boyle, & Murphy, 2003) note that prevalence

rates have been widely reported as having greatly increased in the past 20

years. Rates published before 1985 fall into the range of 4 to 5 per 10,000

children for the broad category of Autism spectrum, and approximately 2 per

10,000 children in the more classic definition of Autism. Since 1985,

prevalence numbers from other countries have consistently been reported as

being higher than the United States, with prevalence ratios of 7 to 10 per

10,000 for the autistic disorder and an estimated prevalence for the ASD of

1.5 to 2.5 times higher. Yeargin-Allsopp et al. (2003) investigated a major

US metropolitan area and found prevalence rates of 34 per 10,000 for

inclusive diagnoses of ASD. Fombonne (2003) reviewed the Yeargin-Allsopp

study and contends that the 34 per 10,000 is most likely a low estimate of the

actual number. He cites reasons for underestimation, citing changes over time

in methods of diagnosis, the probability that an AS individual with a high IQ

is not likely to be diagnosed, and that protocols to assess younger aged

children do not exist, and that it is only until they are older that the diagnosis

is made. Fombonne estimates that based on recent research, prevalence rates for ASD are more likely 65 per 10,000.

Surveys done in the United Kingdom (Fombonne, Simmons, Ford, Meltzer & Goodman, 2001) provide prevalence measures of 1 in 500. Another survey also based in the UK estimates prevalence for the specific diagnosis of Autism as 21 to 31 per 10,000 and 57.9 per 10,000 for the entire spectrum which includes AS (Baird, Charman, Baron-Cohen, 2002).

Transition from High School to College

Searches of the professional literature via use of databases such as Medline, PsychInfo, and EBSCO seeking for journal articles with evidence-based methods of addressing the needs of high school aged individuals with AS who are transitioning to college returned few references. There is one article on the need for support for AS students who are transitioning from elementary school to middle school or to high school (Adreon, 2001). No articles specific to supporting transition to college were found. There exists one book on the subject entitled *Succeeding in College with Asperger Syndrome: A student guide* (Harpur, Lawlor, and Fitzgerald, 2004). The self-help book for the student with AS contains 23 references but does not directly cite research related to the topic of succeeding in college.

These references are provided as recommendations for further expanded reading and further self-discovery. The book contains a comprehensive approach to the details of selecting a college, of staying in

college and finally of transitioning to adult life and work. It also includes a section on sexuality. Numerous examples of activities are offered to help the individual with AS deal with the new and often challenging experiences of college. Additionally there are chapters in books on AS devoted to the needs of college age and young adults with AS (Ozonoff, Dawson, & McPartland, 2002; Tantum, 1991; Tantum 2000). These chapters devoted to young students with AS transitioning into college or work provide recommendations of ways in which to facilitate success. Both Ozonoff and Tantum agree that the prognosis for successful transition into adulthood can be a positive one because young adults with AS appear to continue to develop compensatory skills over time. Tantum (1991) provides data from a survey confirming that the young student with AS will have difficulties in dealing with the demands of college and career. Ozonoff (2002) notes that the same difficulties in transition from grade school to adolescence may still be a problem for the college bound student with AS. Both recommend intervention and support; however, no specific evidence-based interventions are offered. Their recommendations come from time tested work with their subjects and although valuable as clinical observations are not research based.

Despite the fact that most students diagnosed with AS have an average to above average IQ (Coplan, 2003), many students with AS pose a challenge to educators who strive to assist them with strategies for success in an educational setting. In particular it is known that individuals with AS have

difficulty handling transitions on a daily basis and generally prefer routine. Therefore transitioning from the high school environment to the college environment represents a hurdle for which the AS individual will require strategies and interventions in order to negotiate successfully.

The studies published thus far focus on childhood and appear to extrapolate this data to the condition and needs of the young adult individual with AS. Based on the almost total lack of research-based information on the experience of students with AS transitioning from high school to college, there is a clear need to develop a better understanding of this transition, of the themes that surround that process, and of the use of evidence-based, best practices to facilitate that transition successfully.

Multicultural and Ethical Considerations

AS is named after a German psychiatrist, who, in 1943, noted a common thread of communication and social problems among boys that he was treating. Currently, primary researchers of AS come from the English speaking countries of the United States, United Kingdom, Canada, and Australia. There are also researchers in Japan, Taiwan, Norway, and Sweden studying AS. Additionally, a search of internet web sites indicates that there are numerous sites throughout the world for AS and Autism. The non-profit organization, Action for Autism, which is based in India, maintains a list of organizations last updated in May 30, 2004, that provide support for people with ASD (Action for Autism, 2004). There are 85 countries listed that have

agencies dealing with Autism. From this, one can conclude that Autism is a

worldwide problem that affects many of the countries of the world.

According to the Diagnostic and Statistical Manual of Mental

Disorders (DSM- IV) a diagnosis of Asperger's syndrome requires that four

of the five listed criteria be present, including at least two indicators of a

qualitative disability in social interactions, (e.g., serious impairments in peer

relationships, social reciprocity, nonverbal behaviors, and empathy) and at

least one in the category of restricted interest and stereotyped behaviors or

rituals (e.g., rigid adherence to rules or routine, preoccupation with a narrow

interest, parts or objects, repetitive motor movements).   The World

Health Organization (1992) definition and criteria for diagnosis of Asperger

Syndrome is essentially the same as the DSM-IV (see tables 1 and 2 for

comparison). No references were found that detail differences in diagnosis or

in treatment of AS in the professional literature based on cultural or ethnic

considerations.

A best practices approach to treatment of AS should consider the need

to take into account the differences found culturally from one individual to

the next (Ochs, Kremer-Sadlik, Sirota, & Solomon, 2004). Because of the

social deficits found in AS, treatment would have to be specific to the

environment and culture of the individual. Skills that are adaptive and useful

in one culture may be seen as maladaptive in another culture. Professionals

who treat individuals who have AS should consider doing a thorough social

history for each one in order to assess ethnic background and its effect on diagnosis. The DSM-IV offers guidelines for applying diagnoses in a multi-cultural environment. Included in the guidelines are understanding the cultural identity of the individual, assessing the degree of acculturation the individual has in his/her current society, and determining if multiple languages are spoken. Also important are the individual's cultural explanation of the disorder, culturally relevant interpretations of the social stressors, and any cultural issues that might exist in the relationship between the individual and the professional. Professionals who do research on Asperger's Syndrome should consider the utility of Autism screening protocols that have been normed on populations with cultural differences. Fertile ground for future research might be in perceived cultural differences between countries.

Asking for input from an individual with AS who has deficits in ToM (Rutherford et al., 2002) is problematical when assessing or attempting to case conceptualize. Normally to be culturally sensitive one asks clients to provide insight within the cultural setting of the individual's disorder and also to define culturally relevant interpretations of social stressors. This may be very hard for the AS person. Clinicians may wish to consider other methods of gathering this information from others who know the individual with AS. Three questions of an ethical nature result from the consideration of AS and multi-cultural sensitivity. First, to what degree is the individual acculturated into the society he in which he lives, and what factors related to the disorder

of AS affect the individual's successful acculturation? Second, given what is known about the difficulty of AS individuals to interpret subtle, culturally based, non-verbal cues and idioms of language, should professionals who have no background in the individual's culture attempt to train the individual to manage himself or herself in the host culture according to those cultural norms or to manage himself or herself in one's own more familiar culture? Third, although the definition of AS is the same from one country to the next, do cultural/ethnic customs and norms indigenous to some countries predispose for increased or decreased numbers of individuals diagnosed with AS? These questions merit future research.

When doing qualitative research, a primary concern of the researcher is to maintain the ethical and professional standards. Five important points merit ethical discussion in dealing with the AS student when conducting research.

First, do no harm. The AS individual is uniquely susceptible being the victim in social settings. Because the AS individual has a challenged insight into the motivations of others, he or she may not display a concern regarding the implications of participation in research. Would the AS individual be stigmatized by being associated with a research project? It would be important for the investigator to maintain anonymity for the subject under study to avoid doing harm to the student.

Second, individuals with AS tend to gravitate towards interaction with those older than they or with the very young. It appears that they enjoy the predictability of adults and the less threatening interaction with children. Would a proposal of such research to the student with AS unduly bias that individual towards agreeing to participate?

Third, most likely the individual's parents have taken a primary role in supporting their child throughout school. The researcher must strike a balance between the parent's needs to be involved and the individual's need for autonomy. Individuals with AS can reveal information about their parents or about themselves that is sensitive. The researcher must be prepared to evaluate how such information is to be used in order to avoid harm. What filter should the researcher apply to the information revealed in the study?

Fourth, feedback must be provided to the participant so that it is therapeutic. Identification of the student's deficits is potentially harmful if the researcher does not consider the individual's current needs. Researchers need to consider carefully the desired outcomes of feedback given to the subject of the study. What methods can be used to insure therapeutic results from the feedback process?

Finally, the researcher should also consider whether or not to recommend that the student self-disclose his condition of AS. What are the potential benefits of confidentiality versus the need to know? What are the

potential negative aspects of promoting self-disclosure of the student's

diagnosis of AS?

Chapter 3

Method

Criteria for Participants

This study included 9 College students who have the diagnosis of

Asperger's Syndrome (AS). They were recruited to participate in an

interview process that provided the data for this qualitative study. Inclusion

criteria consisted of 1) current or past enrollment as a student at a college, 2)

chronological age of at least 18, and 3) verified diagnosis of Asperger

Syndrome.

Recruitment Process

Recruitment of respondents was accomplished through the use of four

venues: a) formal letters to directors of college programs that support

students with disabilities, b) networking with professionals who treat

individuals with AS, c) email and or letters to websites that provide

information and support for individuals with AS, and d) email and or letter to support groups for individuals with AS.

Prospective volunteer participants were contacted by phone or email to confirm eligibility via a brief survey. Prospective volunteer participants were also given the option of completing the survey by mail. It was decided for the purposes of this study that ideally, prospective participants' AS diagnosis would be verified by a report with specific reference to a diagnosis or by communication with a professional qualified to make the diagnosis. When a written report was not available, diagnosis was verified via contact with a parent or guardian. The prospective volunteer participant was notified of his eligibility status after his diagnosis of AS was verified. Selected participants received a letter detailing the nature of the study. Those who responded to recruitment for the study but were not designated for inclusion received notification thanking them for their willingness to be involved and an explanation of the decision not to include them in the study. Participants chosen for the study were presented with a $25 gift certificate at the conclusion of their participation.

In the course of searching for respondents for this study, emails were sent, phone calls were made, and professionals were seen face to face during workshops. This method of recruitment yielded only one prospective participant for the study. That one person was not included in this study because he did not respond to emails. One initial barrier to recruitment was

due to a narrow focus of inclusion, which involved only current freshman and
sophomores. This limitation was solved by asking for IRB approval to widen
the criteria to include any individual who had some college experience and
was at least 18 years of age. Some of the barriers to finding subjects through
other professionals included rights to privacy and confidentiality, potential
for the need to meet IRB standards from a school that referred an individual,
and the overall secondary contact nature of working through another
professional as the referral source. Although college-based counseling centers
and private practices that were contacted may have passed on information
about the researcher's interest to potential participants, none of these contacts
resulted in the recruitment of a study participant. Recruitment efforts were
successful only after the researcher had face to face contact with potential
participants. These face to face contact opportunities came when the
researcher went to a local adult support group for people with AS that
included parents and also when the researcher attended the annual Fall
Asperger Syndrome Education Network (ASPEN) workshop. The best
referrals came from parents of students who belong to ASPEN. All of the
referrals that were appropriate for inclusion in the study were received
through this network.

Background information on the Participants

All of the subjects (n=9) in this research study were male.
There was one referral for a female college student but the researcher

was unable to maintain contact with her to schedule an interview and eventually she was dropped from the study. Parents of 4 individuals with AS volunteered their children for inclusion in the study but because they were under 18, they were not eligible at the time of the study. All of the participants were interviewed in face to face meetings with the exception of one person who had to be interviewed by phone.

The participants ranged in age from 19 to 28 years. At the time of their interviews, three were attending a four year college, four were attending a community college, one was enrolled in an online course through a community college, and one, currently not enrolled, had dropped out of a 4 year college after two semesters. During the course of their transitions from high school to college until their interviews, one of the respondents had started in a four year school but transferred to a community college, each of two respondents has attended 3 different colleges and one student attended 5 different colleges. The remaining five respondents had each attended only one college. Two students at the time of interview lived in a dorm; the other seven lived at home with their parent(s). Four of the respondents reported that they were in their freshman year; three were sophomores, one a junior, and one non-matriculated.

Overview of the Research Design

The open ended interview as a qualitative method of inquiry was used to examine the social research issue related to the transition of students with AS from high school to college. The nature of the study was exploratory, and therefore was not intended to test a null hypothesis. Instead, a qualitative design was adopted, which posed questions intended to help better understand the journey of the transitioning individual with AS. The words of these individuals formed the data of this research and the data was used to identify themes. These themes were developed using techniques based on Grounded Theory (Strauss & Corbin, 1990). Data was encoded to align with coding strategies suggested by the work of Strauss and Corbin (1990) as tools for qualitative research.

Procedures.

This study was guided and bound by the regulations of the Committee on Research and Other Activities Involving Human Subjects at Philadelphia College of Osteopathic Medicine. These guidelines included the following:

- the subjects were informed as to the nature of the research being conducted prior to their consent to participate in the study;

- a signed letter of informed consent was obtained from each of the participants;

- participants were informed that their participation is voluntary and that they may withdraw from the study at any time without explanation;

- the confidentiality and anonymity of the subjects was protected;

- permission to audio-tape telephone conversations and face to face interviews was requested and all subjects were informed in advance when such an audio-tape recorder was going to be used.

In addition to these guidelines every effort was made by the researcher to uphold the dignity and worth of the individual participants.

Subjects were given consent forms prior to the date of the interview via mail or email and they either returned signed copies of the consent forms in a self-addressed stamped envelope provided by the interviewer/researcher or they provided their signed consent form at the time of the interview. Consent forms described the purpose of the research, as well as procedures, benefits, and any potential harm/risk factors concerning this type of interview. Interviews were done at mutually agreed upon sites. The sites used for interviewing included libraries and homes. One interview was done by phone.

Both interviewer and respondent had paper and pen available for note taking if desired. A tape recorder was placed in full view of the respondent; in keeping with the written protocol, permission to tape the interview was secured. The questions posed to each participant came from the protocol and the same order and wording of questions was used for each subject. Five

open-ended questions were used to elicit the respondent's own ideas and terms of expression, so that questions meant to probe for more information were relevant to the respondent. Naturally each respondent described and used terms from their personal experiences that were different from the other respondents. Therefore the base questions were the same open-ended questions for each respondent but the secondary questions or probing questions differed, based on the words and terms that the respondent used and based also on the interviewer's need to probe for clarification or to encourage the respondent to elaborate. Another criterion for a secondary question was to refocus back to the specific aim of data collection: the period of transition from high school to college.

The Semi Structured Interview

The interviewer's instructions to the participant were as follows: "I would like to thank you for taking the time to see me to be a part of this study. It is my hope that the information that you provide me today will help people better understand what it is like to be a person with Asperger Syndrome. Your participation in this study makes it possible for me to share information about the transition of students with AS from high school to college not only with professionals, but also with other individuals who have Asperger's and with their family members. My hope is that this study not only helps people understand Asperger's better, but also helps people understand how to assist in making students' journeys from high school to

college successful. Your name, address, and school information will be kept

confidential and no information that could identify you will be used in

reporting the results of this study. All information that you provide to me

today will be referenced by an assigned ID number rather than by your name.

In that way, no one who has access to this information or the results of the

study will have any knowledge of your full name or any other information

about your identity. I will be recording this interview so I can create a

transcript. The transcript will be used to help me understand and share the

information you share today.

Over the next hour I am going to ask you questions about high school

and moving on to college. I am also going to be asking you to tell me about

your thoughts and feelings related to being a person with Asperger

Syndrome. The goal of these questions is to use your words to describe the

journey you took to get to college.

You may decide that you do not wish to answer a question if you

choose. You also may stop at any time should you not wish to continue the

interview. At the conclusion of the interview you may want to volunteer more

information that I may not have asked you concerning the topic of transition

to college.

Once again the goal of today's interview is that I may learn about

Asperger Syndrome and specifically what it is like for a student with AS to

transition from high school to college. Before we begin is there anything that you would like to ask me about what we are going to be doing today?

OK, let's start."

Questions Used in Interview

The interview questions were developed based on the review of the literature on Asperger Syndrome. The grounded theory method which includes methods for coding, categorizing, and concept formation was used to identify major themes, issues and patterns within the stories of the student's lives.

The semi-structured interview consisted of these five of open-ended questions:

1) What was starting college like for you?

2) Sometimes people talk about difficulties they had when they started college?

What was difficult for you as you started college?

3) What was high school like for you?

4) Sometimes people talk about what was difficult about leaving high school.

What was difficult about leaving high school for you?

5) Sometimes people talk about what was good about leaving high school. What was good about leaving high school for you?

At the conclusion of the interview the tape recorder was shut off and the respondents were debriefed. Debriefing involved giving the subjects the

opportunity to state whether or not any uncomfortable feelings existed. The

interviewer observed the respondents during the course of the interview to

determine if any change in the comfort level was displayed. All respondents

received information about available therapy support. The plan was that if the

respondent indicated discomfort or the interviewer noted signs of discomfort,

the interviewer would take steps to address the discomfort immediately by

facilitating prompt action that included the option of self-referral by the

respondent. None of the respondents indicated or displayed discomfort during

the interview process and none utilized the numbers provided to self-refer for

counseling. Debriefing was also a time for the interviewer to thank the

respondent for his participation and praise him for his sharing and

collaboration. The debriefing phase concluded with the presentation of a gift

certificate.

Participants' identities were protected by assigning each respondent a

code number. This code number was used on all materials related to this

study. Aliases chosen by the respondents were used in the transcripts and also

in all written references to the study. Consent forms, a code chart depicting

the alias, name and code number, emails, tapes, field notes, and transcripts

were considered as risks that could potentially provide information that

identifies the participants; thus they were all stored in a locked file cabinet by

the primary researcher. Any potentially identifying information collected

during the course of this study was protected through secure measures in

order to safeguard the respondents of the study and also those individuals

asked to consider participation that were not included in the study.

Respondents were informed in writing and verbally that the

transcripts from their interviews would be read by the dissertation committee,

a transcriber, and a colleague.

Investigator activities

Each of the nine transcripts was read multiple times by the

investigator as part of the qualitative research design in search of themes

generated by the data, i.e., the words of the respondents. Transcripts from the

interview tapes included verbatim statements of the interviewer and of the

respondent and also incidental data, such as noticeable pauses, laughter, non

word utterances (e.g. "umm, ahh", etc.) and repetitive words or stammering.

Additionally, field notes were used to place information into the transcript;

these notes coordinated with observations made about facial expressions,

movement, and any other notable nonverbal aspects of the interview.

Occasionally, a process known as peer debriefing (Creswell, 2003) was used

after some of the taped interviews were transcribed to seek feedback from a

peer who reviewed the study and asked questions designed to provide the

investigator with a wider viewpoint or help discover investigator bias that

might threaten the validity of the study.

The open coding method (Strauss, 1990) was used to uncover primary

and secondary themes. The coding process results were used to create a

description of the journey to college by individuals with AS journey. These

descriptions resulted in the development of a small number of themes that

informed the results section of this study. Narratives from the respondents

were used to illustrate how the analysis of the data and resulting themes were

accomplished; the respondents own words were used to describe the themes.

Final investigator activity

Each volunteer participant was provided feedback in the form of a

written summary at the conclusion of the study. Inquiries to discuss the

results verbally were honored as well. Individuals not involved in the study

but who knew about the study from the recruitment process were also given

verbal and sometimes written feedback about the study.

Chapter 4

Results

The data included in this chapter are the words of 9 individuals with AS who have made the journey from high school to college. Each of their interviews was recorded and then transcribed. This chapter describes what was found during the process of data collection.

The results chapter is divided into two sections: Observations and Themes. In the first section, observations are reported that set the stage in terms of the circumstances under which the data was collected and the behaviors displayed by the individuals in this study. This information is provided to help the reader of this study to get a sense of the behavior displayed by the respondents that cannot be captured by their words alone. The descriptions of various interactions with the respondents will supplement the record of their oral statements and provide a sense of the often unusual and socially awkward nature of the behavior of the

respondents during the study. These descriptive passages cover the following time periods: events that occurred during attempts to set up interviews; initial meetings prior to the actual interviews; events during the interviews; and events that occurred after interviews were completed. This section concludes with observations on evidence of atypicality with regard to keen interests.

The second section of this chapter contains the themes developed from the words of the participants in this study. The four themes are: 1) Academic; 2) Social; 3) Independence; and 4) Personal. Within each of these major themes the words of the respondents with AS tell what it was like to make the journey from high school to college. Each person has experienced varying degrees of success in his transition. The information provided within the four themes provides a picture of the major components that related to the level of success in transition. Each individual reports a range of success within the four major themes around which the results have been organized. For example, within the theme number 1, Academic, the reported range of academic success varies from dropping out of college to making the dean's list. This section includes many verbatim statements from the respondents organized within the four themes. The respondents' quotes presented in this chapter are the unedited and unrevised verbatim statements made by the respondents. The disjointed nature of the respondents' communication styles may hinder to some degree, the reader's attempts to understand what the respondents were trying to communicate. The respondents' words are offered

without editing in order to give the reader a flavor for the communication

difficulties that the respondents displayed during the interviews, and to increase

the reader's appreciation of the cognitive processing demands placed on the

interviewer when communicating with these individuals.

Observations

    Observations- setting up interviews. As mentioned in the procedure

section of this study the researcher canvassed groups of people that included

parents of students who have AS, people with AS, professionals such as therapists

who work with individuals with AS. During the course of this process some

encounters with individuals with AS are informative. Before the start of one

workshop, a well known speaker on AS who happens to be an adult with AS was

approached by me and was told about the study and a request was made to hand

out the recruitment letter to the workshop participants. He was very

accommodating and allowed the distribution of the letter around the room. He

showed interest in the study; the explanation that was given to him stated that the

study was about the transition from high school to college, and he said, "Oh, so

you're interested in those 2 months between high school and going to college?"

This response required clarification that the study was not just about that brief

time period but also about how the AS students recalled their time in high school

and college. I realized that he interpreted the title of the dissertation study in

explicit terms.

On another occasion while at work, I was contacted by a potential participant via a front desk phone operator. With no introduction and no explanation about the purpose of his call, this individual requested "an application." An attempt was made to ask questions to find out what he was talking about, but little information was given, except that he wanted "an application." He did not state his name, did not mention the Asperger's study and did not explain how he got this work telephone number. An attempt was made to understand what he was calling for but it seemed that he grew more impatient with each question asked. Finally, he was told by the investigator that there were no applications and he hung up. Given the context of the setting in which the call was received, it was not until later that the realization dawned that the call likely was from an individual with AS. Unfortunately, it was impossible to find out where the call came from or who referred the caller in the first place.

One of the potential subjects was a young woman in college whom the researcher reached by phone. She wanted to do the interview immediately by phone during that first contact. She was told that a face to face interview was preferable. She gave the contact information and was told that she would be called back and an interview would be scheduled. During the next telephone conversation it was difficult to arrange a time because she was home for only a short time and then had to return to school. After that point, there were no replies to the emails sent to her, so this researcher stopped trying to recruit her for an interview. Later the idea occurred that if the thought of meeting a stranger, even

though the referral came through her therapist, was somewhat difficult for her and that perhaps there was only that one chance at an interview with her. It is possible that phone contact would have been a less challenging way for her to communicate with me. It seems reasonable that her stated idea of doing the interview now was very much the kind of straightforward thinking that some people with AS display. She was saying, "Hey we're talking now, so why not do the interview now?"

Another example of the kind of thinking displayed by persons with AS is taken from an incident during which I met one of my respondents at a conference. There had been a previous conversation by phone and he also asked if we could do the interview by phone. After an explanation that it would be preferable to meet him in person instead, he then agreed to a meeting time and date at a local library near his home. Before there was a chance to interview him, the two of us happened to meet at a conference on AS; he was sitting in a hall with about 400 seats as the conference participants were finding seats to listen to the opening speaker. After confirming for him that the meeting would take place on the following week he said, "You're here; I'm here let's do this now." Thinking, initially, that he was kidding, but then realizing that he was serious, that he wanted to talk right then and there, I explained to him that privacy was necessary, and that his responses would be recorded, and therefore this was not a good place for that; besides, the speaker was about to begin his presentation. Later the next week when the meeting took place in the library, he stood in the middle of the

library and said that the interview could begin. Again there had to be a reminder that privacy was necessary and that talking in this part of the library would disturb others. In the course of our discussion about a place in which to talk privately, there was the sense that he might be unaware of the impact that talking in the reference section of the library might have on other people and that he did not seem to mind if we talked about personal information in front of others whom he did not know. In this particular library, private rooms were available on a first come, first served basis. After waiting for a room to become available, the interview was conducted in privacy.

Observations- meeting the respondents just prior to beginning the interview. Once I set up interview appointments with my respondents I then met with them. The descriptions below are intended to help the reader get a sense about how the individuals with AS responded initially upon meeting me to begin their interviews.

I arranged to meet one of the respondents at his home. I rang the doorbell and after a lengthy pause he opened the door, said hello, shook my hand, and then disappeared. Meanwhile I was left on the front doorstep, standing there with the door part way open. I peered around the door and could not locate him. I stepped into the house, closed the door, and waited for him to reappear. The time during which I waited seemed long because I was feeling uncomfortable. I walked into the kitchen and put my folder and tape recorder on the table. Finally I sat down. All the while I was wondering where my subject had gone. I called out his name;

there was no answer. I noticed a closed door down a hallway; it looked as if it might be a bedroom. I knocked and called out his name. He called out through the closed door saying, "I'll be right there." I went back to the kitchen and waited. Finally, he came out to the kitchen with a toothbrush in hand. He told me that he had to go through a routine before we started and then proceeded to brush his teeth over the kitchen sink. He then pulled the brush out of his mouth and told me that I could start asking questions. I told him that I could wait until he was finished with his preparations. He told me, "You don't have to wait; go ahead; start interviewing me." Again I told him I would wait, explaining that I would be recording and it would be a better recording if he were sitting down with me. I started the interview after he finished brushing his teeth.

I met another respondent at a large athletic facility; it has meeting rooms that an AS adult support group uses for its meetings. Unfortunately, the meeting room that the group uses was occupied so we had to find another place to do the interview. My respondent met me in the lobby. When I told him that staff was looking to find a room for us to use, he suggested that we just use the lobby. I had already looked into options and decided the constant traffic in and out of the lobby was not ideal. Not only was there a lot of people traffic, there also was a large screen TV playing. I am reasonably sure that he noticed those things but equally sure that he did not connect them with the idea that these things would be distractions that could be barriers to a private meeting. Staff found us an unused

exercise room and we were able to do the interview in private, with no distractions.

On another occasion I again met a respondent at a local library. This location was ideal for him because he volunteers at a computer technology center connected to the library. I asked him if he could reserve a room where we could talk privately. He told me that it would not be a problem; there was a room right next to the tech center that we could use. When I came into the center looking for him I noticed several young students sitting at computer stations. My respondent was sitting at a computer as well. I introduced myself and, as in the case of other first meetings for interviews that I have described, there was little transition. He was prepared to do the interview right there despite my request for a more private setting. After I explained again the need for privacy, he arranged for someone to unlock a nearby meeting room and I was able to start the interview appropriately.

Observations- during the interview. Although this writer is not an expert in speech assessment, there were significant observable speech patterns that noticeably affected the ability of the respondents to express their thoughts adequately and be understood by others. Some of the qualitative aspects of the respondents' speech that I noticed were consistent with clinical observations in the literature; these included poor pacing of speech; derailment or going off topic; stilted or overly formal patterns of speech; monotone expression of speech; melodic speech; and poverty in the amount of speech.

Robert's speech during the interview was characterized by pressured speech; that is, he spoke rapidly, often did not finish a thought before initiating another thought and then often jumped back to the original thought. He also mixed up his tenses; he would jump quickly from the past to present without explanation. He also mixed locations of events that he spoke about. I had to question him to clarify the school at which an event happened. He spoke excitedly throughout the interview and even when he, himself, pointed out his tendency to speak rapidly, he did not modify his rate of speech. When Robert drifted into one of his keen interests, a business where he is self-employed, he spoke even more rapidly. In reviewing his taped interview I was able to develop a much better understanding of what he was trying to convey by slowing his speech pace electronically and reviewing it several times.

In contrast, Bob displayed a paucity of speech. Although he was responsive, he used very few words to answer each of my questions. I had to elicit a fuller response by asking probing questions such as, "Tell me more about that." Additionally, his speech was delivered at a slow pace and the pitch of speech was at a high tone and somewhat melodic. However, when Bob's interest in pop culture came up in the course of the interview, he spoke more spontaneously about this keen interest, using many more words without the need for prompting.

Red also took a long time to convey information, but his speech was qualitatively different from Bob's. He did not require any prompts because he tended to say more than Bob; instead he tended to take long pauses in mid-

sentence. His voice was low in pitch and in volume and was also very monotone

in prosody. Red also tended to display stilted and formal phrasings when

speaking.

Clint displayed the most normative speech pattern of all of the

respondents. By that, I mean that he displayed an ease of conversation that

facilitated my interview with him; he stayed on topic, asked me questions to

clarify his understanding of the purposes of my study, and did not demonstrate the

kind of unusual speech characteristics that were displayed by the other

respondents.

Table 3 below charts all of the respondents by the most notable aspects of their

speech patterns.

Name	Fast Pace	Slow Pace	Monotone /Flat	Melodic	Off Topic	On Topic	High Level of Content	Low Level Of Content	Formal Speech	Informal Speech
Red		X	X			X	X		X	
Tom	X		X		X		X			X
Robert		X				X	X		X	
GT			X		X		X		X	
Clint						X	X			
Bob		X		X		X		X	X	
Matt	X				X		X			X
Rocky		X	X			X		X		
Dave		X	X			X		X	X	

Speech characteristics were grouped using five pairs: Fast Pace/Slow

Pace; Monotone/Melodic; Off Topic/On Topic; High Level of Content/Low Level

of Content; and Formal Speech/Informal Speech. These parings represent a scale

in which the descriptor in a pair is on opposite ends of a subjective continuum. An "X' for an individual indicates that the speech characteristic was significantly evident. When a specific individual did not display that characteristic or it was not significantly evident, the box was left blank.

Observations- at the conclusion of the interview. At the conclusion of each interview I devoted time for discussion with each of the respondents to see if the process of the interview had created any lingering discomfort. All respondents indicated that they were not upset by any of the questions that were posed during their interviews. I then offered them the chance to ask me questions. In some cases, the interview ended because the respondent did not have any questions for me. In the four interviews done in the home, parents engaged in an informal conversation when I completed the interview. Both Red and Bob initiated conversation about their keen interests when I gave them an opportunity to ask questions.

Observations on evidence of atypicality. People who happen to have AS are known to also have keen, narrowly focused interests. During the course of my interviews some of the most informing social interactions and discussions came before and after the interviews. During the formal structure of the interview interests might not come up but when I was not recording the interviews, respondents would talk informally, some revealing their keen interests. I had not sought to deliberately collect information on my subjects' interests but early on in my interviews I realized that their interests represent a strong part of who they are

to themselves and to the people around them who are exposed to those interests. These interests included Geography, Mathematics, Pop Culture, especially Music; Dating, Computers, Heating and Ventilation, Business, Photography and Ancient Civilization.

Four Themes

Four primary themes were identified in the analysis of the content of the interviews. Primary themes were revealed in the statements of all nine subjects. The primary themes identified were 1) Academic functioning; 2) Social functioning; 3) Independent functioning; and 4) Personal issues.

Biographical material was collected via a survey form (appendix B) and during the course of the interviews. A summary of that information is included in appendix D that summarizes that information. Consulting this summary may help the reader of this study to better understand the perspective of the respondents as they talk about their experiences.

Theme number 1: academic functioning. The respondents showed varying degrees of academic readiness for making the transition from high school to college. Their experiences ran the gamut from failure to success. In one sense, all of them have experienced some degree of academic success because they graduated from high school and were accepted for study at colleges. Several reported academic failures that were turned into successes. Academics are a key

part in their journey towards Success In Transition (SIT). Respondents' own

words are offered to gain a sense of their academic experiences regarding how to

study, learning from their mistakes, and finding ways to adapt to the academic

demands of college (e.g., the advantages of going to community college; taking

courses online).

Clint, in explaining how having AS has affected him, described

how he is challenged academically. He reads passages from books and

highlights the important parts. He sees most of what he reads as important

so he often ends up highlighting most of the book. He understands that this

is not helping him to develop an understanding of the main ideas or to

develop generalizations from the specific content. He describes how he

needs to pay attentions to some details while ignoring detail in other

situations:

> I been better at it recently but I really like to say I have to
>
> resort to using highlight the important parts and even if it's
>
> not important. So I end up highlighting everything or like
>
> paraphrasing was sometimes hard. But I've noticed that like
>
> what I do better to help myself now, is I read the chapter,
>
> think about you know important concepts and what I usually
>
> do is just read a page and then write notes on what I felt
>
> were the most important concepts of that page. And then as
>
> far as paraphrasing goes, that's easier now because what I

do is I'll read something, wait like maybe a minute and then

say all right what they were talking about. And then I

always put it into my own words there and I just have to get

it down on paper. So I think before I was trying to put stuff

in my own words from looking at their words; whereas now

I read it and then maybe wait a minute and then you know,

so I think that helps too as far as summing everything up.

Also, paying attention like to extra detail or other times

extra detail may be not needed. So it could be interesting if

further like state their point, but you know if it's not really

part of what they are doing like for instance, if someone

says someone's like subject is like school cafeteria shouldn't

push health food on students. Maybe one of their parts is

lets studies show from you whoever said this. Okay that

theory supports the research but not as much to take notes

at because that is not really the main topic. Stuff like that,

that's just an example.

GT summed up his expectations for college, how his college

experience unfolded for him, and also the regrets that he had about what he

did not do in college when he stated:

> *Starting college was like a new step towards my future. It*
>
> *was like going into a brand new world. Prior to this I had a*

lot of support with people with my disability. I had

assistance in classrooms; I had mostly in the form of like a

support teacher and that was in public schooling though. I

didn't receive that in college first of all. Also before, I had

trouble keeping tabs on the time, people would just tell me

or remind of where I was suppose to go. Cause I would

generally find myself in the library and bury myself in a

book and lose track of time. Most people knew where to find

me so if I was really late to where I was going to be late

they would gently remind me that I was suppose to go and

then I would eventually go there. So it helped me a lot in my

high school years. In college, though no one was there to do

that. Which is probably why I really didn't last that long

there, approximately two semesters, but really one and a

half. And most of that was because I didn't attend classes

every day. There was a very long interval between my

classes and I was long. I'd tell them I wasn't driving myself

to school each day so I would have to wait until around

5:00 and I would be picked up by my parents usually. And

that's the way I timed myself and I didn't manage my time

properly back then. So going to my classes which I had

plenty of time; I just spent all day in the library playing on

the computer. It was wrong of me; I wish I could go back in

time and change that as I am more mature now. That's the

way mistakes are made. There is no going back now to live

with that now. I do have a feeling that if I was given a little

more assistance perhaps someone to monitor me, keep me

out of the library. I was, easily distracted I would have

attended more classes and possibly still graduated from

college and I would have had a bright future by now

GT regrets his mistakes in college. He believes that if he had had

more help organizing his time when he was in college that he would have

been more successful. In high school he borrowed from the structure

provided by the staff around him; in college he did not have the same

support.

Tom is taking classes at a local community college, but also is

taking an on-line class through a college in another state; this college offers

classes in photography. He communicates via email and mails his work to

his professor. Tom likes this class and explains why:

I go to BLANK Community College and right now I'm

(also) going to one that is not a college but a takeoff from a

college blank Institute for photography. …. But I'm able to

um, do it differently and that one is easy because you are on

tape; you don't talk you ask questions and my mom helps

me with the writing and stuff and the test part and I email

back and forth my pictures and I'm learning very well that

right now. Through the mail and everything. So that's

another opportunity to try if college is hard. is to do to try

and figure them out to try internet classes; you're not going

to be facing the professor the impression next that you made

semester and that's not what they want; you figure an

internet class is more or less money. One bad part is you

don't feel so live and watching unless if you come for

classes.

Tom has a history of being overly eager to make a good social impression; he believes that it has hurt his opportunities in school. An online course is a way for him to learn and not have to worry about the impression that he is making on others.

Dave described what it was like for him to anticipate going off to college and a little later on in his statement, he gave advice about picking a college.

Well I loved that fact that I didn't have to be there all day

and a I was able to have more time, a little bit more time to

work on my homework and I I was able to take classes when

I wanted to take them and not when they were given……. A

it was, yeah, I would highly recommend to anyone that has

> *a Asperger's that they should look for a community college*
>
> *unless they really know what they want to do and want to go*
>
> *to a major university; they should just go to a community*
>
> *and a save some money.*

Rocky left a four year college and dorm-living situation to return to live at home and take classes at a local community college. He gave advice about the reasons why he finds community college good for him:

> *This one, BLANK (community college) it's just*
>
> *classes and I don't even have; it's just a community*
>
> *college so there's no campus; it's not as board so I*
>
> *don't have a roommate. I still live at home but I don't*
>
> *have to worry about people waking me up all hours of*
>
> *the night and like getting my door; the classes are*
>
> *more; I'm only taking one class at a time at the other*
>
> *place I had a full work load. Now I take one class;*
>
> *now I can focus on just that one class. Now I've gotten*
>
> *B's and A's in all my classes. Like my other class, the*
>
> *highest, the best I got was a B in one of my classes. I*
>
> *made up the work load is definitely better at the*
>
> *community college; there's not as much stress.*

Rocky finds community college less stressful; he can live at home, take fewer courses, and his grades are better. In reading this quote one can see that

Rocky's statement is interspersed with more than one thought at a time. He begins a thought in a sentence and then changes to another topic within the same sentence. Listening to him talk, I noted that he made no pauses and the words flowed without regard to sentence structure. In the above passage, he was contrasting the difference for him between room and board in a 4 year college and commuting to a 2 year community college. He was saying that he was more comfortable at home where he does not have to deal with socially uncomfortable situations such as the one in which his roommate screwed shut his door. For Rocky, community college is less stressful because he can take one course at a time.

Robert had a different college experience from the rest of the group. He was taking an online course for computer training through a community college. He found, that for him, that it was easier to deal with issues related to social setting by staying home:

> *... I don't have to worry about making up work that is missed. You are in a room that you don't feel comfortable in being or not knowing where the students or teacher is. They announce that you don't have to worry about not being able to sleep at home but I am at home, but I like being online because that is what I do best.*

Theme number 2: social functioning. The student's with AS described the various social settings they found themselves in during the course of their

transition. The social settings they talked about ranged from ones of isolation to ones eager with over-engagement. All of them have experienced social difficulties but the flavor of those experiences differs by individual. Their words are directed to dating, isolation, success with structure, friendships.

In high school Matt indicated that he had difficulty with relationships because he was preoccupied with girls, as he stated:

> *If that's the topic of high school academically I did just*
> *fine. I stopped caring so much about getting good grades*
> *once I started liking girls. That's just typical. The only*
> *problem about me is that I would start talking excessively*
> *about a girl I like. I mean that was one of my serious issues*
> *in high school. And people who I was friends with would get*
> *really annoyed that I would keep doing that because it was*
> *like interfering with their own well-being for me to*
> *continuously be talking about a girl that it was futile even to*
> *think about because I had already acted kind of strange to*
> *her so or it was almost like I needed somebody to say "Hi"*
> *to every morning, just to feel good about myself during the*
> *day.*

Matt seems aware that his actions made it difficult for him socially and in hindsight, he noted that his social interests affected his ability to do well in school.

Red described several situations in high school that made him feel

isolated:

> *I had very few friends in high school. I felt ostracized.*

Robert also felt isolated in high school, offering:

> *Fitting in all the time was difficult for me. It was a lot*
>
> *harder to make friends in high school. Making friends is one*
>
> *of the hardest things for me in high school.*

Dave also shared similar observations about high school:

> *It was difficult for me to be social; I didn't feel like I fit in*
>
> *anywhere too much. And I usually just kept to myself and*
>
> *didn't talk to many people.*

When prompted to, "Tell me more about feeling that you didn't fit

in," he responded after a long pause:

> *I I just didn't feel, I didn't feel like, because I didn't feel*
>
> *like I could have gotten involved with anyone at that time.*

When asked about his social situation in college, Dave noted that he

has had difficulty with his grades and avoids social interaction:

> *lately in college I haven't focused on social activity since*
>
> *I, I'm more concerned about my grades at the moment and*
>
> *that's I feel that's something I have to fix before I could do*
>
> *anything else.*

Rocky explained that having AS for him results in being shy and unsure in social settings:

> *I'm shy a shy person like meeting people, making friends is pretty hard. I guess I'm unsure about myself usually social situations when I meet people well other than that I don't really that's all. That's about it really."*

Rocky recalled that some people in high school would go out of their way to socialize with him:

> *Some people were kind of nice. I mean they would talk to you, say hello back. I mean they wouldn't harass me. That was a plus.*

Matt, who presents himself as a very social person, but as needing help in finding friends, found a structured and safe place in his college to meet others:

> *I was actually part of a program that was part of their special office of specialized services they call the BLANK Club, which stood for BLANK, which was basically just a group of people just kind of chatting and stuff. It was kind of a nice thing to do. Because I was wondering if there was any place I could go to just kind of meet people and just be friendly.*

Red also stated that he has a close friend who happens to have AS; here he talks about meeting him after high school:

> *...one of my best friends to this day is someone I didn't*
>
> *meet in high school my freshman year. It seems just*
>
> *paradoxical I believe it's hypothetical hypothetical*
>
> *-the fact that the fact that that I didn't meet one of my*
>
> *closet friends today is someone who I never met in*
>
> *high school.*

Clint noted that teasing was not a problem for him in school especially after 7th grade:

> *so you know that could be a problem but you know one*
>
> *that like if I was **tease**d like earlier in school I just*
>
> *would see a guidance counselor and try to calm down.*
>
> *But I say like after about 7th grade or so, teasing*
>
> *wasn't as much of a problem and if I really didn't like*
>
> *someone that I probably just wouldn't talk to them or*
>
> *hang out with them outside of class.*

After our interview was over, Clint shared that his best friend happens to have AS.

Theme number 3: independent functioning. The students with AS vary in their skills and their needs for independence. All of them have needed help from others and noted that they benefited from that help. During the course of talking

about transition, they describe their level of independence within a range between low levels of independence to high levels of independence. Their words describe the situations in which support helped them strive toward independent functioning as they transitioned and situations in which lack of support hindered their transitions. Their words also tell about expectations for independence in adult life, advice on how to help oneself, on people and groups who help, on missing supports that would have helped, and on advocacy to get those things that help.

GT saw college as a transition into adulthood. He describes his expectations for moving into the adult world, seeing college as a promise of training for a career that would result in independence.

> *I feel that is was another, as I would say, another*
>
> *step towards maturity and I felt like I had*
>
> *accomplished stuff and I graduated and I earned my*
>
> *high school diploma which was a major achievement*
>
> *in my life. And I felt good to be wearing my cap and*
>
> *gown. Of course I was nervous about the transition*
>
> *stage and hoped that I would do well, but I feel that's*
>
> *normal with almost everyone to feel nervous when*
>
> *they make a big change like that. Other things that I*
>
> *felt, would be a positive that I was going on to*
>
> *possibly learn about improving my skills in writing to*
>
> *a point where I could write possibly professionally or*

something to do with writing in general, possibly even

teaching.

Clint noted that time management was a challenge in college. He gave advice about what he believes students in college should be doing to manage their time. Clint talked about making rules about time management, about self discipline, and about ways to communicate with teachers and classmates:

> *So you have to be strict with yourself like you can have*
>
> *long breaks and everything between classes and you know*
>
> *some of the time is instead of partying or eating, you might*
>
> *have to study some or do an assignment also; assignments*
>
> *are handed out like you have more work to do but you have*
>
> *more time to do it than in high school. So you don't want to*
>
> *wait until the last minute; you want to make up a set*
>
> *schedule and you know the teachers aren't there telling you*
>
> *what to do. You know a lot of the stuff; you have a course*
>
> *syllabus so you have to pay attention to that and e-mail*
>
> *them if you have any questions. You also could get you know*
>
> *phone numbers from kids in class. So in that case you know*
>
> *you know in college you could meet some classes; you meet*
>
> *less then in high school and isn't like you know six straight*
>
> *hours of nothing but class. But in the same you are*

challenged more independently in making decisions about

also like to driving to school, you know, like once a week

with traffic and everything.

Robert stated that he could not imagine managing the demands of

college. Time management was a concern of his as well:

> *Well, I have always wanted to go to a real college. I just*
>
> *wanted to find somebody that I could relate to but I am*
>
> *happy to be online because it's something that I'm good at.*
>
> *Something that I do well, something that comes easy to me. I*
>
> *can't see myself having to rush from room to room and*
>
> *worry about that whether I make the bell on time.*

GT talked about people who helped him when he was in high

school. However, in college as he described in a previous statement, he did

not feel that support:

> *Subsequent environment (college) I had to be my own*
>
> *advocate. Back in high school there was a counselor that I*
>
> *could usually go to and a setup of people who were my*
>
> *teachers who I could also confide in and ask for assistance*
>
> *and who knew about me and my disability. And then the*
>
> *work found out. At college I didn't usually have that thing at*
>
> *all at that end. People who were in charge of that everyone*
>
> *else quit. I spoke to a lot of people during school there, and*

> *they didn't want to do anymore than they had to as where as*
>
> *I was concerned.*

GT was disappointed in the lack of availability in college of the kind of help that he felt made him successful in high school. He appeared to understand that in college he needed to ask for help and not to expect it to be given without request. He did not have to disclose his disability in high school; people already knew about it. Later in our conversation he restated how teachers in high school helped him and how his expectations for similar assistance in college were not met. He concluded that he should have advocated for more help:

> *People would help me, my teachers would be there after*
>
> *school and I could ask them if they could help me out*
>
> *organize my book bag, improve my writing, ask the proper*
>
> *thesis, things of that nature. They were around to give me*
>
> *measures and little hints, and just a helping hand when I*
>
> *need them. In college I didn't really have or seek any of that*
>
> *and I think I expected to see that.*

Clint found help at his community college:

> *...what is really good about BLANK (community college)*
>
> *is their project connections. Which not everyone gets into,*
>
> *but what happens is this project connection is a place where*
>
> *you can have tutoring for homework. You could meet with*

advisors to set up, you know like if you wanted to get tests in

a different place. Also, they could set up with you like how

many credits you want to take you know if you are working

that kind of thing. So you know you're not really alone in

that sense.

Clint found help in college in a program called "Project Connections" in which he found a valuable resource in people who could provide tutoring, test accommodations, and advice on work load.

Dave had sought out help from a counselor in college because he needs to get better grades:

> *My a grade future wasn't looking so well in the classes*
>
> *and recently I've been to see a counselor to help improve*
>
> *my GPA*

Later in our conversation Dave added that he found programs offered in high school such as the study skills class and a peer mediation group to be helpful for him for his academics and for respect for diversity:

> *Well in high school was that a it was hard to like, but*
>
> *there was a few good things. I like the help that they offered*
>
> *at the school with the class with the study skills. And they*
>
> *would um they would um and they would have a mediation*
>
> *group every week that every Monday of the week and that*
>
> *that actually helped out with knowing people better…. they*

helped, they talked about diversity; I'm remembering about

diversity and they talked about cultural issues at times, and

how you can get help for them.

Theme number 4: personal issues. The students with AS revealed a great deal of information about their personal lives during these interviews. In the course of speaking about their transitions to college they talked about deeply troubling topics that they identified as private and hurtful. They told me what it is like for them to have AS. They talked about their personal relationships or lack of satisfying ones, about being traumatized by people who bullied, harassed and in some cases assaulted them, about loss of loved ones, about wanting to date, and about how they are different from others.

Red described relentless and continuous harassment by his peers in high school. Talking about teasing he noted:

> *...there were several students who constantly, on a*
>
> *consistent basis would because I used the lap top as part of*
>
> *my accommodations in high school in accordance with*
>
> *IDEA. I would I would carry it; I would have to carry it*
>
> *over my shoulder the case for it. And I happened to carry*
>
> *the case over my shoulder and a number of students would*
>
> *say that I, quote 'carry a purse' unquote. And they would*
>
> *never; they would never cease doing that.*

Rocky was asked what high school was like for him. He noted that

he was teased, physically attacked in middle school, threatened, and called

names:.

> *I was harassed by a lot of, kids always tease, being mean,*
>
> *being picked on, it was a little awkward. I mean like I was*
>
> *attacked on the school bus like back in middle school.*
>
> *Somebody he threatened to shoot me in class. Just really*
>
> *bad and people would call me names...*

Tom's recollections of high school also contain descriptions of

teasing, name calling and physical assault:

> *High School was was very bad. Kids would always tease*
>
> *me call me names and stuff, like retard reject and anything*
>
> *they could come up. They just just called me names and*
>
> *stuff. And retard wasn't that big. I really wasn't upset… But*
>
> *when I was going there, cause kids were calling me names I*
>
> *transferred to BLANK (another school) …*

Later, on the same topic, Tom noted:

> *They would say, oh you slow or you talk too fast and stuff*
>
> *stuff like that and one of them when I was at like third*
>
> *level(reference to token reward system) when I was going to*
>
> *speech class they broke my fingers and they called me*
>
> *names and stuff like that. And I remember kids they were in*

special ed school; they weren't nice to me and everything;

they would just make fun of me and my sister would protect

me when she was in the school going by and stuff and

everything, and one say oh he didn't break his fingers; he

just fell and everything and stuff like that and the teachers

wouldn't want to walk you to the speech class, actually had

to go by yourself with the other kids in the classroom; so

that was hard.

Matt indicated that he was accused of stalking people more than

once. Listening to him describe his difficulties, I had the impression that he

tended to misinterpret social signs of casual friendship and attempted to

force relationships to a more intense level by jumping past the usual steps

one takes in establishing a new relationship. In his own words he stated:

I just started getting in trouble because I was; girls were

filing harassment complaints against me because I just

didn't really know how to handle myself. What would

happen is that I would lose my temper one night and

anybody who was even slightly nice to me, I would try to get

them to be friends with me. I tried to force them almost and

eventually they would have enough with me and they would

tell me to go away from them and the next thing I would do

is try to apologize to them that I had ever acted so weird

that some of them were not that forgiving or willing to. So I

would just get very frustrated and what happened is that I

would just get extremely frustrated, but they wouldn't get

over it. So I would resort to getting even more mad at them.

And telling them basically that they better forgive me or

else. I don't think I ever said that they would be sorry, but

somebody once accused me of doing that.

Matt expressed frustration in interpreting the social cues of people

he is interested in being friends with. Although he wants to be a part of the

social "scene" of college, he is ostracized because of his poor social skills.

His difficulties in this area created a number of difficult situations for him.

Matt said he had learned from the mistakes that he made in these situations,

but commented that he still has difficulty avoiding them. For example, he

told me that on the day that he was to be interviewed for a television news

program about his life as a student with AS, he again was accused of being

too forceful in his approach to friendship with a female student. During

times when Matt is excited and feeling good about himself, he tends to

experience difficulty with managing his relationships.

Rocky explained that his roommate harassed him; I asked him to

explain more about it:

Well um not so much that it was teasing but um like

bullying; like he'd come home like get there real late and at

night and wake me up and drunk and his friends would all

be drunk and stoned and all be on drugs, and eventually I

had to get my own room. And prank calling throughout the

night. They screw(ed) my door my lock shut like locked it

from the inside so I couldn't get into my room. Um they

entered my room turned on all the electrical so it blew the

fuse to my room, so I had no power in my room. And at that

point you know what I eventually threatened to call the

police on them. The next day after the first semester ended I

didn't go back.

Leaving college and the events leading up to his departure seem to have been very upsetting to Rocky.

Tom remembers difficulties with his roommates in college too. He experienced being voted out of his dorm by the other three members of his suite:

When I was at the (blank) campus but I tried to go to

college for hospitality and it was very hard and there was a

lot of stuff because of my Asperger's Syndrome I would give

too much information. When I was up there were people

that were on drugs in my dorm and everything. And with the

AS we tend to give too much information, like to report them

right away to the RA not knowing that the RA was the one

who was dealing the drugs. They voted me out of college

there.

Through the interview process I was able to learn that this

experience occurred at the first of the 5 colleges that he attended. He had

not yet been diagnosed with AS at the time of this experience. He displayed

the characteristic of being a "rule police" with his roommates, telling on

them when they broke school policy. His roommates did not understand

him and voted him out of the dorm. Without housing on campus, the

commute made it difficult for Tom to stay in school, so he dropped out.

Matt wants people to know that AS is expressed differently in each

person who happens to be diagnosed with it. He warns that individuals

should not assume that one person with the diagnosis will be similar to the

next person. Within the AS community, some individuals with AS describe

themselves as Neuroatypical and those without AS, as "normals" or

neurotypicals. Matt notes that just because a person has AS does not mean

that all individuals who have AS are socially compatible with others who

have AS. He would prefer to date a Neurotypical:

> *Everybody who has it is totally different. So never, it's*
>
> *okay to say somebody is diagnosed with it, but don't ever*
>
> *assume that because they are diagnosed with it they are*
>
> *going to be a specific way. Everybody who has, has it to a*
>
> *different degree. And it is not necessarily always compatible*

with other people who have it. Like you just have to realize

that because everybody who has it, has it totally differently.

Like honestly, I feel like I get along better with people who

don't have it, except with people who have it similar to me;

like regarding the whole scheme of dating, I would much

rather date somebody who's so called more typical that

might be a little bit different. My goal is to date somebody

who is more typical but the same time is not just a boring

person such as a dumb blonde. Dumb blonde doesn't even

necessarily have to be blonde; it could just anybody who

was totally superficial like on the surface. Asperger's

people need people who has some depth to their

personalities, like to be truly good friends with."

Bob described his strengths or interests and brings up the topic of

what having AS means to him:

> *It just that we don't always have the same social skills as*
>
> *everyone else. Personality wise we just tend to be really*
>
> *different, like interests tend to be different. I have more of*
>
> *an interest in numbers that anyone else. Oh, memorizing*
>
> *facts is an interest I had that tends to be kind of different*
>
> *from everyone else.*

Later in our conversation, Bob continued to describe how he views

his reasoning ability:

> *A lot of things, I have a different interests…. I think more*
>
> *concrete then you, not as abstract….. I don't have the social*
>
> *skills like most people have; Oh, by having Asperger's*
>
> *Syndrome I tend to be easily distracted.*

Matt volunteered that he knows that having AS means that a person

approaches social situations differently, and that despite positive support

from others, he still finds it difficult to change so as to pass as "normal". He

notes that he looks normal but his social actions are misunderstood by

others. He is aware that people sometimes view him differently and

understands why they do:

> *We didn't have that part of the brain properly*
>
> *developed. I couldn't; it didn't matter how much*
>
> *people tried to tell me if you think you can or you think*
>
> *you can't you are right. I could not do it. I was like a*
>
> *fragmented brain. Didn't matter how much I went to*
>
> *see any doctors that could help. It helped keep me*
>
> *more relaxed but it didn't really seem to be able to fix*
>
> *my inability to be socially appropriate. Like if you*
>
> *remember Wolfgang Amadeus Mozart; he had some*
>
> *craziness. His social graces were totally messed up. I*

think he did have a girlfriend at some point though,

but with his social graces were completely odd. Just

think about it like that. I would just like run around the

place sometimes and I would just run around the place

and start almost like shouting at people, like excited

say "Hi!" "How are you?" in that kind of loud voice.

Like very monotonous, unusual something that most

people would not really understand because people

mostly didn't get it about me because most would say,

as you can see today, I look perfectly normal. So it's

like if I start talking differently, people would think

that I, something was totally wrong with me.

GT described having AS as being both a strength and a weakness. He sees himself as being able to pay attention to details that others do not notice:

> *I feel like I'm like the hunter; my senses are sharper than*
>
> *most people. I'm able to hear things; I'm either able to hear*
>
> *peoples conversations from across the hall and even from*
>
> *across the street. I can spot things easily and I also*
>
> *remember certain events longer than others.*

Later GT noted that having AS presents challenges for him in social settings. He has difficulty being organized, interpreting the nonverbal cues.

His lack of emotional control often gets in the way, and he can be impatient with others:

> *I'm more disorganized, I get excitable at certain times*
>
> *depending on which medication I'm on. How well the*
>
> *medication is affecting me. I can blow up things*
>
> *inappropriately at time because I lack certain social*
>
> *abilities. Or I might miss non-verbal cues. I always had*
>
> *trouble with for some reason, like maybe…a head is tilted*
>
> *that might be a silent cue to stop talkin and not answering*
>
> *the conversation that I might miss. I also had some trouble*
>
> *organizing my time properly, getting to places at the correct*
>
> *moment I'm supposed to. And, wandering off when I get to*
>
> *bored or don't feel like I'm being challenged of course. And*
>
> *that's also a problem. Although I have been working at that*
>
> *a lot in the past two years or so.*

Robert spoke at length about what having AS means to him. The passage below sums up several issues that he brought up, related to his having AS. He notes that he talks too much and asks questions that are too personal in nature. Robert attempts to explain the reasons why the give and take of a conversation is challenging to him:

> *Ahh sometimes I talk too much. I might jump from one*
>
> *topic to another topic. I'm getting better at eye contact. But*

it's still hard; I might ask personal questions to somebody

and my psychologist doctor is helping me to do better on

that. Not to ask those many questions. Ahhh to listen to

other people, see how they react and let them talk first, and

say hi and see what they do. But the Asperger Syndrome

sometimes I might talk too much or not listen to them or

they might talk a lot and give me too much information and

I'll forget what they're saying. Like when you read that stuff

that was a little bit, but if you read all ten pages and asked

me to do it I would forget most of it

Robert's father was a teacher at his high school. Robert recalls that

his helpers in high school were people he missed when he graduated:

Leaving behind the people that I knew; some staff

members that have helped, some staff members who knew

my father before he passed away. They were willing to help

me and in their own way said, "Well, there is someone who

looks like they could use some help" in the school system.

So I always thanked them for being there for me. That's

what I miss most.

GT recalls high school as a time when he had lots of support from

teacher and friendship with his classmates:

> *High school was a good time of my life there, but I had*
>
> *plenty of support from my teachers, friendships and*
>
> *classmates there. It was a positive environment where I felt*
>
> *support that I needed but people didn't look down on me. I*
>
> *didn't feel as if I was being babied, I felt like I was part of*
>
> *the general class as student body. I also felt that I was doing*
>
> *well with my studies at the time. I didn't feel like I needed*
>
> *an exorbitant amount of help with a little bit on certain*
>
> *items. And with their help I think I was able to manage.*

Red recalled his case manger from high school as someone who helped him:

> *My case manager at the high school very, very sweet lady.*
>
> *She did an unbelievable amount for me.*

Matt was talking about how people with AS have strengths that motivate them to excel. While talking about Asperger's Syndrome, he mentions his friend who also has AS.

> *...people who have Asperger's are much more capable*
>
> *of doing it because the thing is when they find what*
>
> *their true interest is, they get so motivated that they*
>
> *will do anything to do that and invent something that*
>
> *they feel will be right for the world. So I don't know;*
>
> *find some way or another write music; that's another*

way. A lot of people who have Asperger's will have

some degree of musical interest. So you sing or song

writer like one of my friends is. Perform in a rock

band, sing in a choir or compose you own style of

music.

Red explained how enjoyable he found the change from high school to college:

> *I felt it to be a completely enthralling experience. I*
>
> *found that that I had found something at college this*
>
> *fall that had relations with other students that were*
>
> *virtually 100% civil ... there was quite a few friendly*
>
> *students in high school (but)   I truly found a caring*
>
> *community at BLANK County College. I have gained a*
>
> *number of friends, male friends. There are a number*
>
> *of students with whom I go out often.*

Three respondents recalled loss of a loved one as causing significant stress, making it difficult for them to manage the demands placed on them in college.

Rocky talked about the difficulty he had starting college and losing his Uncle.

> *Well the first one the first college obviously; I lost*
>
> *my Uncle in 9/11 that was the influencing that just*

made us it a little harder for me more. That this

happened. He was a police officer.

In recalling what was good about leaving high school and starting off to college, Tom mentions the loss of his father. You can see from his words that he has so many thoughts to present. He does not talk about what must have been a painful loss, but mentions the business "On the Move" that his father was encouraging him to start before he died.

Ahh that I was able then to go to college county

college of BLANK and where I got to EP classes and

stuff. One professor didn't believe that I was a --- she

didn't believe that I did the paper; she said, "With

your reading level and IQ, good that you could do

this, but I don't believe that you did it." She made ---

the good thing was I was eager to go to college start a

business with DVD, On the Move, the nice thing that

my dad was alive for a little of it and when he passed

away we started it. The good thing was that I was

leaving a lot of teasing and stuff and going to the

college.

Robert also mentioned the loss of his father who taught at the same high school he attended and was already quoted on this subject.

Chapter V

Discussion

This chapter is divided into five sections. The first section contains a

summary of the general findings for each of the themes developed in chapter IV:

Academics, Social Relationships, Independent Functioning, and Personal Issues.

The second section describes an adaptation of a theoretical model from the

literature as a way to describe the findings and put them within a context of a

developmental model. The third section provides additional observations and

comments about the findings, including information about dealing with keen

interests; how students with AS view themselves; and problem solving during

transition. The fourth section describes applications of the research findings to

psychological practice. The fifth section provides a discussion of the study's

strengths and limitations, suggestions for improving research procedure,

implications for future research methodology, and plans for the collected data.

Summary of the Four Themes

Summary of academic functioning. All of the students with AS interviewed in this study experienced some degree of academic success. All of them were accepted to and enrolled in college programs. During the time of transition into college some of the students were academically successful but some were not. Those who were academically successful in transition described their approaches to course work in a manner that reflected good time management, organization, and self-direction or the adaptive strategy of looking for supports within the school to help develop these capacities.

Those who were academically unsuccessful in transition described difficulties with time management, with organization, and with self-direction. Several subjects noted that they had trouble focusing in an efficient manner when studying for exams. They reported the tendency to study everything provided in the course and indicated difficulties with summarizing or limiting their focus.

Summary of social functioning. During the time of transition from high school to college all of the students in this study experienced some degree of social difficulties consistent with individuals diagnosed with AS. The ones who experienced the greatest difficulties socially had no prior experience in living with a roommate and did not know how to interpret the college social context. Most were teased and harassed by their roommates. Those that were more successful in negotiating the college social context did so in a rather restricted fashion. They employed strategies that tended to isolate them from the social setting of college

such as spending time alone in their rooms, escaping for prolonged periods of time with regular trips home, or immersing themselves completely in their studies.

During the interviews, many subjects spoke of the difficulties of managing the social part of school. All of the subjects recalled negative social experiences. Matt wanted to have a girlfriend, Red and Robert told of feeling isolated, Dave felt he did not 'fit in' Dave and Tom were teased, and Tom and Rocky recalled physical assaults.

Most of the subjects indicated that they had experienced negative social situations in college. Dave avoided social life on campus because he indicated that he needed to spend more time on his studies, Matt noted that he was obsessed with having a girlfriend but his lack of social skills resulted in complaints of stalking filed against him, and Rocky and Tom recalled that their roommates played jokes on them that were hurtful, and were part of the reasons why they left school.

The more socially successful students dealt much more effectively with social challenges. They tended to take advantage of clubs and other social supports offered by the college. Although these students demonstrated greater social competency, not a single one of them could have managed the social complexities of a college setting without help from significant people in their lives: family members, case managers, teachers, professors, advisors, etc.

The assistance that these students received came from various sources. GT praised the high school staff that helped him in his transition, including his counselor, teacher aides, and teachers. He also talked a lot about belonging to clubs and about his enjoyment in participating in them. In college he noted that he realized that he had to be his own advocate; people he sought help from did not provide the same level of support that he had in high school. In contrast, Clint found help at his community college from advisors and tutors. Red had good recollections of people who helped him in high school. As isolated as Rocky felt in high school, he did appreciate the effort people made to socialize with him. Dave felt he was helped socially by his inclusion in groups. Matt found a group in college that offered him an effective way to socialize.

Summary of independent functioning. The independent functioning capacities of the subjects in the study varied greatly. This was particularly evident when they talked about people they saw as helpful in their lives. Some noted that just following a daily high school bell schedule was too difficult for them without help, but others expressed no difficulty with negotiating the school environment. In college, the varied levels of independent functioning were evident in the subjects' descriptions of their efforts to handle the demands of the college environment. Some students had to drop out of college because they did not go to their classes. The subjects who were successful in transitioning from high school to two-year community colleges lived at home. Living at home offered them a chance to have supports from family while negotiating the

demands of transitioning into college. Even those who clearly have been academically successful in four year colleges have needed much family support. In some cases, their parents brought them home every weekend.

Summary of personal issues. Many of the students who were interviewed spoke of personal issues that made the transition to college more difficult for them. These issues included the loss of family support, loss of loved ones, and seeking romantic relationships. For example, three of the students had lost close family members during the transition period. They recalled that the loss of the support of these family members made it more difficult to manage the demands of college. Family has been very important to these three individuals; they were able to articulate their losses and describe how the losses affected them in school.

The challenges inherent in dating and forming friendships in college also contributed to making the transition difficult for some of these students. Although they expressed a strong desire to have relationships similar to their peers, they also confided that they know neither how to start a relationship, nor how to maintain one. They do not give up trying but the process of seeking relationships was a source of trouble for them because they struggled to find ways to explore sexuality safely in the context of college life. Some handled this by avoiding the issue and holding themselves socially apart from others; some as described in the summary for social issues have relied on involvement with structured groups to fulfill their personal needs for friendships.

Conceptual Models

The investigation into the transition from high school to college for students who have AS resulted in the development of 4 major themes: Academics, Social Relationships, Independent Functioning, and Personal Issues. These themes were established from the words of nine individuals with AS who have made the transition from high school to college. Because of the wide range of responses provided within each theme, each theme can be viewed as representing a continuum in terms of degree of capacity within that area. Each person experienced and recalled very different and personalized facets of the transition experience. One common finding was that all of the subjects considered the transition from high school to college and the change that naturally came from it to be fraught with difficulties and failures. But not all of the information that was related in the interviews focused on difficulties; some elements of the discussions revealed successes. And in many cases, determining whether or not an experience was a failure or a success seemed to be a highly relative endeavor. For example, Tom who was 28 had attended 5 colleges. Would this string of school changes represent success or failure? Perhaps most relevant in the lives of each of these students is the perspective with which they chose to interpret their experiences. Tom did not give up and at the time of his interview he saw himself as successful in school and reported that he was enjoying his classes.

The four themes identified in this study represent areas within which competence must be demonstrated in order for a student with AS to be considered Successful In Transition (SIT) from high school to college.

Coplan's model. In the process of organizing the results from chapter IV, this researcher tried to construct a model that would summarize the findings and capture the developmental aspects of the transition from high school to college for persons with AS. Coplan (2000, 2003) put forth a model (see Figure 1 and Figure 2) that he suggested might help professionals and families to understand the developmental nature of Autistic Spectrum Disorders (ASD) of which AS is a part. This model was discussed in the review of the literature in chapter 2.

Adapted transition model. Similar to Coplan's, the model proposed here uses four quadrants divided by X and Y axes (Figure 3). For the X axis, the atypicality continuum was used as a way to describe the clinical manifestations of AS captured in my study. For the Y axis, the term Success In Transition (SIT) is used to describe a continuum ranging from Low Level of Success to a High Level of success.

The addition of the Z axis representing time in terms of the age of the AS student acknowledges the role of time in the developmental process. For example, a student who experienced a high level of success in transition with clinical signs of only mild atypicality could be represented by point A in Figure 3, but a student who experienced a low level of success in transition and demonstrated more severe signs of atypicality could be represented by point B in Figure 3. Adding

the axis Z, of time, to the model reflects the developmental effects on transition.

Revisiting Tom's situation from the perspective of this model, it can be seen that

Tom, who exhibited moderate to severe symptoms in his teens was not very

successful with his initial transition to college, placing him somewhere within

quadrant III of the model at that time. Now at age 28, Tom still exhibits moderate

to severe atypicality, but his successes with the transition process now place him

in quadrant II.

In many developmental models, the effect of time is often conceptualized

as a gradual upward slope. In a three-dimensional model that incorporates time as

a dimension along with severity of AS symptoms and success in transition,

however, movement along the dimension of time does not necessarily produce a

steady, positive slope, primarily because the degree to which AS symptoms are

exhibited by an individual do not necessarily decrease over time and the degree of

success in transition does not necessarily increase over time. As a result,

individuals can appear to "jump" from one quadrant to another when their

situations are viewed at two or more different times. For the subjects of this study,

this kind of jumping from one quadrant to another across time was the rule more

than the exception, and the quadrant changes reflected in their recollections of the

transition process over time generally indicated a positive movement along the

SIT dimension, even when their recollections did not necessarily reflect any

apparent reductions in atypical behaviors.

From the content of the interviews, it was apparent that, over time, many of these individuals learned from their early failures and were able to experience success at a later time. These successes were achieved through learning and motivation rather than as the result of some sort of inevitable upward developmental progression.

Using the adapted model to plan for transition. Based on his dimensional model, Coplan (2003) offers recommendations for ways in which his model can be used to help counsel parents about the nature of ASD. These recommendations include 1) describing the level of atypicality within a range of severe to mild; 2) emphasizing the dynamic aspect of change within the model, wherein significant qualitative changes can occur over time; 3) explaining that any degree of severity can occur with any degree of cognitive ability, and 4) pointing out that long term outcomes for any given individual are a result of the joint effects of global cognitive ability and ASD.

The model proposed here also could be used to counsel parents of students with AS, the students themselves, and professionals who are considering the supports that could be put in place to create a successful transition for students with AS. Based on Coplan's model, recommendations for transition using the SIT model would include 1) describing where the student falls within the range of Atypicality for individuals with AS relative to the thematic areas of Academics, Social Relationships, Independent Functioning, and Personal Issues, 2) identifying developmental shifts that have occurred up to this point in time, and 3)

using knowledge of developmental shifts to identify future shifts likely to occur during the transition from high school to college. The information gained from an analysis of the students' situations through the use of this model could improve targeted interventions designed to promote success in transition.

Additional Observations and Comments on Findings

Dealing with interests. During the process of interacting with the subjects of this study, and consistent with the findings of the research literature on AS, it was very much apparent that when a topic of great interest to the student was introduced into conversation, these individuals were unable to resist dominating the conversation with long, exceptionally detailed monologues about their specific experiences with, and knowledge about the topic. Red, for example, whose area of interest is Geography, revealed this interest prior to the start of his interview through his questioning of me about where I was from, where I was doing my internship, and at what college I was doing my studies. He had memorized all of the state capitals along with almanac type information about geographical locations. He continued to present his knowledge until his mother was able to direct him away from the topic. Bob, whose interest is pop culture, especially music, was listening to music playing in the background and identified the group name, the name of the song, and the year the song was first heard on radio as a song from the 1970's. Further statements by Bob revealed an encyclopedic knowledge of pop music across many decades. Matt, self- described his interest as dating women and indeed showed an extreme preoccupation with this topic while

interacting before, during and after the interview. He spoke very rapidly and with every question asked in the interview, he redirected his comments back to this topic of great personal interest to him. He also revealed a second interest – heating and cooling systems; he said he tends to think about these when he feels stressed. During his interview, Bob engaged in an elaborately detailed side bar that focused on the topic of ancient civilizations.

What AS means to those who have it. Although AS is typically characterized by difficulties appreciating the perspectives of others, it was very clear from the interviews with these nine students that all of them had very distinct perspectives of their own about what it means to have AS. Matt noted that people with AS are unique individuals, meaning that although they may be different, they also defy generalization. From Matt's perspective, each person with AS is very different from every other person with AS. He offered the hypothesis that Wolfgang Amadeus Mozart likely was a person with AS; he was a brilliant composer who focused intently on his music but who lacked 'social graces'. Bob defined his AS in terms suggesting that he is comfortable with who he is and related his interest in numbers as a strength and a difference, a good difference. He also said that for him, having AS meant that he was easily distracted.

GT also believed that his attention capacity was different from that of most people. He compared himself to a hunter with sharper senses than most, stating that he could hear conversations across street, visually spot details in the

environment better than most people, and remember certain events longer than others. GT also said that he saw himself as more disorganized, had difficulty interpreting non-verbal cues, and displayed a lack of emotional control. GT and Clint noted that for them having AS also means that they have difficulty coming up with summarizing statements. They realize that they often give too much detail although a summary would be better suited.

Clint noted that for him, having AS means that identifying the meaning of passages when reading is difficult. He has had to work at developing skills that could help him find the main meaning when reading a passage. He noted that in the past he would find himself highlighting the whole book, but now he has improved at sorting out the important details from the details that are not so important. Robert said that he knows he talks too much and does not know when to avoid asking personal questions. Rocky said that having AS means he is shy and uncertain in social situations.

From the contents of the interviews, it is clear that individuals with AS have definite opinions about what having AS means to them. From their words it is apparent that although they share some common views about the challenges that having AS presents, each one of them offers a unique insight into what having AS means to them.

Acceptance of who I am. Six of the nine respondents indicated having social problems in high school and four of the nine indicated having social problems in college. Although social problems were clearly a common

occurrence, they were not a universal theme among the subjects of this study.

Some of those interviewed appeared to have experienced much less difficulty

within the social realm. Additionally, a number of the subjects talked about

positive social interactions such as making friends in high school or college.

Although Matt, as noted before, is not satisfied with his friendships with women,

he enjoys the company of a friend with AS who is musically gifted and shares his

keen interest in music. Bob also has a friend who has AS and is musically gifted.

Two of the participants in this study happened to be good friends who spend a

good deal of time with each other. The individuals with AS who participated in

this study tended to gravitate toward others with AS. Each of them seemed to find

their social comfort zone most effectively with other individuals who have AS.

People with AS can problem solve in transition situations. The subjects

of this study were quite comfortable with offering advice to others students with

AS who are thinking about going to college or who are already in college. GT

gave advice that created a cautionary tale of his failings in college. Clint

suggested that students adopt his strategy of listing rules to make better use of

time; he also highlighted the importance of developing independence. Robert, for

financial reasons, was taking an online college level course that was enabling him

to avoid the problems that he had experienced in school with time management,

and with being at the right place at the right time.

Tom is taking classes at a community college, but like Robert he was also

taking an online course that removed the social pressure from him so that he did

not have to worry about the impression that he was making on the other students. Rocky, who felt isolated at a 4 year college, noted that he now enjoys commuting to community college and in taking only one course at a time; he no longer has the worries he associated with having a roommate. Matt took summer courses that saved money when he transferred to a 4 year college. He advised other students to think about using community college to earn credits as he did.

The advice offered by each of the subjects clearly shows that they are capable of finding effective solutions for many of the problems that their AS often creates for them. Although the transition for each has presented many challenges, these students often responded adaptively to those challenges in ways that enabled them to make progress toward achieving their academic goals.

Application of the study findings to psychological practice

Similar to the findings reported in the literature, the subjects of this study have required support systems to help them realize their potential in school and as young adults in the workplace. Interventions are needed in the schools to address the difficulties typically demonstrated by students with AS. As evidenced in the interviews with these students, the accommodations vary depending on the specific needs of the student and their transition situations. Some students had organization problems and could not get to class; some had academic problems and did not seek help from their professors; some were socially isolated and unable to initiate conversations with their fellow students.

Perhaps the only consistent finding of this study is that each student with AS who engages in the transition process is likely to present a unique set of strengths and weaknesses that will require a unique approach to adapting to the specific demands of their transition processes. Hence the strategies that are applied will be very different from person to person. An example can be found in the case of two individuals with AS who were too young to participate in this study. Both students finished high school and graduated with associate degrees from community colleges. Their transition experiences were very different from those of the individuals who participated in this study.

Because of the relatively unique experience that transition to college will present for each student with AS, the suggestions offered below are meant to stimulate thought about ways to assist students with AS to make the transition from high school to college rather than to suggest general rules that apply equally well to all students with AS. The suggestions presented here are organized according to seven major facets: identification, self disclosure, living situations, community college, choosing a college, importance of structured groups, family, and language.

Identification. Two of my subjects were not identified as having AS until they were already in college and were over 20 years old. Diagnosis may be seen by some as stigmatizing and demeaning. However supports in public education are not available unless the student is evaluated as displaying a handicapping condition. In order to get supports in place in college, the student has to meet

federally mandated criteria. Without evaluations that support a disabling condition, services need not be offered. Early diagnosis and intervention may be a key facet in structuring improved outcomes during key transitions in the life of an individual who has AS.

Self disclosure. Before heading off to college students with AS may want to self-disclose their conditions to the school and ask for accommodations that address their needs. Some individuals opt not to self-disclose their AS condition, preferring to do so only when necessary, or revealing only as much as they are comfortable with as situations arise. For example, students who want to make a fresh start socially, might not want anyone they meet at the college to know that they have Asperger's. They may want to be treated the same as any other students in social situations, and may elect to tell others that they have a focusing problem or an auditory processing problem as a means of explaining any unusual behaviors related to the AS that they may exhibit in social situations.

Self-disclosure is a personal choice. Deciding to self-identify depends on the students' individual circumstances and the need to balance their aspirations with the realities of their conditions. For example, the degree of atypicality exhibited by the student would likely be an important factor in making the decision whether or not to self-disclose. Some students will need to disclose so that the school can prepare for a successful transition. My clinical experience is that personnel who understand the unique needs of students with AS are available at the college level to provide supports. Students who did not self-disclose

experienced difficulties in transition that they might otherwise avoided had they taken advantage of services offered.

Living situations. The degree of atypicality exhibited by the AS student is likely to be the major factor that must be considered when thinking about college living situations. Students, along with their parents, will need to consider whether they want a roommate or whether a single room would be better suited to their needs. Exposing the student to different living arrangements prior to entering college can help student and parents make more informed decisions about what these living situations might be like for a full year. As was the case with some of the students in this study, students may opt to live at home rather than immersing themselves in a less predictable, and possibly stressful, social environment.

Community college. Some students with AS may not want to start college in a four year school and may opt for a community college where options include a reduced schedule, and a campus that is within commuting distance. Another advantage of community college might come from the continued support from family members while the student lives at home. Community College is also a less expensive educational option, thereby offering a lower cost way to get exposure to college life.

Choosing a college. Students with AS can consider enrolling in schools that have staff who understands how difficult transition is for AS students and that provides help to assist with the transition process. Professionals in helping roles have positively impacted the social lives of the AS individuals in this study.

Professionals are important potential advocates for helping others understand the

'how to' of transition to college for people with AS. College based professionals

can also be agents of support for self advocacy by the student. There is at least

one college in New Jersey that has developed a program specifically for students

with AS, and the likelihood is great that more colleges will follow suit in the

future.

Structured groups. Joining organized groups can provide a student with

AS with a sense of belonging to the college community. When looking for a

college, the student should consider choosing a college that offers structured

groups or clubs that address the AS students topics of great interest. Groups

formed around similar interests offer a way for individuals with AS to experience

relatively more predictable social interactions centered on the topic of common

interest. Group or club situations greatly reduce the need for the kind of social

risk-taking and flexibility of thought that is often part of less structured attempts

to find individuals with common interests. Some colleges have structured support

groups based on specific learning challenges or health issues, and some even have

AS support groups.

Family. Family as a support is very important to student's with AS. It is

important for professionals to encourage continued family support while at the

same time supporting the student's efforts at developing independence. Parents

are also strong advocates for the needs of their children and can help their child to

self advocate during transition.

Language. Professionals seeking to facilitate communication during the transition process will need to know the AS student very well. Extra time in conversation with these individuals often is needed to be able to clarify the meaning of their statements. In order to understand what the AS student is trying to communicate, professionals my find it useful to lend structure to the student's statements by asking questions and summarizing details that help to clarify meaning. It will often be necessary to impose structure and limits on the communication process in an effort to keep the AS student focused and on topic. Restating and summarizing major points are usually needed to in order to ensure that the student understands information that they need to know in order to adjust to college life.

Limitations of the study. The open coding technique is designed in its purest form to analyze data in the words of the respondents. All explanations or theories are developed from the dataset itself rather than from the a priori experiences or theories of the researcher. Throughout my years as a school psychologist I have encountered individuals with AS. I am aware of their struggle to maintain friendships despite their ability to succeed in the academic sphere. I knew that I expected them to reveal barriers to their success in transitioning from high school to college. However, during the course of this research, I consistently examined the data for other themes that might develop other than the ones I expected. In order to correct for my own bias concerning expectations I sought consistent feedback from a colleague as part of the qualitative design.

The data collected are the words of the respondents. Because it is their recollection of events in the past the data may be clouded by faulty recall of past events.

The sample is small and may effect how much the findings can be generalized to the population under study. The group chosen for this study is one of convenience but more important, it is a purposive sampling; students with AS who are college bound or who are in college are not traditionally included in studies concerning best practice for college transition.

All of the individuals with AS recruited to participate in this study happen to be male; I was unable to recruit a female respondent.

The results of this study could be compared to results of other studies to increase rigor of the qualitative design. Triangulation with other studies would help to confirm or refute the internal validity of the data collected and possibly provide corroborating evidence.

Improving study procedures. One way to enhance the findings of this study would be to use a case study design in which a student with AS would be followed from high school to college. This would include collection of biographical data, reports from professionals and school, and interview with others familiar with the subject (parents, siblings, teachers, etc.). Additionally, this design could provide an opportunity for the respondents to validate the data by providing them with the transcripts and an opportunity to clarify statements they made.

Implications for future research methodology. Very little information is available via qualitative or quantitative methodology concerning the study of the transition from high school to college for individuals with AS. More research is needed to illuminate the subtle aspects of what AS is and how it affects the individual with AS and those around the individual with AS. More information is needed about best practice in the systems of which AS individuals are a part such as families, schools and places of work. Further research could assist in development of information that would inform families and professionals about ways to remove barriers to their success in school, work and other social settings.

Implications for a follow-up study. A cross sectional or longitudinal design. A time study would help to further reveal the developmental nature of this syndrome. Another study could be devoted to development of best practice interventions that are proven through evidence based research.

Plans for collected data. I would like to share my data with other researchers, individuals with AS, parents and professionals. Ideally I hope to have my data, the words of these students, published. I would also like to use this data as a starting point to help develop a cognitive behavior therapy approach for the manualized treatment of adolescents and young adults with AS to help them deal with the social skills and communication deficits that are characteristic of their condition.

Concluding remarks

I started this thesis noting that a considerable number of individuals with AS are going to college. The number of individuals identified with a diagnosis of Autism has increased to a degree that some call an epidemic proportion. Diagnosis of individuals with AS is also more common and has also increased significantly. Throughout their lives, individuals with AS face challenges meeting the demands of major transitions in their lives. In our society, the transition to college is a major part of the lives of millions of students each year. This study chronicled the difficulties faced by nine students with AS as they experienced the transition process firsthand. The students displayed varying levels of academic skill, social competency, independence, and needs for dealing with personal issues, all of which had an impact on their success in transition. High school for these individuals was a springboard on which some individuals honed academic skills, sought relationships, explored independence and dealt with personal challenges. Catapulted as they were into college, they varied greatly in their readiness for the transition. Once in college, through their experiences they were presented with opportunities to develop knowledge, friendships, independence, and coping skills. From the start of their transition, they began accumulating experiences that will help to prepare them for the next transition: adult life and a career.

During the high school years, professionals are engaged in putting in place

supports for individuals with AS that help them transition into college. Once they

are in college, plans for the future transition to the world of work and adult life

also need to be made. Individuals with AS will also need supports in place that

help them make the transition to adult life. Surveys of adults with AS concluded

that they transition into the adult world of work overeducated for the jobs they

hold (Gerhardt, 2003; Miller Schuler, Burton, & Yates, 2003, Hurlbutt &

Chalmers, 2004). It is my hope that this paper helps professionals, parents and

individuals with AS consider ways to plan and prepare for important transitions in

the life of a person with AS.

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Table 1 DSM-IV Diagnostic Criteria

(I) Qualitative impairment in social interaction, as manifested by at least two of the following:

(A) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction

(B) failure to develop peer relationships appropriate to developmental level

(C) a lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)

(D) lack of social or emotional reciprocity

(II) Restricted repetitive & stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

(A) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(B) apparently inflexible adherence to specific, nonfunctional routines or rituals

(C) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)

(D) persistent preoccupation with parts of objects

(III) The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.

(IV) There is no clinically significant general delay in language (E.G. single words used by age 2 years, communicative phrases used by age 3 years)

(V) There is no clinically significant delay in cognitive development or in the development of age-appropriate self help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood.

(VI) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia

Table 2 ICD-10 Diagnostic Criteria

Diagnostic Criteria of Asperger's Syndrome from ICD-10
(World Health Organization, 1992).

A. There is no clinically significant general delay in spoken or receptive language or cognitive development. Diagnosis requires that single words should have developed by 2 years of age or earlier and that communicative phrases used by 3 years of age or earlier. Self-help skills, adaptive behavior, and curiosity about the environment during the first 3 years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary feature). Isolated social skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.

B. Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:
failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction;
failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities, and emotions;
lack of socio-emotional reciprocity as shown by an impairment or deviant response to other people's emotions; or lack of modulation of behavior according to social context; or a weak integration of social, emotional and communicative behavior;
lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., a lack of showing, bringing, or pointing out to other people objects of interest to the individual).

C. The individual exhibits an unusually intense, circumscribed interest or restricted, repetitive and stereotyped patterns of behavior, interests, and activities manifest in at least one of the following areas:
an encompassing preoccupation with stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in the content or focus; apparently compulsive adherence to specific, non-functional routines or rituals; stereotyped and repetitive motor mannerisms that involve either hand/finger flapping or twisting, or complex whole body movements;
preoccupations with part-objects or non-functional elements of play materials (such as their color, the feel of their surface, or the noise/vibration that they generate).

However, it would be less usual for these to include either motor mannerisms or preoccupations with part-objects or non-functional elements of play materials.

D. The disorder is not attributable to the other varieties of pervasive development disorder: simple schizophrenia, schizo-typal disorder, obsessive-compulsive disorder, anankastic personality disorder, reactive and disinhibited attachment disorders of childhood.

Appendix A

Consent to Participate

PHILDELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
4190 City Avenue,
Philadelphia, Pennsylvania, 19131-1693

Department of Psychology
215-871-6442
215-871-6458 FAX

<u>INFORMED CONSENT FORM</u>

TITLE OF STUDY

Transition: Recollections of Students with Asperger Syndrome of the journey from high school to college.

PURPOSE

The purpose of this study is to find out about the journey from high school to college for individuals with Asperger Syndrome. It is hoped that the findings of this study help professionals, students, parents, and most importantly students who happen to be diagnosed with Asperger Syndrome better understand the journey and better prepare for this transition.

You are being asked to participate in this study because you were listed as a potential volunteer by a professional who heard of my study, a referral made by your school, or because you were contacted through a support group on Asperger Syndrome. Please provide written documentation of your Asperger Syndrome diagnosis along with this consent form. Since this study is about transition to college only individuals in their first or second year of college will be a part of this study.

INVESTIGATORS

<u>Responsible Investigator</u>
Name: Jon Lyman
Address: 17 Jeremiah Lane
               Pittstown, NJ 08867
Email: lymanjon@aol.com
     Phone: 908-735-4657
<u>Principal Investigator</u>
Name: George McCloskey, Ph.D
Department   Psychology
Address: Philadelphia College of Osteopathic Medicine

Rowland Hall
Suite 226
4190 City Avenue
Philadelphia, PA 19131-1693

Email: GeorgeMcC@pcom.edu
Phone: 215-871-6563

The doctors and scientists at Philadelphia College of Osteopathic
Medicine (PCOM) do research on diseases and new treatments. While this is **not**
a study about disease, it may provide vital information to mental health
professionals that will help better understand Asperger Syndrome. Additionally
this study may help individuals with Asperger Syndrome better manage the
transition from high school to college. The interview you are being asked to
participate in is part of a research project.

Thank you for agreeing to participate in this study which will take place
from (date) to (date). This form outlines the purposes of the study and provides a
description of your involvement and rights as a participant.

DESCRIPTION OF THE PROCEEDURES
The methods to be used to collect information for this study are explained
below. From this information, I will write a summary report about you.

This study will involve 5 respondents; students with Asperger Syndrome. I
will be collecting information about his/her journey from high school to college
using an interview. Each interview will last approximately 60 minutes and will be
recorded then transcribed to text. This information along with notes taken by the
researcher (Jon Lyman) will form the basis of a qualitative study in which this
data will be analyzed and concentrated into themes that shed light on your journey
from High School to College.

You are encouraged to ask any questions at any time about the nature of
the study and the methods that I am using. Your suggestions and concerns are
important to me; please contact me at any time at the address/phone number listed
above.

I will use the information from this study to write about you (the
respondent /student) and the other four individuals selected for this study. All
reference to your name and potential identifying data will be removed from this
report. This study will be used for my doctoral dissertation and will be read by my
dissertation committee (four people), and by a validation panel consisting of four
individuals. The validation committee will include me, an individual with

Asperger Syndrome (who is not a part of the study), and two doctoral candidates or graduates. Their purpose will be to check on the accuracy of the report. The dissertation, with your permission will be available publicly, when completed for inclusion in the literature about Asperger Syndrome.

POTENTIAL BENEFITS

You may potentially benefit from being in this study because sharing your story may benefit your understanding of Asperger Syndrome and the ways that it affects you. You should also know that the possibility exists that you may not perceive any positive benefit from participating in this study. Other people are likely to benefit from what researchers learn from this study because the results will inform persons with AS, their family members, and professionals who work with AS students about the challenges AS students might face in their transition from high school to college.

RISKS AND DISCOMFORTS

It is possible that during the course of the interview, or after the interview you might experience some emotional upset. This may happen as the result of being asked to recall life-experiences that were distressing to you as some point in the past. Because of this possibility, you will be given the names and phone numbers of two mental health professionals that you can contact should you feel the need to pursue follow-up counseling.

ALTERNATIVES

You have the alternative choice of not participating in this study.

PAYMENT

Participant will receive a $25.00 gift certificate at the conclusion of the interview for being in this study.

CONFIDENTIALITY

All information and records related to your participation will be kept in a locked file. Only the research investigators and the members of the Institutional Review Board will be able to look at these records. If the results of this study are published, no names or other identifying information will be used.

REASONS YOU MAY BE TAKEN OUT OF THE STUDY WITHOUT YOUR CONSENT

If health conditions occur that would make participating in the study interview possibly dangerous to you, or if other conditions occur that could affect you or you health, Dr. McCloskey or Jon Lyman and their associates may take you out of this study. In addition, the entire study may be stopped if dangerous risks or side effects occur in other people.

NEW FINDINGS

If any new information develops that may affect your willingness to stay in this study, you will be told about it.

INJURY

If you are injured as as result of this study, you will be provided with immediate necessary medical care.

However, you will not be reimbursed for medical care or receive other payment. PCOM will not be responsible for any of your bills, including any routine medical care under this program or reimbursement for any side effects that may occur as a result of this program.

I guarantee that the following conditions will be met:

If you believe you have suffered injury or illness in the course of this research, you should notify John Simelaro, D.O., Chairperson, PCOM, Institutional Review Board at (215) 871-6337. A review by a committee will be arranged to determine if your injury or illness is a result of your being in this research. You should also contact Dr. John Simelaro if you think that you have not been told enough about the risk, benefits, or other options, or that you are being pressured to stay in this study against your wishes.

VOLUNTARY PARTICIPATION

1) Your real name will not be used at any point of information collection, or in the written case report; instead, you and any other person and place names involved in your case will be given pseudonyms that will be used in all verbal and written records and reports.

2) If you grant permission for audio taping, no audio tapes will be used for any purpose other than to do this study, and will not be played for any reason other than to do this study.

3) Your participation in this research is voluntary; you have the right to withdraw at any point of the study, for any reason, and without any prejudice, and the information collected and records and reports written will be turned over to you.

4) You will receive a copy of the summary before it is handed in, so that you have the opportunity to suggest changes to the researcher, if necessary.

5) You will receive a copy of the report that is handed in to my chair.

Do you grant permission to be quoted directly?

Yes _____ No _____

Do you grant permission to be audiotaped?

Yes _____ No _____

I have had time to read this form and I understand its contents. I have been given a copy for my personal records.

I agree to the terms

Respondent _____ Date _____

I agree to the terms:

Researcher _____ Date _____
        Jon Lyman

Appendix B

Participant Demographics Form

Please take a moment to fill out this form.

1. A pseudonym or alias will be used in this study to protect you identity. Take a moment to consider a name the interviewer will use with you during this interview, then write it down in the space provided.

Alias:_____

M   2)   Male
              Female

3   3) Current college level
f   freshman
                    sophomore

M   4)   Major area of study
                    undecided

              _____

5) Current Age

_____

Appendix C

Semi Structured Interview

Open ended questions

Questions
1) What was starting college like for you?

2) Sometimes people talk about difficulties they had when the started college?

What was difficult for you as you started college?

3) What was high school like for you?

4) Sometimes people talk about what was difficult about leaving high school.

What was difficult about leaving high school for you?

5) Sometimes people talk about what was good about leaving high school. What was good about leaving high school for you?

Appendix D

Biographical Information

| Alias	Age	Type College	Year	Number of Schools	Major	Living
Red	19	2 year	Freshman	1st school	History	Home
Tom	28	2 year	Non Mat.	5 schools	Business	Home
Robert	23	2 year	Non Mat.	1st school	Computer	Home
Clint	20	2 year	Sophomore	1st school	Education	Home
Bob	19	4 year	Sophomore	1st school	Mathematics	Dorm
Matt	21	4 year	Junior	3 schools	Computer	Dorm
Rocky	24	2 year	Freshman	3 schools	Undecided	Home
Dave	20	4 year	Sophomore	1st school	Undecided	Home
GT	21	N/A	N/A	1st school	History English	Home

Figure 1
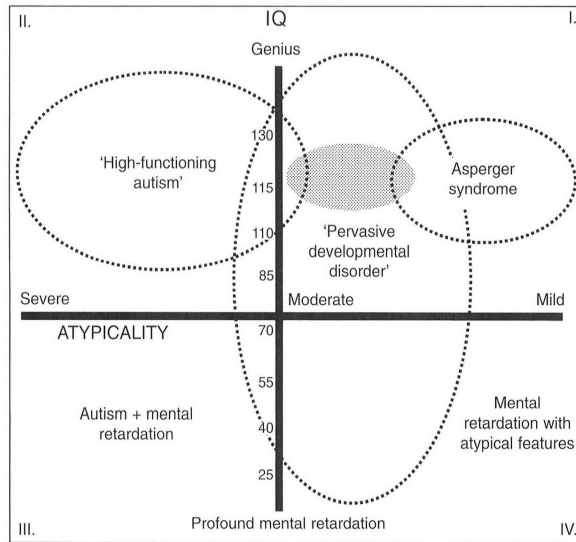
Coplan, 2003

Figure 1: *Relationship between degree of atypicality and intelligence. Origin corresponds to moderate atypicality (x-axis) and an IQ of 70 (y-axis). Children with severely atypical features and an IQ in normal range (quadrant II) are sometimes referred to by the term 'high-functioning autism' (HFA). Children with moderately atypical features have pervasive developmental disorder (PDD). PDD can occur in presence of normal IQ (quadrant I) or in the presence of mental retardation (MR; quadrant IV). Children with mildly atypical features, normal general intelligence, hyperverbal behavior, narrow interests, and physical clumsiness have Asperger syndrome (AS) (quadrant I). There is a zone of potential overlap among children with HFA, PDD, and AS (stippled region); treatment is similar regardless of the diagnostic 'label'. Children with mental retardation might have fully expressed autism ('low functioning autism', quadrant III), or their primary developmental disability might be mental retardation, with a smattering of atypical features (quadrant IV).*

Figure 2

Coplan, J. Pediatrics 2000;105:e65
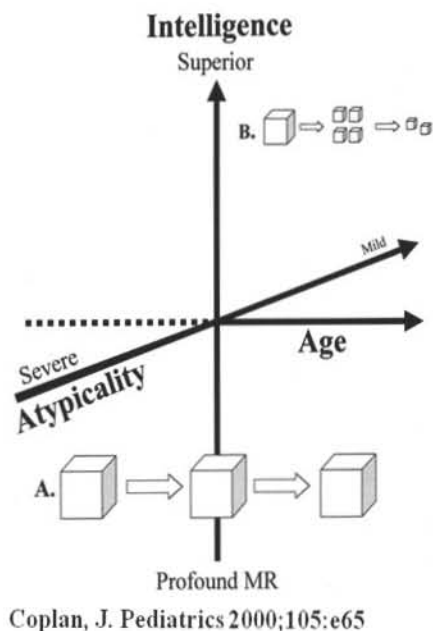
Triaxial model for discussing prognosis in ASD. Age is represented on the x-axis, with birth at the origin. The x-axis to the left of the origin is indicated as a dotted line, because no child's age is less than zero. Intelligence is represented on the y-axis, with an IQ of 70 (the cutoff for MR) at the origin; children above the imaginary horizontal plane running through the origin have IQs in the normal range, whereas children below this plane have MR. Degree of atypical behavior, ranging from severe to mild, is depicted on the z-axis, with diminishing severity running into the plane of the paper.

Child A represents an individual with severely atypical behavior plus MR. The cube represents the magnitude of the individual's clinical deficit, which is a compound of ASD plus MR. As this person ages, he or she continues to manifest a readily recognizable symptom complex consistent with the diagnosis of ASD plus MR. Child B represents an individual whose atypical features are moderate to mild, and whose general intelligence is average or better. As such an individual ages, the core features of ASD break up into isolated fragments, which diminish in severity with the passage of time. Other combinations (severely atypical behavior with normal intelligence; severe MR with mildly atypical behavior) are also possible, but not shown.

Figure 3
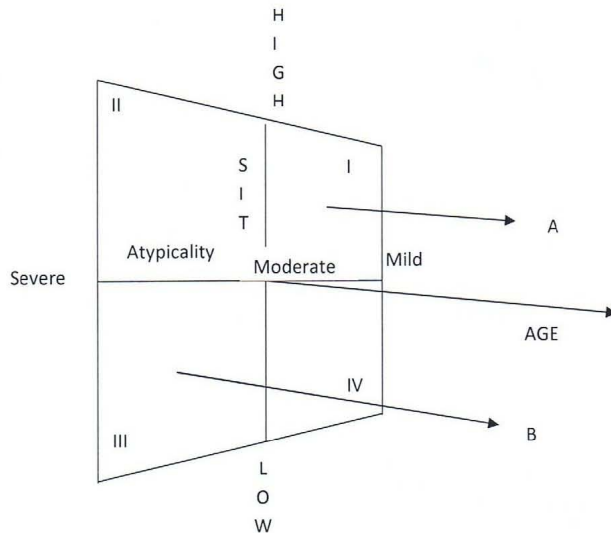
Triaxial model applied to the transition from high school to college. The x-axis is the range of atypicallity within the expression found for individuals with Asperger's Disorder from a range of Severe, Moderate, andMild. The Y-axis represents Success In Transtition from Low, Moderate, and High. The Z-axis represents Age. Line A represents a student who displays a mild level of atypicality and has experienced a high level of Success In Transition (SIT). Individuals who fall within quatrant I, as a group would be those who display skills in the four themes of: Academics, Social Relationships, Independent Functioning, and Personal Issues. Line B represents a student who displays atypicality in the sever range and has experienced low levels of SIT. Individuals that fall within quadrant III would be those who display low levels of skills in the four themes of: Academics, Social Relationships, Independent Functioning, and Personal Issues.