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Adolescents with Aspergers Syndrome and Self-perceived Social Competence

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ADOLESCENTS WITH ASPERGERS SYNDROME AND

SELF-PERCEIVED SOCIAL COMPETENCE

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Dissertation Approval

This is to certify that the thesis presented to us by _Shawn M Mullen_

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acceptable in both scholarship and literary quality.

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Abstract

This study explored the self- perceived social competence of adolescents with Aspergers

Syndrome (AS). The study's participants were 14 adolescents (11 male, 3 female)

between the ages of 10 and 17 years old who were diagnosed with AS. The participants

were questioned, using a scripted set of seven questions involving their own perceptions

of their interactions with their peers; the study also involved what adult (parents and

teachers) think of their ability to get along with peers. The answers to these questions

were analyzed qualitatively, and six common themes that the participants found

important to them or to their peers' interactions with others were extracted from their

responses.   These themes were friendliness/approachability, being misunderstood by

others, interests, communication, viewing self as different and perception of AS. The

impact and interactions of these themes and the ways in which the participants view the

impact of these factors on their social interactions are discussed in depth.   Overall, the

majority of the participants reported a positive perception of their social competency

skills. They largely saw AS as consisting of a profile of strengths and weaknesses, but

were overall satisfied with their interactions with peers.   Although more research is

needed, these findings may bring into question the effectiveness of social interaction

intervention programs on a population that may feel that such interventions are

unnecessary.

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Chapter 1

Introduction

Statement of the Problem

Hans Asperger initially described a group of seemingly high functioning children with social impairments in 1944 (Asperger, 1944 as cited in Attwood, 1998). Although the research on Asperger Syndrome (AS) has grown exponentially in the past decade, there continues to be diagnostic controversy. Many researchers have struggled to determine whether or not AS is a separate diagnostic category apart from autism or if it falls along the spectrum of autistic disorders. In particular, researchers continue to debate whether or not AS is simply High Functioning Autism (HFA) or if it is a stand-alone category with different diagnostic features. Because of this dichotomy in the literature, and the frequently interchangeable nature of these terms in the current research, this researcher will merge findings for individuals with AS and with HFA because there may be overlap due to a lack of diagnostic clarity.

According to the most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition-Text Revision* (APA, 2000), Asperger Syndrome (AS) is a pervasive developmental disorder characterized by a "qualitative impairment in social interaction" and "restricted, repetitive and stereotyped patterns of behavior, interest and activities" in the absence of a "clinically significant general delay in language" and a "clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior, and curiosity about the environment" (DSM-IV-TR, 2000, p. 84).

The DSM-IV also notes that AS can be associated with variability in cognitive functioning, often characterized by strengths in verbal abilities coupled with weaknesses in areas of nonverbal ability. Motor clumsiness, although typically mild, may add to difficulties with peers and with social isolation. In addition, inattention and hyperactivity are often found in individuals diagnosed with AS, meriting a diagnosis of Attention Deficit/Hyperactivity Disorder. Other disorders, including Depressive Disorders, have also been found to be associated with AS. (DSM-IV-TR, 2000)

The DSM-IV indicates that AS is diagnosed at least five times more frequently in males than in females. Definitive prevalence data regarding AS is limited as is data regarding familial patterns. However, there seems to be a greater likelihood of AS in families in which other members have been diagnosed with AS. There is also a greater likelihood of Autistic Disorder and other social difficulties among family members of individuals diagnosed with AS. (DSM-IV-TR, 2000)

 The course of AS varies by age, but it is a lifelong disorder. Because of strong verbal skills, deficits can sometimes appear minimal in younger children. Social difficulties typically become more notable with age. Although some individuals are able to utilize areas of strengths in order to offset noted areas of weakness, isolation and increased self-awareness may add to the feelings of anxiety and depression in adolescents and young adults with AS. The long term outcomes for individuals with AS are significantly better than for individuals diagnosed with Autistic Disorder, because many individuals are able to work and be self-sufficient as adults. (DSM-IV-TR, 2000)

Individuals with AS typically have average to above average levels of intelligence (Barnhill, Hagiwara, Myles, & Simpson, 2000). This can create particular difficulty for

children and adolescents with AS because of "relatively high cognitive ability and their

apparently competent use of language" (Howlin, 1998, p. 317) often belies their

significant social impairments. Green, Gilchrist, Burton & Cox (2000) found that parents

of children with AS rated them as less effective in their social relationships and in their

ability to live independently and to meet their own needs, despite their average cognitive

functioning. This can be quite detrimental to the individual with AS because he or she is

often misunderstood by those around him or her (Church, Alisanski, & Amanullah, 2000)

and can be keenly aware of this misunderstanding (Attwood, 2000). Specifically in the

school setting, staff and peers unaware of the characteristics associated with AS may be

frustrated by an individual with superior cognitive ability who struggles with

unscheduled transitions, organization, and who may not consistently complete

assignments (Myles & Adreon, 2001).

Howlin (1998) summarized the plight of the adolescent with AS best when she

stated that:

> Because of their relatively high cognitive ability, and their apparently competent
>
> use of language, this group of children is often least well served or understood. In
>
> fact, many have extensive linguistic and comprehension difficulties; their
>
> understanding of the more subtle aspects of social interaction is often profoundly
>
> limited, and their obsessional interests and behaviours also prove a barrier to
>
> social integration. Many, too, are painfully aware of their deficits and differences.
>
> (p. 317)

As noted by Howlin, this is a population whose experiences and self-perceptions are not

well understood. At a time when the prevalence rate of diagnoses of AS is experiencing a

steady increase, this lack of understanding is particularly problematic. A clearer understanding of the self-perceived social competency of this population is essential, especially in moving towards more effective planning and interventions that will target areas of greatest need.

Purpose of the Study

Although various internal and external interventions have been targeted at addressing deficits in social competence and emotional sequelae, Myles and Simpson (2001) stated, "Social skills represent a complex area within human behavior. Although somewhat rule-governed, these rules vary across location, situations, people, age, and culture, making it difficult to acquire and subsequently generalize these skills" (p. 279). At a time when the prevalence rate of autism spectrum disorders has increased to 1 in every 150 births, as reported by the Centers for Disease Control (CDC, 2007), this lack of generalizable interventions is problematic. A clearer understanding of the self-perceived social competence of this population, specifically self-perceptions of social interactions, including how others view these interactions, is essential in order to create more individualized and targeted interventions with increased generalizability. Simpson (2005) noted that "successful outcomes require not only that an effective method be chosen but also that it be properly matched to the needs of a particular student" (p. 144). Although researchers such as Church et al. (2000) have explored the social experiences of children and adolescents with AS, the reports have typically been from the perspective of parents and teachers.

A few researchers have taken this noted gap in the research as an opportunity to expand the knowledge base through qualitative means. Conner (2000) explored the daily

school experiences of 16 middle school students diagnosed with AS through individual interviews to determine major areas of concern. The concerns that emerged included limited social confidence and performance anxiety. Carrington and Graham (2001) examined the school-based experiences of two 13 year-old boys with AS and with their mothers. Carrington, Templeton, and Papinczak (2003) explored the perceptions of friendship of 5 teenagers diagnosed with AS. Carrington et al. (2003) found that the participants struggled to describe their understanding of friendship because they missed many of the subtle nuances of reciprocity and shared interest that are central to friendships.

These qualitative studies have also reported similar themes of stress and anxiety in relation to social deficits and have laid the framework for further research. The purpose in conducting this investigation is to continue to explore the self-reported social experiences of adolescents with AS, specifically self-perceptions of social interactions and perceptions of how others view these social interactions, in order to understand and support this population more thoroughly through interventions targeted at self-reported areas of concern.

Research Question

The following research questions will be considered: 1) How do adolescents with AS perceive their social interactions with peers? 2) How do adolescents with AS perceive other people's opinions of their social interactions with peers?

Chapter 2

Related Research/Literature Review

Social Impairments

Pragmatics and nonverbal communication.

Individuals with AS are socially isolated, with some frequency, from their peer groups because of their pervasive social impairments. Social impairments in AS often manifest themselves in various areas of everyday functioning. One particular area that causes this population to stand out from other developmentally typical peers is their weakness in pragmatic or social language skills. Their speech is often characterized by "formal and pedantic language" (Barnhill, 2001, p. 261). This awkward speech that is often characteristic of the AS population is described by some as "robotic' because it does not include the inflection and expression that typically helps to communicate feeling and intent in conversation (Moyes, 2001).

Landa (2000) identifies these pragmatic impairments as likely "the most stigmatizing and handicapping aspect of these disorders" (p. 125) because social language is a key skill that begins impacting peer interactions at an early age and continues throughout the lifespan. Although the majority of individuals with AS are likely exposed to appropriate social language throughout the developmental process, Landa (2000) posits the idea that there are numerous other facets of development that are crucial in developing pragmatic skills. Unfortunately these necessary foundational skills, including executive functioning and social thinking, are notably lacking in this population and efforts at social communication are often viewed as inappropriate because they do not meet the demands of the given social situation. Landa (2000) notes that over time, as

individuals with AS are faced with persistent social communication demands that they are not able to navigate appropriately, the likelihood increases that social situations will begin to elicit anxiety and avoidance. This dynamic leads to fewer opportunities for successful interactions, with less likelihood of establishing relationships and the likelihood of increased isolation.

Landa (2000) attributes a part of this pragmatic deficit to the tendency of individuals with AS to hold certain presuppositions that impact their relationships. She defines presupposition as "the knowledge, expectations, and beliefs that a speaker postulates to be shared with conversational partner" (p. 132). Stone, Baron-Cohen, & Knight (1998) refer to this concept as theory of mind or "the ability to make inferences about others' mental states" (p.640). Individuals who have AS typically hold rather inflexible presuppositions about their peers and about other people with whom they speak. They tend to assume that other individuals have the same knowledge and experiential base that they have. This inflexibility impacts conversations negatively because individuals with AS approach a wide variety of conversational partners in the same manner. No alterations are made to accommodate for individual differences or differences in social rules dependent on the given situation. This inflexibility can often lead to difficulty in establishing and maintaining various relationships, particularly because communication skills and theory of mind are thought to be interdependent in their development (Hadwin, Baron-Cohen, Howlin, & Hill; 1997).

Additionally, their rigid mindset and cognitive inflexibility negatively impacts their ability to comprehend figurative communication (Barnhill, 2001; Church et al., 2000; Safran, Safran, & Ellis, 2003). Individuals with AS have a great deal of difficulty

grasping sarcasm, humor, and other forms of figurative communication, common both in the classroom and in interactions with peers (Safran et al.). Not only do these individuals not comprehend the intended meaning of the communication, but they also often interpret words literally and can react inappropriately to requests or comments based on this misunderstanding (Safran et al.).

Adding to this difficulty in social communication skills is the highly technical and specialized vocabulary frequently utilized by individuals with AS (Myles & Adreon, 2001). This specialized language is most frequently displayed when each speaks about his or her one particular restricted area of interest (Church et al., 2000). Although Church et al. (2000) stated that these areas of interest can be utilized as resources in connecting individuals with AS to their peers, more often they serve to ostracize them further because their interests reach a level that is close to obsession. This is particularly relevant when the area of interest is notably immature, given the individual's chronological age (Myles & Adreon, 2001), such as a high school student who is still engrossed with Pokémon cards.

Along with this perseverative discourse, is the inability of individuals in the AS population to comprehend the appropriate nonverbal give and take that is an essential aspect of socially appropriate conversation (Church, et al., 2000). Individuals with AS typically lack essential social skills such as the ability to initiate and/or maintain appropriate eye contact, observe physical boundaries, and facial expressions when interacting with others and they are frequently unable to interpret the body language and other nonverbal communications of others when interacting (Attwood, 2000; Church et al., 2000). One type of nonverbal communication is joint attention, which is the process

of two individuals attending to the same stimulus at the same time (Landa, 2000).

Because of deficits in joint attention, an individual with AS may not realize that the

person he or she is speaking with is signaling disinterest, frustration or even anger

through facial expressions or body posture; the attention of the individual with AS is fully

engaged by his or her own discourse (Moyes, 2001). Often, the individual with AS fails

to recognize that his or her monologue was not as intriguing to others as it is to him or

her, despite clear body language on the part of the listener.

Theory of mind deficits.

This inability to consider the thoughts and feelings of others was referred to as a

theory of mind deficit in 1995 by Ozonoff and Miller (as cited in Barnhill, 2001). Martin

and McDonald (2004) also define theory of mind as the ability "to distinguish between

one's own beliefs and the beliefs of other individuals" and "the ability to form

representations of other individuals' mental states" (p.312) for the purpose of navigating

the communication and actions of others. Theory of mind is a skill that emerges initially

through joint attention and through pointing behaviors as an infant and continues to

develop through age eleven (Stone, Baron-Cohen, & Knight;1998). These researchers

posit the idea that individuals with AS may experience breakdowns in the development of

theory of mind at any stage. However, they do recognize that higher-functioning

individuals may be able to develop some first order-theory of mind skills or the ability to

think about others' thoughts. Nevertheless, they are typically not able to master the

second-order theory of mind skills involving the interpretation of one person's belief

about a third person's beliefs.

Theory of mind deficits can negatively impact individuals with AS because they are typically unaware that other people may think or feel differently from them, (Barnhill, 2001) and this is most evident in their inappropriate social interactions. "In general, the inability to take the perspective of another was at the root of many ineffective social interactions" (Church et al, 2000, p 15). Individuals with AS often lack empathy for others because of their theory of mind deficits, coupled with their inability to decipher the nonverbal cues that would indicate the emotional states of others (Attwood, 2000; Tantum, 2000a; Barnhill, 2001; Groden, Cautela, Prince, & Berryman, 1994). Particularly in adolescence, when what is said (words) and how it is said (tone, inflection, facial expressions) are frequently central to the message communicated between peers, individuals with AS can be at a distinct disadvantage (Myles & Adreon, 2001).

Individuals with AS also encounter some difficulties because they lack insight into the behaviors of others. This lack of insight into the behaviors of others, as well as the impact of their own behavior on their peers, is frequently detrimental to social relationships. Individuals with AS can be hurtfully blunt, particularly in their comments to others, without realizing the impact of their words. What they may perceive to be honest and even helpful insights may, in reality, be biting criticism to those on the receiving end. Individuals with AS struggle to understand the reasons why people react to them in a negative manner; this occurs because these individuals are not aware of the ways in which their behaviors are perceived by other people. This disconnection between intention and perception is the source of many misunderstandings, which cannot be easily remedied because individuals with AS frequently also lack the empathy to understand why an apology would be necessary or know how to soothe hurt feelings (Moyes, 2001).

These skill deficits are particularly troubling when researchers have shown that efforts to teach theory of mind did not enhance social communication skills or social skills in generalized situations (Hadwin, Baron-Cohen, Howlin, & Hill; 1997).

Social competence.

Although communication skills and theory of mind play a key role in the social impairments seen in AS, there is a broader and more overarching deficit area that has emerged in the research. This overarching deficit is in the area of social competence. Social competence is defined as "the skills and strategies that allow individuals to have meaningful friendships; forge close, emotion-based relationships; productively collaborate with groups, teams, work partners; manage public social settings; and participate in family functioning" (Gutstein & Whitney, 2002, p. 161). Taken together, these are the skills that are central to effective day to day functioning and are positively correlated to future life successes. Gutstein & Whitney (2002) noted that researchers have found adults with AS likely to be underemployed, unemployed, unable to live on their own and lacking in significant relationships because of these deficits in social competence.

Social competence is a broad and complex concept that involves the simultaneous and integrated development of 3 specific developmental areas. In order to develop social competence an individual first needs to have formed a secure attachment to a parental figure so he or she can experience safety and support. The second key developmental area is instrumental social learning, which involves learning the behaviors or communications that will evoke particular reactions, thereby having their needs met. For example, a child may learn that pointing to the refrigerator gets them food when they are

hungry or that completing their homework will result in their being allowed outside to play. In general, instrumental social learning requires the individual to acquire certain scripted cause and effects scenarios to have their basic needs met successfully. (Gutstein & Whitney, 2002).

The third key developmental area necessary to attain social competence is engaging in effective experience-sharing relationships. According to Gutstein and Whitney (2002), this is the crucial piece of the puzzle that is missing in individuals with AS, because previous studies have indicated that this population seems to experience secure attachments and utilize instrumental social learning. Experience-sharing relationships are a more difficult area because there is no clear external reward for being a good friend or valuing another's point of view. People engage in these relationships for the sake of the experience-sharing and not as a means to an end. Sharing social experiences with others is the area in which individuals with AS struggle most severely in the development of social competence. This involves enthusiasm and shared enjoyment, social and emotional coordination and ongoing relationship maintenance and repair. As Gutstein and Whitney summarize:

> The child with AS may continue to actively pursue social interactions throughout life. However, by never entering the arena of experience-sharing, he or she misses out on the most challenging, exciting, and rewarding aspect of the social world. Without the motivation to engage in experience-sharing, the youngster with AS does not conduct the extensive personal research and self-discovery by which typical children become such experts at relationship building and maintenance. (p. 165).

Social isolation.

As a result of their average cognitive and verbal skills, adolescents with AS are presumed to be developmentally typical by others and, thus their awkward behavior and social faux pas are often misunderstood and may be perceived as defiant and oppositional by adults (David, David, & Riley, 2003; Moyes, 2001; Myles & Adreon, 2001). Peers may also misunderstand the reasons for these young people's social ineptness and may view them as purposely inappropriate in their behavior (Church et al., 2000). This interpretation only adds to the social isolation of this population because they may want to make themselves acceptable but do not know how to adapt to meet the social demands of their peer group (Barnhill, 2001). These rules for social behavior and interactions are often unspoken and are outside the realm of knowledge for the AS population. This lack of knowledge regarding appropriate behavior makes it difficult for individuals with AS to assimilate and become acceptable in any social situation. This social isolation only increases for this population as they head into adolescence, and the gap between their social skills and those of their developmentally typical peers continues to widen (Church et al., 2000; Safran et al., 2003). As Church et al. found, over time, "novel and more complex social situations placed greater demands on the children" (p. 14).

This social isolation may not be problematic for a certain portion of the AS population who lack interest in interacting with others. However, there are a number of individuals with AS to whom this social isolation can be devastating because they are not only keenly aware of it (Attwood, 2000), but they also have an interest in establishing friendships (Barnhill, 2001). Despite their desire to gain and maintain friendships with peers, Barnhill (2001) reports that individuals with AS typically do not have the social

knowledge necessary to initiate such relationships. As Groden et al. (1994) indicate, social skill deficits make it quite difficult to engage in positive social interactions with peers.

Cognitive inflexibility/rule orientation.

Church et al. (2000) also posit that this population has difficulty maintaining friendships because they do not understand the role they should play in the interaction, and therefore cannot adjust their behavior to meet the situational requirements. Because of deficits in cognitive flexibility, individuals with AS often encounter difficulties with problem-solving when challenging situations arise in relationships. These individuals typically have one, rigid way of handling any situation, and they continue to utilize this strategy even when it fails to give them the desired outcome. Therefore, if an individual has only one strategy for initiating a conversation (ex. asking about a specific type of train) and this has failed to result in successful conversations with peers, he or she will continue to use this strategy because he or she is ill equipped to problem-solve and initiate a new and more effective strategy. Additionally, when a friendship is successfully initiated, it is often difficult to maintain because of the numerous social impairments previously cited, as well as the characteristic rule-oriented nature of individuals with AS (Barnhill, 2001). Individuals with AS have many rules to which they strictly adhere, and they expect a similar compliance from others. In relationships, there are often odd, rigid rules that surround the individual's image of friendship and if these are broken the friendship may end suddenly (Attwood, 2000; Barnhill, 2001).

This rigid, rule-oriented mindset not only impacts friendship, but also other important aspects of social life for individuals with AS. This population demonstrates

rigidity in the need for consistent routines as well as adherence to rules (Barnhill, 2001) and may have emotional outbursts when such situations arise to the contrary (Church et al., 2000). This can frequently be observed in children with AS in the classroom as schedules change and unexpected transitions occur (Church et al.).

The conclusions made by Church et al. (2000) and others on the cogitative inflexibility and the rule-governed behavior of children with AS, have typically been based on the perspective of parents and teachers. A few researchers have taken this noted gap in the research as an opportunity to expand the knowledge base through qualitative means. Conner (2000) explored the daily school experiences of 16 middle school students diagnosed with AS to determine major areas of concern. Carrington and Graham (2001) examined the school experiences of two 13 year-old boys with AS and their mothers. Carrington, Templeton, and Papinczak (2003) explored the perceptions of friendship of 5 teenagers diagnosed with AS. These qualitative studies have reported similar themes of stress and anxiety in relation to social deficits and have laid the framework for further research.

Emotional Impact of Social Deficits

Several studies have examined the issue of comorbid emotional concerns that may emerge in individuals with AS. The predominant concern is that, as a result of their overarching rigidity in both thought and action, individuals with AS may become notably anxious (Church et al., 2000) and may not have the necessary coping mechanisms to handle everyday stress effectively (Groden et al.,1994). This population struggles to adjust to any novel situation and some of the odd and stereotypic behaviors may be their means of coping with and stabilizing their levels of anxiety (Church et al.). Therefore, if

these coping behaviors are suppressed, there will be a significant increase in anxiety. (Gillott, Furniss, & Walter, 2001). Unfortunately for many children with AS, the school environment, in particular, can be such a setting.

Anxiety.

Several researchers have posited the idea that individuals with AS experience anxiety because they lack comprehension of their environment and because of their rule-oriented nature (Groden et al.,1994; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). It was found that the rule-oriented nature of individuals with AS predisposed them to anxiety. In particular, those individuals who manifested the greatest number of repetitive behaviors earlier in life and had higher verbal than non-verbal ability were more prone to internalizing disorders such as anxiety and mood disorders. These researchers also found that anxiety had a significant impact both on children and on families because anxious children required more of their parents' time and had more negative interactions with family, peers, and teachers. (Kim et al., 2000)

Other researchers have found that anxiety was linked with AS; however, the origin of the anxiety was not as straightforward. Tantum (2000b) explored whether anxiety was comorbid with AS, or whether individuals with AS had more negative life experiences which led to anxiety disorders. This researcher was also able to link several precipitants to anxiety in individuals with AS. He found that years of teasing and bullying because of social deficits, in conjunction with family tension, and of self-esteem lowered by continuous rejection often leads to anxiety in this population. Because of this anxiety, individuals with AS tend to involve themselves further in their specific area of interest. After years of anxiety, this researcher found that individuals tended to become depressed,

socially withdrawn, and some even became involved in substance abuse and displayed aggressive behaviors.

Green et al. (2000) also explored comorbidity in individuals with AS, finding that it can be very difficult to distinguish AS from other psychiatric disorders. When an individual with AS is experiencing anxiety, it may manifest itself through an increase in behaviors that are also associated with AS, such as stereotypical and ritualized behaviors. Therefore, it may be virtually impossible to separate the symptoms that are characteristic of AS from those that might be associated with a comorbid diagnosis of anxiety. These researchers also found that the sense of awareness in this population can be associated with their increased risk for anxiety and depression. "It could also be argued that their social impairments and lack of close relationships make individuals with AS vulnerable to secondary affective symptoms similar to those that can arise in other socially impaired individuals" (Green et al., 2000, p. 282).

Bellini (2004) focused his research directly on the impact of social impairments and poor peer relationships on the comorbidity of anxiety in individuals with high-functioning autism. Because social functioning and social anxiety are so closely linked, the varied and overarching social deficits which are characteristic of autism spectrum disorders would predict that this population is at greater risk for anxiety. "The present study found a link between self-reported social skills deficits and social anxiety, although the strength and direction of the association is dependent on the particular social skill being considered" (Bellini, 2004, p. 83). Two particular social skills that emerged were empathy and assertion skills. Assertion skills were found to be inversely related to social anxiety, because when assertion skills decreased, the level of social anxiety increased.

Interestingly, empathy was found to have a curvilinear relationship with social anxiety. Therefore, when empathy levels were low, so was social anxiety. However, as empathy increased, social anxiety did as well, until a certain point at which empathy reached a plateau and social anxiety levels began to drop. Considering the low levels of empathy observed in individuals with AS, it seems likely that they would experience commensurately low levels of social anxiety. Nevertheless, this hypothesis has not been supported in the research to date. In fact, "children with AS described themselves as being just as anxious as a clinically diagnosed group of anxious children" (Russell & Sofronoff, 2005, p. 637). Farrugia and Hudson (2006) also found that adolescents with AS exhibited levels of anxiety comparable with adolescents diagnosed with anxiety disorders.

Despite the growing body of research linking AS with comorbid anxiety, there have been a number of researchers who have found contrary evidence. Although Groden et al. (1994) did find that individuals with AS were more vulnerable to anxiety, they posited that the anxiety may be the result of their hyposensitivity and the hypersensitivity to environmental stimuli. An example of hypersensitivity might be a child who covers his or her ears and cries when there is a fire drill at school because he or she is overly sensitive to the high-pitched alarm sound. This under or overstimulation can be anxiety producing in and of itself, but it is also compounded by the inability of individuals with AS to communicate their sensory needs to others and seek support to mediate their emotional needs. Therefore, Groden et al. support anxiety as comorbid with AS, but for reasons relating to sensory stimulation (i.e. difficulties regulating perceptual input) in addition to social impairments.

ADHD.

Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin (1998) also examined the psychiatric disorders that can be comorbid with AS. These researchers found that comorbidity was relatively common in the AS population; the disorders most often associated with AS are Attention Deficit/Hyperactivity Disorder (ADHD) and depression. Ghaziuddin et al. (1998) further discovered that the comorbid diagnosis of ADHD was found predominantly in children and adolescents and the comorbid diagnosis of depression was found predominantly in adults. Comorbid ADHD was characterized by aggressive and odd behavior in individuals with AS, whereas depression was linked with social impairments and the inability to cope with the emotional impact of social isolation. These researchers stated that, although symptoms of anxiety had been observed in many individuals with AS, they did not feel that the anxiety was significant enough to receive an additional diagnosis of anxiety. (Ghaziuddin et al.).

Tantum (2000b) also found ADHD to be comorbid with AS and hypothesized that these attentional issues only compound the social understanding deficits in this population. Myles and Adreon (2001) also explored inattention and distractibility in the AS population. They posit that the source of distractibility comes from sensory overstimulation. Being overwhelmed by environmental stimuli can lead to what appears to be inattentiveness.

Depression.

Barnhill (2001) also found depression in the AS population, citing the fact that the comorbid diagnosis of depression was most significant for individuals with AS. This researcher posited that it was depression, rather than anxiety that resulted from social

isolation. Barnhill (2001) also hypothesized those individuals with AS may be predisposed to depression through a biological link between the genes that cause AS and the genes that cause depression. Safran et al. (2003) also supported depression as the main comorbid diagnosis in individuals with AS. These researchers associate the increased rates of depression with the isolation that the AS population encounters despite their desires to initiate friendships. (Safran et al.).

Myles and Adreon (2001) reported "alarm about the high number of individuals with AS who have been diagnosed with depression" (p. 21). These researchers posit the idea that depression may result from the perception of being different, in conjunction with perceived successes and failures in interactions with friends. Because of frequent experience of failure, particularly in social situations, individuals with AS begin to approach all situations with a negative, failure prone mind set (Farrugia & Hudson, 2006; Myles & Adreon, 2001). Farrigua and Hudson (2006) hypothesize that this negative mindset leads to negative automatic thoughts. These negative automatic thoughts may be at the root of depression and depressive symptoms.

Tantam (2000) noted that depression may go unrecognized in the AS population because it frequently manifests through an increase in core symptoms. Therefore, depression may not be noted as a separate concern, but may be seen only as an extension of AS. This may be a particular concern because depression is common in the AS population and, although deliberate self-injurious behaviors are uncommon, suicide may occur. Therefore the skill deficits that may result in depression need to be addressed effectively in order to prevent these possible negative outcomes.

External Interventions

There are several external or skills-based intervention approaches described in the literature. These approaches aim to modify inappropriate or maladaptive behaviors through external means. These interventions include peer mediated modeling, direct instruction, behavior management techniques, medications and Relationship Development Intervention (RDI).

Peer mediated approaches.

The first category is peer-mediated approaches, such as the "Circle of Friends" (Moyes, 2001; Greenway, 2000; Rogers, 2000; Whitaker, Barratt, Helen, Potter, & Thomas, 1998), in which typical peer volunteers are educated about AS, and provided with training in order to better understand and respect more fully the individual with AS. The hope is that these volunteers will "elicit, prompt, and reinforce social behavior" (Rogers, 2000, p. 403). Rogers (2000) also described other, less structured, interventions involving trained peers who would either elicit interactions from children with AS, or simply respond to their independent attempts to interact in a reinforcing manner.

The outcomes for peer-mediated interventions reported by Barry et al. (2003), Greenway (2000), Rogers (2000), and Whitaker et al. (1998) are increased interactions with trained peers that continued past the initial implementation period. However, despite qualitative reports of positive outcomes for these peer-mediated interactions, there was no empirical evidence provided by the authors to back their positive evaluations. The articles did caution that, although the frequency of interactions increased, the ability of children with AS to initiate these interactions was not impacted by the intervention. Therefore the increased frequency of interactions belied continued difficulties with initiation and

maintenance of social interactions. Additionally, each study indicated that this approach demonstrated limited generalizability of skills outside of the controlled confines of the studies (Barry et al, 2003; Greenway, 2000; Rogers, 2000).

Peer mediated modeling can also be relayed through video modeling (Moyes, 2001). Apple, Billingsley, and Schwartz (2005) examined the impact of watching appropriate peer interactions, the giving of compliments in particular, on the subsequent behavior of children with high functioning AS. The individuals seen interacting on the videos were typical peers as well as adults providing information regarding how and why to make compliments. The children watched the video and were subsequently returned to their classrooms for the remainder of free play during which time their interactions with peers were closely observed. When no initial changes were observed, Apple et al. (2005) added a preferred, tangible reinforcer, which the adult explained could be obtained after the child was observed giving four compliments during free play. The reinforcer produced a significant increase in compliment-giving by the AS students. Ultimately, when both the video and the reinforcer were withdrawn, the children maintained their increased levels of compliment giving, solely in response to peer-initiated interactions (Apple et al.).

Direct Instruction.

Another skills-based approach is direct instruction of social skills and instruction other deficit skill areas. This intervention is typically implemented in a group setting with the leadership of a trained adult who facilitates the learning process. Greenway (2000) described a social skills group in which adults utilized games, role-playing, and modeling to enable the children with AS to learn better and more effective ways of interacting with

their peers. Several specific games may be used in the social skills group settings that are particularly geared towards children with AS, including *The Idiom Game* and *What's Up?* (Ganz, 2001). Ganz (2001) explains that these games are aimed at providing children with practice in the non-literal and pragmatic language that is widely used by typical peers and is essential knowledge in enabling them to interact appropriately with same age peers. Through repeated practice of these communication skills, children with AS may be better able to overcome their executive functioning deficit of cognitive inflexibility and consider a broader range of word meanings and uses in social settings.

Although most research on direct instruction of social skills is based in the school setting, two researchers explored the efficacy of utilizing outside settings in such endeavors. Barnhill, Cook, Tebbenkamp, and Myles (2002) utilized four weekly, hour-long social skills training sessions at a local university to deliver direct instruction. The direct instruction was divided into five topics, which were addressed during the intervention. The first weekly session focused on recognition and expression of happy, sad, angry and fearful tones of voice. The second sessions focused on explanations of the meanings of various subvocalizations (i.e. - "mmm") and practice of such sounds during group role-plays. The third session involved interpretation of an individual's rate of speech and any associated meaning and the fourth session focused on the emphasis of particular words in a sentence and ways in which these could alter the underlying meaning. (Barnhill et al., 2002).

The fourth week of the session focused upon "identifying and responding to the facial expressions of others" (Barnhill et al., 2002, p. 113), utilizing various media and mirrors to aid the children in role-playing and in identifying the various facial

expressions they display. In addition to the university setting in which the direct instruction took place, the group also spent approximately 2-3 hours in the community following each social skills session in order to generalize their skills to outside individuals across multiple settings. Barnhill et al. reported an improved ability of the participants to identify nonverbal communication across settings; however, the findings were not statistically significant. It is possible that this intervention was not effective; the students were given the training to be more cognitively flexible and to evaluate the emotions and non-verbally communicated thoughts of others, but they were not instructed in how to initiate interaction or to modify their own emotions and behaviors based upon this knowledge. Therefore they were more aware of how others were feeling but they still lacked the social skills necessary to initiate and maintain peer interactions appropriately. More obvious deficit areas could have been addressed. (Myles & Simpson, 2001).

Myles and Simpson (2001) also discussed a direct instruction approach to social skills intervention, focusing on the *hidden curriculum* which "includes the skills that we are not taught directly yet are assumed to know" (Myles & Simpson, 2001, p. 279) regarding socially accepted behavior. This program was developed to instruct children with AS in this *hidden curriculum* in a very strategic manner. Myles and Simpson (2001) delineate several components to this approach, including both instruction and interpretation. During the instruction phase, the scope and sequence in which social skills are acquired was taken into consideration in order to determine which developmentally appropriate skills the individual was lacking. Therefore, it could be determined whether or not there were pre-requisite skills that the child was currently lacking before more obvious deficit areas could be addressed. (Myles & Simpson, 2001).

After the deficit areas had been addressed, very specific direct instruction in these areas began. Myles and Simpson (2001) noted that children with autism spectrum disorders, and AS in particular, are better able to acquire information when it is presented in a meaningful format. Therefore the children must understand the relevance of learning the behavior in their lives in order for them to see a purpose in working with the instructor. The next step was for the instructor to teach the specific social skills identified as deficit areas by the scope and sequence evaluation. Myles and Simpson (2001) stressed the fact that this instruction should be broken down into small, stepwise increments and presented in multiple modalities to ensure comprehension. (Myles & Simpson, 2001).

In addition to this presentation of the material, the teacher modeled the newly learned behaviors for the children and monitored the emotional reaction of the children to the information. Following the modeling and monitoring stage, the instructor evaluated the children's understanding and use of the newly learned skills. Finally, the instructor worked to ensure the generalization of the new material through various opportunities to practice across school settings. In addition to this direct instruction, the children were provided with tools to aid in their interpretation of social situations. Myles and Simpson (2001) suggest the use of social autopsies and other decision-making models. Social autopsies are utilized in a situation in which a child makes a mistake in the social realm. In such a case, the student meets with an adult, subsequent to the problematic behavior, and discusses what went wrong, who had been affected, and how better choices could be made in similar situations in the future. (Myles & Simpson, 2001).

Overall, the direct instruction approach to social skills intervention has a positive impact on the cognitive flexibility of children with AS and on their decision-making

skills. The program discussed by Myles and Simpson (2001) seems to be the most individualized in terms of evaluating the particular developmental gaps in the social skills of the child in order to guide the instruction. However, the majority of reports of gains given by each of these articles are qualitative but there is limited quantitative data to demonstrate the efficacy of such programs and to support their widespread use with this population.

Behavior Modification.

Another external source of intervention is behavior modification. Beyond the basics of reinforcement and punishment, there are more specific means of increasing appropriate behavior. One such strategy that Myles and Simpson (1998) discussed was behavioral contracts. These contracts can serve several functions in treatment. They can encourage new, appropriate behaviors as well as help stabilize appropriate behaviors that have been learned in the past. The incentive for the child with AS to follow the contract is that he chooses what he will receive upon meeting his behavioral goal. In this way, the caregiver can decide the necessary behaviors and establish the limits of the contract, yet the child is actively involved in the process.

Medication.

Pharmacological treatment is another means of external intervention. The most widely used class of drugs for patients with AS is the Selective Serotonin Reuptake Inhibitor (SSRI) (Martin, Patzer, &Volkmar, 2000). These medications help to control the repetitive behaviors associated with AS. According to Martin, Patzer and Volkmar, (2000) it is also hypothesized that a serotonin transporter gene could be the source of the syndrome. Obviously, more research is needed before any conclusions can be drawn

about a distinct genetic cause. Until then, treatment will continue to focus on managing

the social and behavioral symptoms that are characteristic of this disorder. Ozonoff

(1998) reported that medication can be used to address executive functioning deficits

such as ADHD that may emerge as comorbid conditions.

Relationship Development Intervention.

The Relationship Development Intervention (RDI) program was created by

Steven Gutstein (2000) in response to his concerns about the weaknesses of typical social

skills intervention programs, which he identifies as teaching only instrumental skills.

Instrumental skills are those behaviors, which result in having a need met in non-

emotional interactions. For example, children learn that when they point to the television,

their mothers turn on their favorite shows. In this scenario, a child is interacting with his

or her mother, not as an enjoyable end unto itself, but as a means to have his or her needs

met. Therefore, Gutstein's primary concern was the focus of these programs solely on

instrumental skills (making eye contact, waiting one's turn, etc.) rather than more

complex interpersonal skills (joint attention, emotional coordination, etc.) that form the

foundation for lifelong social successes in experience sharing.

Gutstein and Sheely (2002) note that, unlike instrumental social skills,

relationship skills cannot be taught in a scripted and predictable manner. There is a great

deal of variability that takes place in relationships and scripted social skills frequently do

not stand up to the demands of flexibility inherent in interpersonal interactions.

Therefore, relationship skills are initially taught in environments free of other

distractions, unlike instrumental or social skills that are taught in the specific context

where they will typically be applied. Once acquired, relationship skills are practiced with

a variety of people and in increasingly distracting and varied environments. Unlike the predictable if…then…of social skills, relationship skills require constant monitoring and flexible adapting to limitless combinations of people and places.

The particular concentration of RDI is the initiation and maintenance of friendships as well as other meaningful relationships (family, significant other, etc.). "It is based on the premise that relationships are self-motivating, ends in themselves" (Gutstein and Sheely, 2002, p. 23). RDI attempts to improve the emotion-based, experience-sharing skills of individuals on the autism spectrum through providing them with the motivation through positive relationship experiences. The targeted skill areas include: *enjoyment, referencing, reciprocity, repair, improvisation and co-creation, we-go, social memories, maintenance, alliance, and acceptance*. Each of these relationship skills is taught through a gradual, systematic scaffolding of levels and stages. There are six levels (Novice, Apprentice, Challenger, Voyager, Explorer, and Partner) and each level has four stages. The pace of the instruction varies, depending on the individual needs of the child; the child should be challenged without being overwhelmed by the task demands.

RDI begins with an adult functioning as a relationship coach who both participates and guides the child through each activity. The role of the coach is to model the excitement and enjoyment that can result from social interactions and to invite the child to join him or her in exploring such interactions. As the intervention progresses, the child is given more and more responsibility for being a partner, first with an adult and then with a peer of similar skill level. Gutstein and Sheely (2002) note that it is critical to monitor the difference between purely instrumental interactions, when a child is being

entertained by his or her partner, and acquired relationship skills in action, when the child is enjoying the shared social experience. The goals of RDI are for participants to:

Understand and appreciate the many levels of Experience Sharing. Become an equal partner in co-regulating Experience Sharing interactions. Understand and value the uniqueness of other people – their perspectives, ideas, and feelings. Value and work to maintain enduring relationships. Become adaptive and flexible both in social and in non-social problem solving. Recognize each one's own unique identity that can continue to grow and develop.

By meeting these goals, the aim is that each individual act like a competent relationship partner and be fulfilled through valued relationships rather than through more solitary and socially isolating activities (i.e. video games or computer games).

Internal Interventions

There are several internal intervention approaches described in the literature. These approaches aim to modify inappropriate or maladaptive thoughts and behaviors by altering internal processes that impact behavior. These interventions include cognitive behavioral techniques and social stories.

Cognitive Behavior Techniques.

Because of the negative automatic thoughts characteristic of this population (Farrugia & Hudson, 2006; Barnhill, 2001; Barnhill & Myles, 2001) and subsequent anxiety and depression, Cognitive Behavioral Therapy (CBT) is posited to address these concerns at their root cause. CBT is a short-term, highly structured therapy, which posits the idea that difficulties arise from faulty or dysfunctional thinking as well as from misinterpretation of situations. These patterns of thinking can lead to rigid and ineffective

patterns of behavior, similar to those characteristic of AS. However, Ingram (2006) notes that CBT can be difficult to use with the AS population because of noted difficulties with theory of mind skills. However, the desire of individuals with AS to be accepted by peers can be utilized as a motivator. (Ingram, 2006).

Sofronoff, Attwood, and Hinton (2005) found that CBT can be utilized successfully to reduce anxiety, including the social worries that negatively impact peer relationships. Sofronoff et al. (2005) formulated a highly structured program that appealed to the AS population by introducing the program as a scientific exploration. This strategy helped the adolescents to become engaged in the treatment and they willingly participated in the subsequent interventions. After the six-week treatment period, these researchers found reduced levels of anxiety on post-test measures as well as parent reports of friendships among study participants. Parents also reported a reduction in negative emotional reactions; the adolescents became upset less frequently and recovered more quickly from upsetting situations.

Sze and Wood (2008) modified *Building Confidence*, a previously established CBT manual created by Wood and McLeod (2008), in order to address anxiety in a single case study model. Subsequent to the treatment, the 10-year-old participant with AS no longer met diagnostic criteria for GAD or Social Phobia. The participant self-reported reduced anxiety symptoms and the application of learned coping skills from the CBT program. The participant also reported increased overall functioning and a decrease in core symptoms associated with AS.

Sofronoff, Attwood, Hinton and Levin (2007) also explored the use of a highly structured CBT program to address anger in a group of 10-14 year-old adolescents

diagnosed with AS. In addition to six, two-hour sessions with the adolescents, parents were concurrently placed in a group and a therapist reviewed the program components. The CBT program resulted in a significant increase in parent reports of effective strategies to manage anger. Parents also reported that the number of angry episodes had decreased significantly and that the decrease was maintained at follow-up. It was also noted that the program provided common language so that parents and teachers were able to discuss anger and other emotions with the study participants.

Social Stories.

The most widely researched approach to intervention is the use of social stories, "in which written stories are created to teach social rules and the reasons for them in a supportive, non-critical, and understanding way" (Rogers, 2000, p. 403). These stories are written from the perspective of the child with AS, at the child's reading level, and in response to any behavior or situation he or she encounters (Safran et al., 2003). The topics covered in the social stories vary in relation to the child's individual difficulties and the demands of particular settings (i.e.-classroom, lunchroom, school bus). Social stories attempt to utilize the rule-based thinking of the child with AS as a strength, in order to help him or her to follow the behavioral directives contained in the story very closely. Additionally, they are written in a clear and concise way in order to minimize any confusion regarding the desired behavior (Agosta, Graetz, Mastropieri, & Scruggs, 2004).

Social stories can be implemented in three ways, according to Sansosti, Powell-Smith, & Kincaid (2004). The stories can be read independently by the child or read to the child by an adult, presented auditorially by a tape recorder, presented through

computer software, or through a videotaped presentation. Agosta et al. (2004) presented

social stories in a book format, with the addition of visual images based upon the research

demonstrating that children with AS can benefit from visual cueing. In research

performed by Agosta et al., the social story intervention was implemented by having the

child's teacher read the story to him or her and allowing him or her to see the visual cues.

In Adams, Gouvousis, VanLue, & Waldron's (2004) research, also a single subject study,

the stories were read to the subject by his parents in the home during homework time.

Both studies indicated significant reduction in the targeted inappropriate behavior

because of their impact on the executive function of adaptability; however, neither study

examined the maintenance of these behavioral changes past the conclusion of the

research. Additionally, both studies involved only a single participant and each contained

confounding variables that interfered with the ability to ensure that only the social stories

had a positive impact on the child's targeted behaviors. (Adams et al., 2004; Agosta et al.,

2004).

Although a number of researchers have explored the social experiences of

children and adolescents with AS and the comorbid disorders and intervention programs,

the reports have typically been only from the perspective of parents and other adults. A

few researchers have taken this noted gap in the research as an opportunity to expand the

knowledge base through qualitative means. Conner (2000) explored the daily school

experiences of 16 middle school students diagnosed with AS, through individual

interviews to determine major areas of concern. The concerns that emerged included

limited social confidence and performance anxiety. Additionally, the adolescents were

able to identify some of their own idiosyncratic interests as well as areas of academic

strengths (factual knowledge) and dislike (group work and whole group discussions).

Overall, Conner concluded that the possible mismatch between students with AS and the

mainstream classroom setting may be offset by efforts of school staff to address areas of

concern. Conner (2000) suggests that such efforts could include role-playing and

rehearsal, social stories, social skills groups or other types of solution-focused therapy,

and buddy systems.

Carrington and Graham (2001) examined the school-based experiences of two 13

year-old boys with AS and their mothers. Carrington, Templeton, and Papinczak (2003)

explored the perceptions of friendship of 5 teenagers diagnosed with AS. These

qualitative studies have reported similar themes of stress and anxiety in relation to social

deficits and have laid the framework for further research. The current study aims to

continue to explore the self-reported social experiences of adolescents with AS,

specifically self-perceptions of social interactions and perceptions of the way that others

view these social interactions, in order to better understand and support this population

through interventions targeted at self-reported areas of concern.

Chapter 3

Methods

Participants

     Subjects.

The subjects in this study were adolescents ranging in age from 10-years-old through 17-years-old, with a prior diagnosis of Autism Spectrum Disorder (AS) from a qualified professional (i.e.-developmental pediatrician, licensed clinical psychologist, psychiatrist, etc.). The diagnosis of AS was the participant's primary diagnosis. However, the participants also had comorbid conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Anxiety Disorders (Obsessive-Compulsive Disorder, School phobia) and Mood Disorders because they have been reported to be associated with AS (APA, 2000). ADHD is a disorder characterized by overactivity and inattention, which are frequently noted in individuals diagnosed with AS. Obsessive-Compulsive Disorder (OCD) is a disorder characterized by obsessions, which cause significant anxiety, and of compulsions that function to decrease anxiety. School Phobia is specific phobia that is characterized by significant anxiety provoked by school, often leading to school avoidance. Anxiety Disorders and Mood disorders have also been associated with AS. In keeping with the fact that AS is diagnosed at least 5 times more often in males than in females with AS (APA, 2000), the gender of the participants was predominantly male, with 11 male and 3 female participants. Individuals who had not been diagnosed with AS or individuals diagnosed with AS that were not between the ages of 10-17 were not eligible for this study and were therefore excluded.

Participants were recruited through the Asperger's Support Group of West Mont, the Autism Society of Berks County, the Center for Autism of Philadelphia and the suburban school district in which the researcher is employed. The Asperger's Support Group of West Mont is a Montgomery County Asperger support group for parents. Monthly meetings provide support, information, educational programs, and social/buddy groups for children. The Autism Society of Berks County, a registered chapter of the Autism Society of America, is an all-volunteer organization made up of parents and family members of individuals affected by an autism spectrum disorder, as well as professionals working in the field. The mission of the Autism Society of Berks County is to provide information and support for individuals within the autism spectrum, for their families, and for professionals through community awareness, education, and research related to autism. The Center for Autism of Philadelphia is a private, non-profit organization that focuses on treating individuals with Autism Spectrum Disorders in the Greater Philadelphia area. The demographic make-up of the suburban school district is largely Caucasian, upper middle-class students. The researcher obtained subjects by contacting persons from each organization. These individuals helped to identify adolescents who, with their parents' permission, were willing to participate in the interview process. The sample grew as parents from each group allowed their adolescents to participate in the study and informed other group members and friends about the study from a first-hand perspective. A total of 14 participants formed the convenience sample. Subjects were recruited until saturation was reached. Saturation refers to the point at which no new information is gathered through the interview process.

Informed consent and assent.

Because of the status of the subjects as minors, informed consent, including consent for audio-taping, was obtained from parent(s)/guardian(s) with adolescents prior to participation in the study (Appendix A). Additionally, assent forms were given to each adolescent for his or her agreement to be involved in this research and to be audio-taped (Appendix B). This researcher contacted each parent/guardian who had a child meeting the above criteria via telephone, to provide a brief description of the study and to obtain verbal consent. The brief description was taken directly from the parent/guardian consent form, including the $10 Barnes and Noble gift card given the participants. After verbal consent was obtained, the researcher worked with the parent/guardian to schedule a convenient date, time and place for the interview. At the scheduled meeting, the parent(s)/guardian(s) was presented, in person, with the informed consent to read and sign. Subsequently, the adolescent was given the assent form to read and sign. Both the informed consent and assent form included pertinent details about the study that aided parent(s)/guardian(s) and adolescents in determining whether or not they would like to become involved, including the $10 Barnes and Noble gift card given the participants. This information included a description of the study, what participation would entail, the time commitment, the voluntary nature of the study, and steps that would be taken to protect confidentiality, including the assignment of a pseudonym for each participant and the separation of consent and assent forms from any interview and demographic data collected. Additionally, the forms included contact information for the researchers.

Judges and Interviewer

A total of 5 individuals were involved in this research project, including the principal investigator, the research investigator and a research team. The principal investigator was the chairperson of the research investigator's dissertation committee. The research investigator, a doctoral student, conducted all of the interviews with the participants and reviewed each of the transcripts in depth to determine emerging themes, using a constant comparison model. The research team consisted of two doctoral level graduate students familiar with the research topic and the second committee member, who was familiar with the research topic and with qualitative research methodology. After the research investigator had conducted and analyzed a majority of the planned interviews, the research team met to review the transcripts and discuss emerging themes, validating the research investigator's initial insights. The research investigator considered the findings of the research team and continued to conceptualize the emerging themes at subsequent meetings with her first and second committee members.

Overview of Research Design

Grounded theory and methodology.

A qualitative research design was used in the current study. The research design was based on the methodology of Strauss and Corbin (1998), whose methodology of grounded theory originated in the work of Glaser and Strauss (1967) and is based upon the field-based collection of data to build theory. Strauss and Corbin (1998) emphasize the fact that theory is developed through the ongoing interplay between data interpretation and theory building. "In speaking about qualitative analysis, we are referring not to the quantifying of qualitative data but rather to a nonmathematical

process of interpretation, carried out for the purpose of discovering concepts and relationships in raw data and then organizing theses into a theoretical explanatory scheme"(Strauss and Corbin, 1998, p. 11).

Qualitative research on the basis of grounded theory uses a strategy of theory *building* rather than theory *testing*. Theory derived from data is more likely to reflect the realities of a situation than is data built to test preconceived speculation. To this end, grounded theory provides procedures to interpret and organize data. These procedures are conceptualization of data, generation of themes that emerge from review of the data in order to continually develop theory that materialize from the data. Another important aspect of qualitative research is the concept of saturation. Saturation occurs when no new information emerges from the interviews and the categories have been developed in detail.

Qualitative research was chosen for the current research study because of the nature of the research question. Because the perceptions of adolescents with AS were being sought, it was important that this researcher interact directly with these adolescents, through interviews, in order to capture their self-reported thoughts and feelings in an objective manner. Because the current literature base on the self-reported experiences of adolescents with AS is limited, the current research may be the first step in analyzing the self-perceived interpersonal experiences of this population and piecing together emerging themes.

Measures

There were three different measures used in the course of this study. The first measure was a demographic information questionnaire completed by the adolescent's

parent(s)/guardian(s) (Appendix C). The second measure was a semi-structured interview designed by the researcher (Appendix D) and conducted with the adolescent participants. The questions were developed through research regarding adolescents with AS, relative to their self-competency. The semi-structured interview was composed of 7 open ended questions aimed at gaining a better understanding of the adolescent's thoughts about and experiences of social competency. The third measure was a demographic information questionnaire (Appendix E) completed by the adolescent participant after the interview was completed.

Procedures

Because of the qualitative nature of this study, the units of data being collected were not numbers but rather words, as the participants described their perceived social competency skills. This data was collected through a semi-structured interview as well as through parent and adolescent demographic questionnaires. The interview questions (Appendix D) were developed based upon the current literature on adolescents with AS, in conjunction with the literature on social competency skills. The interviews were conducted at a location determined through conversation with parent(s)/guardian(s).

Parent/guardian consent and participant assent were sought in order for the interviews to be audio-taped for later transcription. One practice interview was conducted prior to beginning the official interviews in order to rehearse the semi-structured interview format. The researcher also distributed demographic questionnaires to parent(s)/guardian(s) in order to gather additional information about the adolescent. In particular, the researcher was gathering information about the adolescents' treatment histories and social connections (school, friends, family, and clubs/organizations).

Prior to interviewing the adolescents, the researcher was introduced to the participants by the parent(s)/guardian(s) in order to increase familiarity prior to the interview and to decrease anxiety about the unknown nature of the research procedure. The interview took place in a location determined by the researcher and by parent(s)/guardian(s). The sites were chosen in order to minimize any anxiety that may have been created by the overall nature of the situation. Eleven of the 14 interviews were conducted in the participants' homes. Each semi-structured interview was conducted by the researcher investigator in order to ensure that the protocol was maintained with each of the participants. The interviews took place in one session and varied in length from 6 minutes and 31 seconds to and 79 minutes and 33 seconds, with a mean length of 25 minutes and 33 seconds.

The interview process began with an explanation of the purpose of the study and a definition of social competency. For the purpose of the study, social competency was defined as the ability to have positive interactions with other people, particularly peers (Appendix E). The researcher reviewed the assent form with adolescents, including the voluntary nature of the study, the $10 Barnes and Noble gift card that they would be given for their participation, their right to refuse to answer questions at any time, and information regarding how their information would be kept confidential. The researcher also explained the use of the tape recorder as a means to ensure that all the information they shared would be accurately recorded.

After the interview process was reviewed with the participant, the semi-structured interview began. The interview consisted of several open-ended questions. These questions were presented in such a way that the adolescents were able to share their

experiences fully, from their own points of view. The questions explored social competency skills from various perspectives. The researcher also asked clarifying questions to ensure that the adolescents shared their thoughts and perceptions fully, so that the information gathered was an accurate depiction of their experience. After the interview was completed, the adolescent was asked to complete the demographic questionnaire. After the demographic questionnaire was completed, the researcher answered any remaining question from the adolescents and parent(s)/guardian(s). A list of referrals for supportive services was created in the event that any participants displayed distress at the end of the study. (Appendix F). However, no participants displayed distress during the interview process. Parent(s)/Guardian(s) and adolescents were informed that a summary of the research findings would be available to them after the study was completed.

In order to ensure confidentiality, each participant was assigned a pseudonym chosen by the research investigator. The assigned pseudonym would be used for the interview and demographic information. Additionally, the consent and assent forms were kept separate from any interview and demographic data collected. In this way, no identifying information could be linked to the interview recordings or transcriptions. Additionally, the data was kept in a locked drawer when not in use and the drawer was accessible only to the research team members. The research investigator transcribed the recordings verbatim in order to enable a closer analysis of the information provided.

After the research investigator had conducted a majority of the planned interviews, each interview was read several times and examined in close detail in order to identify themes emerging in the data. The research team met to review the transcripts

and discuss emerging themes, validating the research investigator's initial insights. The

research investigator considered the findings of the research team and continued to

conceptualize the emerging themes at subsequent meetings with her first and second

chair. Involving additional people in the process of reading and analyzing the data helped

to increase the validity of the study because any bias on the part of the researcher could

be minimized by the convergent findings across members of the research team.

Interviews continued to be conducted until no new information emerged and the

categories were considered saturated.

Chapter 4

Results

Data analysis and interpretation

The analysis of the interview data followed a constant comparison model. The constant comparison model is a method of data analysis that begins with the analysis of the first piece of interview data and is ongoing throughout the research process. After the first interview was conducted, information from the interview was transcribed and the data was read and analyzed for emerging themes through Strauss and Corbin's (1998) process of open coding. The research investigator read the interview material closely in order to analyze the data for any emerging concepts. After the first interview had been analyzed and concepts began to emerge, the second interview was conducted and analyzed. The second interview was analyzed with the conceptualizations from the first interview in mind, looking for similarities and differences. This process of ongoing analysis continued in this manner throughout the study as the research investigator moved between the data that had already been gathered and the current interview data in order to facilitate the emergence and evolution of overarching categories. Data gathered from each subsequent interview was integrated into and used to expand the existing categories and conceptualizations. Interviews continued to be conducted until no new information emerged and the categories could be considered saturated.

As interview data approached saturation, the members of the research team subsequently read and analyzed the interviews for emerging themes. After individual analyses were performed, the research investigator, the team, and the second chairperson conferred about the various themes that emerged, focusing on the convergent concepts

that emerged through various raters. This method worked to ensure that the analysis and conclusions drawn from the data were not biased. Additionally, demographic information about the participants was collected (gender, age, current grade placement, etc.), graphically displayed and aggregated.

Discussion of Findings

The research findings are split into two separate categories: (a) demographic findings and (b) descriptive findings. The first section describes the demographic information about the adolescents who participated in this study. This information was gathered through parent/guardian and adolescent demographic questionnaires. The descriptive findings provide a description and analysis of themes that emerged within the responses regarding self-perceived social competency. This section includes verbatim examples from the adolescents' responses to the questions asked throughout the semi-structured interviews. The pseudonyms assigned to each participant were utilized in order to provide anonymity.

Demographic Findings

The study participants consisted of 14 adolescents (11 males, 3 females) who were diagnosed with Asperger Syndrome. The participants were recruited through the Asperger Support Group of West Mont, the Autism Society of Berks County, the Center for Autism of Philadelphia and the suburban school district in which the researcher is employed. The participants ranged in age from 10-years-old to 16-years-old, with a mean age of 11 years 3 months. The students were in 4th through 10th grades; at least one student from each grade participated (Appendix G). The age at which the participants were diagnosed with AS ranged from 3- years-old to 14- years-old, with a mean age of 8

years 4 months (Appendix H). Parents reported that all 14 of the participants were aware of their diagnoses of AS.

Eight of the 14 participants had other mental health diagnoses including: Attention Deficit Hyperactive disorder (ADHD), Mood Disorder, Nonverbal Learning Disability (NVLD) and Anxiety Disorder. Six of the 14 participants received Early Intervention services including, Speech and Language Therapy, Occupational Therapy and Physical Therapy (Appendix H). All 14 participants currently had Individualized Education Plans (IEPs). The supports provided in the participants' IEP's varied, but most frequently included were speech and language, occupational therapy and counseling (Appendix H). Eight of the 14 participants also received supports outside of school. These supports were primarily counseling and social skills training (Appendix H).

In terms of interests, athletics/physical activities and video games emerged as top interests as reported by both parents (Appendix H) and adolescents (Appendix G). Eleven of the 14 participants reported being involved in various clubs, teams or groups, both inside and outside of school. Five of the 14 participants reported that class was their favorite part of the school day, but eight of the 14 participants reported that it was their least favorite part of the school day. One participant reported that class was both her favorite and least favorite part of school, because she was currently attending a cyber charter school but disliked the experience in a typical classroom setting.

Regarding friends, the parent and adolescent reports indicated that all 14 participants had one or more friends at school. All 14 participants reported having one or more friends outside of school (Appendix G). Parents reported that 12 of the 14 participants had one or more friends outside of school. Parents reported that 50% of

participants had friends that were also on the autism spectrum and that the majority of their children's friends were from school. (Appendix H).

When asked if they had a best friend, 10 of the 14 participants reported having a best friend. Two participants specifically shared their thoughts regarding best friends. Adam stated,

> I like to stick to one best friend because I find that I can focus on them better. A lot of people have like 16 best friends and it's like, how are you ever going to get to know the one if you have so many. I see the term best actually fits with one person in your life. Best is a simple analogy for one above the rest. That's how I see a best friend. We just seemed to fit together, you know, like two puzzle pieces.

Adam also shared that, "If anyone would truly understand you, it would be your best friend. They know you, they understand you; they know what you are going through. They can feel your pain, as to say". Dan stated, "I really don't have a best friend. I really have two best friends, but they're not best friends because I really don't qualify people at the top". One participant indicated that he was undecided about whether or not he had a best friend. Two participants reported they did not have a best friend and one participant did not respond to the question.

Descriptive Findings

   Peer interactions.

The participants generally reported positive interactions with peers. As Laura stated, "I tend to get along pretty well with my friends. I don't know my classmates too well because it's online, but I tend to get along with people pretty well".

The type of interactions that participants reported varied from a simple acknowledgement in the hallway at school to spending time together outside of school. A number of participants mentioned that being greeted by peers at school was a significant interaction and that these peers were typically viewed as friends.

Adam stated, "J. actually said hi to me, a thing that not many people do except for my friends. In a valentine card I sent her, I was like thank you for saying," hi" to me. It really makes my day". Bart also shared how a small gesture can be meaningful, "I am also friends with J. I guess we go to the same math class and before we go in, he just talks to me for a little bit". Charlie also commented about how even routine interactions make him feel close to his peers on a sports team, "I am really close with most of the guys. They say hi and are really nice to me and if during weightlifting I am doing something wrong, they help me out".

A number of participants reported that their peer interactions typically revolved around shared interests, predominantly video games. Adam reported, "We like to play video games and we like to climb trees and get swords and start chopping up thorn bushes. We make swords out of sticks and bamboo". Charlie stated,

> We maybe like talk about some video games. I know like most of my friends have video games at home that they like to enjoy. Maybe if they come over to my house or I go over to their house we might play some video games.

Although most of the adolescents who were interviewed reported that they got along fairly well with their peers, some participants did note some social difficulties, Dan stated,

I have had some incidents with people I really don't like as much. When I want to I can make my voice really, really, really loud. I get loud. …The big arguments are about…I don't know if I would consider them big things. They are sorta like medium things. Kinda funny things too. Not really something to get upset over, but we get upset about it. I don't think we want to do it, but our brain tells us to do it and we do it.

Ed commented,

I can get mouthy and a lot of people know about it so they don't want to be my friend. I can call people names if they get me agitated. And I get agitated really fast. Sometimes kids argue with me and I get in trouble because I call them names.

Fran shared,

When some people think that I said something wrong and they just get in their moods and say, „I don't want to be your friend anymore'. Then they want to make up and sometimes I say no and sometimes I say yes. Sometimes I say something and I might have said it the wrong way and they may have taken it personally.

One participant, the only participant with a one-on-one aide, discussed his experience of having an aide and the fact that he felt that she had a negative impact on his social interactions. George reported,

I feel like I get along pretty well. The only thing is that my aide, like…kinda gets in the middle of the social life because I constantly have to work and if I am not she will walk over and grab my papers and like.t's

just… kinda embarrassing. I take a step towards people but they don't take

a step. I guess because of my aide.

There were also some participants who expressed ambivalence to or an avoidance of

social interactions that were taking place around them. Bob stated,

Like every guy in school knows each other. It's all kind of like some kind

of intricate network, like everyone knows who everyone else is …I try to

stay out of that kind of thing. I am usually indifferent to them. I mean, I

really don't consider each of them someone I'd end up meeting with for a

ski trip in 20 years. And I really think after high school they'll be kind of

drops of water in the ocean type thing.

When talking about his school experience prior to beginning a cyber charter school, Mike

reported a similar avoidance of social interactions, "I didn't interaction with everybody

and I stayed by myself while everybody was socializing with each other. I was in the

back of the class reading a book or just drawing on a piece of paper".

Two participants described the specific approaches they employ when

approaching peer interactions. Ian explained,

I'll probably just stay a good distance away from them. Watch them. See

what they do and how they act around others. And try to think in my head

what an encounter with that person would be like. Like if I think it would

be ok to go and talk to them, then I would go and talk to them. It is more

of a neutral situation…It's just mostly because I don't see it to be worth it

to talk to them as much as other people.

Ken shared a very specific and repetitive set of steps he follows in initiating an interaction with peers. He stated,

> Basically, I just say" hi", then leave. Then come back then say "hi" again then leave and then come back and say "hi" again and then go away and then come back until he wants to be my friend. Like one each day …until he becomes my friend…then he starts hanging out with me.

Ken also expressed that this repetitive approach to peer interactions can have negative consequences. He commented,

> After like ten times of not become friends, they start to get annoyed…and then he tells me to stop and they every time I go near him he thinks I am going to say" hi" to him so he tells me to go away.

His frustration led him to report feelings of failure in terms of establishing and maintaining friendships. Although other participants reported difficulties with social interactions, Ken was the only participant to express feelings of social failure. He reported,

> They see me trying to get some friends and I end up a failure. Sometimes it's just hard to make friends in my life…because they never want to be my friends…they never want to start hanging out with me until like 20 times I say "hi".

Friendliness/approachability.

Another theme that frequently emerged during interviewing was the characteristics of peers whom they viewed to be successful in social interactions. Most

participants described socially successful peers as being generally friendly, outgoing and approachable. Dan provided the following description of such a peer,

> Well, she's always smiling pretty much and she's like happy. She says "hi" to everyone in the morning. She doesn't really have any enemies or anything. I know it's not a thing that you're born with; it's just about how to get along well with other people.

Similarly, George described a socially successful peer as follows, "He's funny. He's animated, a very animated person. He…I'd says he is just like a happy person in general. Just nice".

Several participants mentioned that humor was a central part of being seen as friendly and approachable. The capacity to make other people laugh was identified as a particularly coveted skill. As Henry stated, "He gets along with everyone because he is funny too. He makes everyone laugh". Jazelle shared a similar description of her friend, "She's nice, she's really funny, like she tells lots of jokes. She makes a lot of people laugh even me. She has a lot of friends". A sense of humor and the ability to make people laugh was widely viewed as an important skill in initiating social interactions. Participants reported that a shared sense of humor was a tool that could break the ice and potentially link them to their peers.

Communication.

Another theme than emerged through interviewing participants about their social competence was communication. Participants expressed views on their communication skills as well as the communication skills of their peers. They often discussed the difficulties they experienced in communicating, particularly in light of how easily their

peers are able to communicate. A number of participants described the difficulties they
have in communicating effectively with peers. Bob stated,

> I try to talk to people. I try to commence conversation, but I screw it up
> somehow and end up leaving. I can reason as well as an average adult. By
> average I mean an IQ of 110. I have an IQ of 149. Those top percentile
> things, I don't really care. It all comes as a double-edged sword because I
> can barely communicate with people without screwing it up.

Ian described a similar frustration, "Sometimes I think to myself, how can I talk to this
person, when other people do it as easy as breathing".

Laura characterized her communication with peers as "awkward". She commented,

> I would kinda go off by myself a lot and I wouldn't talk to people. And
> when I did it was kinda weird. It wasn't like normal conversation. I don't
> actually know how to describe it. I would be very…like I'd talk to people
> about having OCD and explain it to everyone I met. I would overshare.

Some participants also reported that they were better able to communicate with their
peers if the topic was familiar to them or an area of particular interest. They expressed a
level of comfort with conversation in which they had information to contribute. However,
this was sometimes reported to have a limiting effect because peers did not always share
the same interests. Bob reported,

> Usually, when I talk to someone I say, „Did you see that episode of House
> last night?" Only, its D. and I are the only ones that watch House. The
> other kids seem to be interested in reality shows and stuff. I could really
> care less.

In terms of communication, the participants also indicated that they limit the communication they have with their parents, regarding their social competency. A number of participants reported that they were not sure what their parents thought about their social interactions because they assumed that their knowledge was limited to what they was told by teachers or by self-reported accounts. Participants frequently reported that they did not typically discuss their social life with their parents. Adam described,

> I don't really talk to them about how much of a social outcast I am. It is just something that you don't want to share…Yeah, I don't want them to help me. I am content with the few friends that I have. Even if I only had one friend and it was T. I would be ok.

Bob remarked,

> She doesn't have a 2-way mirror where she can look in and see what is happening. If she doesn't get any bad emails from my teacher, she assumes my day went good.

A number of participants expressed similar feelings, explaining that their parents did not have much information about how they were interacting.

Interests.

The majority of participants noted that their interests were paramount in terms of their ability to communicate and their ability to interact with their peers. These shared interests were frequently the primary link between participants and their friends. Ed described one of his good friends as follows, "He is interested in the same things as me…He likes to do the stuff that I like to do. We both like animals. And I am not sure if he likes building, but we both like drawing". Ian stated, "We both like a good joke and

have a good sense of humor. Um, we are both into music and stuff…like the musicals and stuff like that".

Similarly, Henry stated the following about his friends, "They are kinda nice. We all have the same interests, video games". George also noted that his interactions with friends typically revolved around his area of interest, the playing of video games, "After school I usually play video games…it is like the greatest invention ever. Telephones, who cares, who wants to communicate with people?

This sentiment that direct communication was not necessary for friendships was expressed by a few participants who described their interactions as consisting primarily of parallel play rather than more interactive exchanges. Dan reported, "Me and C. stay in and isolate ourselves from the rest of the world. I play video games and he sometimes plays pool by himself". One participant described how his interests are, at times, even able to bridge gaps in communication with his peers, "I started bringing Lego's to camp because I wanted to fit in. If I don't know what they are talking about they might think I'm not cool but I bet they'd still let me play Lego's".

Misunderstood by others.

Another theme that emerged through the interviewing process was a reported feeling of being misunderstood by others. Adam stated,

> I think outside the box way too often and people just discard my ideas. I
> am like Einstein. It's like, I think of something and they just blow it off
> like it is nothing…and they just shunned me. But if they actually got to
> know me and saw my potential, they would like me but no one even takes
> that chance. Well, as I said before I am like a cactus. If you peel the skin

off, I am gentle and soft and harmless inside, but the prickly exterior just

eliminates that and nobody every peels the cactus until they are ready to.

Don't judge people before you get to know them, if you are going to be

telling people this. Just tell people not to be judgmental of people. Because

we see someone on the outside, that's like a cactus, don't be afraid to pet

them.

Several participants reported that teachers and other adults were included among

those who misunderstood them. In particular, the school environment was noted as one

setting in which this group of adolescents felt their needs, both academic and social-

emotional, are not well understood. Fran reported, "All they see is that everything I do is

great and I don't have problems. But not everything is perfect. They don't see me

frustrating. Like other kids, they see them frustrating but not me".

Ian shared,

Well, teachers would probably say I try to avoid people more because of

my analyzing the situation. Since most people I find are not the kind of

people I want to talk to, I'll stay away from them. So they see me staying

away from most people and they see that as more, I don't like that person

when actually I don't want to talk to that person. Because they see me

staying away from those people but don't see me with other people, they

think I stay away from everybody when I only stay away from most

people, not everybody. Which is a good group of people that I can talk to.

One participant, in particular, expressed his frustration with adults and how grateful he

was to be asked about his perspective. George stated,

You are the first person who has even asked me what I think. Most

professionals don't so that. And my teachers don't understand me either. I

think they know what it is, but they don't understand. They know that I

have some kind of syndrome and think, „Now I know what I need to do for

this kid, give him extra help'. I wish people knew what it was. That people

knew about it because none of the kids in my school know what it is. Most

of them have no idea. They think it is a food…Aspergers? Is that a

vegetable? Is that a new restaurant?

Ian shared a similar frustration with the lack of knowledge about Aspergers syndrome

and how it can lead to being misunderstood.

I think Aspergers isn't like AIDS; it isn't something that everyone fears. It

is something anonymous; it is something that people have not heard of.

You know, it is something that can get mixed up with hamburger. It is still

hidden. It is still obscure. If Aspergers becomes a more common thing and

more noticeable, then people would know what it is and you wouldn't

have to say as much to let people know what you have. With Aspergers,

you have to give people a whole tutorial for them to understand about it

because they have never even heard about it before.

View themselves as different.

Another theme that emerged during the interview process was the participant's

self-perception of being different or atypical. Adam explained,

It's really freaky because when I'm in school with like one and two people

I'm fine, I'm normal, I'm happy. But when I get into a group like this

something shorts circuit in my head and I start acting all weird. I'm not

really sure why that is.

Adam also shared that being different from his peers could be a positive experience. He

commented, "I'm just abstract. That is the word I was looking for…I am an abstract

person. That's what I am. I like to do things differently from everyone else; that pleases

me greatly".

Several participants described feeling how their emotions or brains make them

think or act differently. They shared an experience of wanting to behave or engage in

activities as their peers do, but that this can sometimes be a hurdle to overcome. Ed

stated,

"Well, I get angrier quicker. I get angry quicker than most people do". Charlie reported,

"It was difficult to talk and stay calm and…just, I am trying to think of a good word for

this, be more behaved".

Laura shared,

It's hard because sometimes there are things that other kids do have fun

and stuff that my brain won't let me. Like, my family was on vacation and

they had a karaoke night and everyone else was having fun, but I just

couldn't do it. My brain wouldn't let me. I don't want to look stupid and I

have a bunch of rules and that stinks sometimes.

Perspective on AS.

Finally, a number of participants shared a very distinct perspective on Aspergers

Syndrome. Because all of the participants were aware of their particular diagnosis, some

participants shared how they conceptualize Aspergers in general, both for themselves and for others. Adam shared,

> I'm kind and I'm gentle, but not many people see that because I'm always in this hard exterior. I'm like a cactus. I'm thinking about writing a book called how to pit a cactus, a book on Aspergers. I'm like a cactus on the outside, but I'm really nice and juicy and happy on the inside. But the outside is so bent out of shape, it's just not useful.

Bob reported that there are both positive and negative characteristics that are associated with Aspergers, "Well, I think that if I didn't have Aspergers syndrome I would be able to communicate with people pretty well, then again I would probably be a lot stupider. Kinda a toss up there". Other participants provided the description of Aspergers that they give to peers and others when questions arise regarding their diagnosis. George expressed, "I tell them that I have this disease, I think it's a disease, Aspergers and I am not as social as everybody else. And that is all I say, just that I am not as social as everybody else".

Ian shared the description of Aspergers that he provides when asked,

> I just keep it really short and simple. I keep it as if it is certain strengths and weaknesses. The strength is you get a higher intelligence, easier learning curve. The downside is you don't have that innate sense of social skills, like sometimes I think to myself „How can I talk to this person' when other people do it as easy as breathing. It's something…I think having Aspergers makes you think much more deeply. Like, how social skills work, how we know how to talk to people, how does all that work?

Ian also shared an intriguing analogy about how one of his friends responded to his explanation of Aspergers Syndrome and his diagnosis in general,

C. hasn't treated me any different from before I told him and after I told him. So I think he just sees it as „well, he doesn't really act very weird, so I don't see what's the problem'. It's like, people eat a food and they are like „aww, this is great, what's in it?' and you say liver and they are like, „yuck, this is disgusting'. Dude, you just ate it and you just said it was good, so the fact that you know what's in it doesn't really change the taste. Does it? It's still good and now you can say liver is good. You tasted it before you knew it, it was good, before you knew it was liver.

Other participants shared what they wished others knew about Aspergers Syndrome. Fran stated,

I think you should know about Aspergers, that don't take it really seriously. Well, take it seriously but don't think that it's a disease and don't tell the parents that it won't go away. It won't go away, but it just gets better. Just for parents to know that it won't go away but it will get better. Mine got better in the past two years.

Chapter 5

Discussion

Self-Perceived Social Competency Skills

The purpose of this investigation was to explore and begin to illuminate the perceptions of adolescents with AS, particularly regarding their social competency skills. For the purposes of the current study, social competency was defined as the ability to have positive interactions with other people, particularly peers. The results of this study demonstrate that the majority of the adolescents with AS who participated in this study reported a positive perception of their social competency. The majority of participants indicated that their interactions with peers were positive ones. In fact, all 14 participants reported having one or more friends both at school and outside of school and 10 of the 14 participants reported having a best friend. It is notable that the descriptions of those specific characteristics that qualified a peer as a friend varied from participant to participant. However, there was an overarching sense that a friend is a peer who is friendly, nice and shares similar interests.

In regard to peer interactions, the majority of participants reported that their interactions with peers were positive. There were some participants who described negative interactions with peers, but they were described as isolated incidents. Participants frequently reported that they got along well with most people, but there were some difficulties that they had encountered in the past. These descriptions of negative interactions were largely isolated to a particular person and/or group of people that they found to be frustrating. For some participants, that group involved peers who they reported made fun of them. For others, these peers were other adolescents with

disabilities who may have been in the same special education classroom or school. There was no specific characteristic that set this group of peers aside from the rest.

Negative interactions ranged from simple misunderstandings to name calling by peers. Some participants reported that their quick emotional reactions sometimes made these bad situations worse, either because their peers saw that they could upset them or because they would get into trouble for their reactionary behavior (i.e. calling names). It is notable that only one participant reported that the majority of his interactions with peers were negative. There were also a few participants who reported avoiding or being ambivalent towards a majority of their peers because they chose to interact only with those peers with whom they had previous, positive interactions. This avoidance was also reported to be helpful in avoiding negative interactions because participants avoided those individuals with whom they had previous negative interactions.

Among the accounts of positive interactions, there was a great deal of variability in terms of the types of interactions described. For some participants, being acknowledged by a peer in the hallway of school was a positive interaction; however, others described their interactions with friends with whom they felt they could talk and upon whom they could rely. Some participants reported that both interactions were meaningful and had a positive impact. It should be noted that no participant reported getting along with all of his or her peers. Participants typically mentioned a few specific peers in regard to these positive interactions, not an extensive list of friends and acquaintances.

The interviews revealed that there are a number of factors that participants believe impact their peer interactions, either positively or negatively. These factors emerged as

key themes underlying the interviews conducted for the current study. The first factor impacting peer interactions is friendliness/approachability. The majority of participants related friendliness and approachability to successful interactions with peers. As described by the participants in the current study, friendly meant nice, outgoing, and easy to talk to. Another key characteristic of friendliness that was noted by a number of participants was humor. The ability to make one's peers laugh was regarded as a central skill in initiating interactions. Many participants expressed a belief that people who were able to make others laugh were socially successful.

In terms of how friendliness/approachability impacted the interactions of the adolescent participants in the current study, there were varied responses. The majority of the participants reported being friendly and approachable, but this was to a degree lesser than their peers. Many participants noted that they were friendly and approachable to those peers that they were already familiar with, but were reserved in interactions with strangers and unfamiliar peers. Other participants reported that because they were not friendly and had isolated themselves from their peers, negative interactions sometimes resulted. Overall, participants expressed the fact that they were not as friendly as some of their peers, but that they were friendly and approachable to friends and other people familiar to them.

The second factor that was noted as impacting social interactions was communication. The majority of participants reported that communication is an area of weakness that can have a negative impact on their social interactions. Being unsure of how to approach unfamiliar peers or start a conversation seems to be a particular difficulty. Participants commented on the amount of time and thought it took for them to

initiate an interaction; their peers, however, were able to communicate effectively with little effort. Some participants reported that they were able to communicate better with their peers if they had knowledge about the topic they were discussing, particularly if it was a friend with shared interests. However, participants noted that not all attempts at communication with peers were successful or resulted in a positive interaction.

The third factor that was noted in impacting social interactions was interests. Most participants reported that their main connection with peers and friends was through shared interests. Both conversations and time spent together typically revolved around these interest areas. Shared interests emerged as a positive factor in allowing adolescents with AS to initiate conversations and to maintain interactions with peers. The downside to the important role that interests play in initiating and maintaining interactions is that the participants' interests are often different from the majority of their peer group. Nevertheless, the participants in the current study typically reported that they had at least one person with whom they shared interests and were able to interact and communicate with regarding this topic. Some participants even expressed the fact that they did not feel that communication was a necessary part of their interaction with peers.

The fourth factor noted as impacting social interactions was the perception of being misunderstood by others. A number of participants reported that they felt it was primarily teachers and other adults who misunderstood them. They expressed the fact that their teachers see them getting their work done, but largely do not observe the difficulties they experience. Participants reported that a lack of knowledge and information about AS is a major contributing factor in being misunderstood by their peers. Some participants acknowledged the fact that their teachers knew their diagnosis, but were not sure how to

support them. They reported feeling that AS is so uncommon that teachers and peers have not heard of it and have little sense of what to expect.

In terms of social interactions, some participants reported that peers do not interact with them because they may perceive them to be so different that they appear unapproachable. A number of participants reported that they, particularly when they were younger, were very quiet and kept to themselves. They shared the idea that their peers did not accept them, largely for this reason. There were a few participants who acknowledged that their behavior and emotions can get to a level that might lead peers to avoid interacting with them. Teachers also mistake caution and hesitation in initiating social interactions as a sign of avoidance or of limited social interactions.

The fifth factor noted in impacting social interactions was a self-perception of being different. The majority of the participants reported viewing themselves as different from their peers. The differences they reported varied from being more "abstract" to having "faster", more noticeable emotional responses to situations. Some participants also noted feeling that their brains were different and caused them to engage in certain behaviors or kept them from doing things their peers were able to do easily. Regardless of the difference, it was clear that most participants had an internal, self-identified feeling of being different that was separate from their feelings of being misunderstood by others. It is important to note that these reported differences were not always seen as being negative. However, the participants did note that their perceived differences impacted how they approached and interacted with peers.

The final factor noted in impacting social interactions was the participants' perspectives on AS. Because all of the participants were aware of their diagnosis of AS,

the majority had developed not only a perspective on AS, but also what it meant for them. In terms of social interactions, some participants had developed a specific explanation that they would provide to friends with whom they disclosed their diagnosis. The description noted primarily that AS had a profile of strengths and weaknesses. Strengths included intelligence and learning ability, but the reported weaknesses included communication with peers and innate social skills. Some participants referred to AS as a double-edged sword because of these positive and negative attributes.

Those participants who had disclosed this information regarding their diagnosis did not report that their friends had reacted negatively to the explanation, but that there was some general confusion regarding AS. Participants reported feeling that AS is typically an unknown disorder to most peers, as well as to teachers, and that there is a lack of public awareness about AS. Some participants expressed the idea that the information people do have regarding AS is negative and they hoped that people could understand that it can get better. A number of participants described the behavioral improvements that they had made thus far in their lives and shared the ideas that there is hope, especially for parents of children with AS.

This perception of AS as consisting of a profile of strengths and weakness, in conjunction with other factors such as interests, friendliness/approachability, communication, perception of being misunderstood by others and view of themselves as different, was reported by a number of participants. All of these factors play a role in the perceived social competency skills of adolescents diagnosed with AS, either in a positive or negative manner. In addition to influencing the social interactions of this population directly, these factors also interact and impact each other. No one factor stands alone in

influencing social interactions; rather, an ongoing interaction along all the factors evolves and informs future social interactions. For example, communication can be positively or negatively impacted, depending on whether or not the topic being discussed by peers is an area of interest, which in turn influences social interactions. If the social interaction is negative, the adolescent with AS may attribute this negative experience to their difficulties with communication and be less likely to approach that peer in the future. Therefore, each of these 6 factors was reported to play a crucial role in the initiation, maintenance and perception of social interactions with peers.
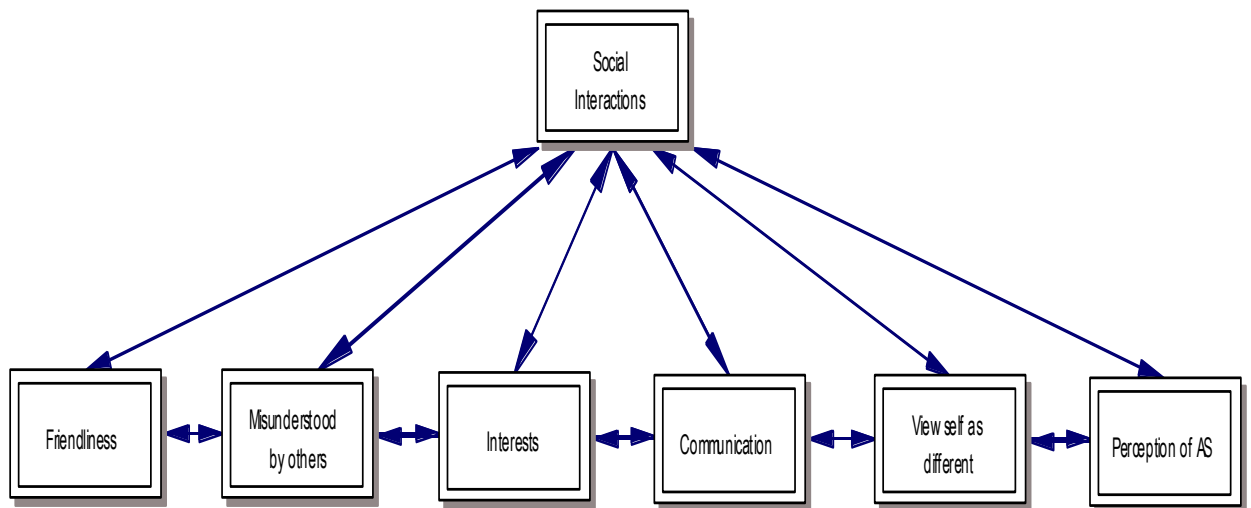
Figure 1. Factors Impacting Perceptions of Social Interactions in Adolescents diagnosed with AS.

Perception of Other's View of Their Social Competency Skills

In keeping with previous research regarding theory of mind deficits in AS, the participants in the current study had difficulty in determining what their teachers and parents might say about their social competency skills. Martin and McDonald (2004) defined theory of mind as the ability "to distinguish between one's own beliefs and the beliefs of other individuals" and "the ability to form representations of other individuals'

mental states" (p.312). The participants in this study typically reported that their parents and teachers would share the same view they had reported regarding their social competency skills. For example, if the participants reported that they got along well with the majority of their peers, they believed that adults would share the same view of their interactions.

Another frequent response was that the participant reported that parents and teachers did not have enough information to form an opinion about their interactions. Some participants expressed the fact that unless their teachers called their parents to report difficulties, or if they self-reported what had taken place during the day, parents were largely unaware of their social interactions with peers. This lack of information was likely maintained because participants reported minimal communication with adults, particularly their parents, regarding their peer interactions. Communication was especially limited if there were negative interactions. Finally, a number of participants reported that they were not sure about what adults would say about their interactions. One participant, in particular, reported that he did not like thinking as someone else and could not tell me what someone else would think.

Recruitment and Interviews

Any discussion of the results of the current study would not be complete without a description of the process of recruiting and interviewing participants. At the onset of the study, the investigator sought and obtained the support of members of Asperger Syndrome support groups in the hope of being able to recruit participants through these organizations. Although recruitment information was distributed to members of these groups, very few parents responded or expressed an interest in the study. As recruitment

information was shared with an increasing number of groups, an interesting pattern emerged.

Of the 14 parents involved in the study, 13 were mothers. If the participant's mother, agreed to take part in the study and found it to be a positive experience, she would send the study information to her friends, typically via email. The friends were not necessarily members of the same group, but also had adolescent children diagnosed with AS. Therefore, as people participated in the study, information regarding the study spread beyond the first groups that were directly provided with the recruitment information. This snowball effect resulted in a total of 14 participants from Philadelphia, Montgomery, and Berks Counties. There was even one out of state parent from Ohio who expressed interest in the study; however, the data collection was already complete at the time that he contacted the investigator.

In terms of the interviews themselves, 11 of the 14 interviews were conducted in the participants' homes. Parents were given the option concerning the most convenient location and most parents determined that the interview should be held in their homes. The willingness of the majority of parents to welcome the investigator into their homes demonstrates the openness of this volunteer population to engage in the research process. In addition to consenting to their child's participation in the study and the completion of a Parent Input form, the majority of mothers spent time talking to the investigator. The discussions ranged from 15 minutes to 3 hours and covered various topics regarding AS and their children. Mothers shared their experiences with the local school district, other parents, and professionals as well as the impact that their children's diagnosis had on their marriages and their families. A number of mothers had more than one child with

special needs in the home and appeared to be the primary caregiver involved in direct

contact with schools and professionals regarding their children's needs. This powerful

network of mothers in Philadelphia, Montgomery and Berks Counties was critical in the

completion of the current study.

Limitations

Although beneficial to furthering our knowledge and understanding of AS, this

research study has some inherent limitations, based on the study design. Although, it was

determined that saturation had been reached after 14 interviews and no further interviews

were necessary, the sample size of 14 participants is limited in number. The convenience

sampling method utilized in recruiting study participants also limits the generalizability

of the study's results, because the adolescents whose parents responded to the recruitment

information and allowed them to participate may differ from parents who did not respond

to the recruitment information or allow their children to participate. Additionally, because

the recruitment information was distributed largely through email, the results may not

generalize to families that do not have computers or families that are not connected to

email. The sample also lacks diversity because the participants are only from

Philadelphia, Montgomery and Berks Counties in Pennsylvania. This will notably reduce

the generalizability of the findings to any other locations.

Additionally, because most of the parents are involved in Asperger support

groups, they are likely knowledgeable about AS and have sought treatment to address

known deficit areas. It was noted that 6 of the 14 participants received Early Intervention

services and all of the participants currently had IEP's. Therefore, these participants may

demonstrate fewer or less significant deficits, because they have received interventions

and support to address noted weaknesses. These participants may differ from other adolescents with AS that may have not received any interventions to address areas of weakness. It is also notable that all of the participants in this study were aware of their diagnosis of AS. Therefore, their perceptions may differ from adolescents with AS who are not aware of their diagnosis.

Although AS was the primary diagnosis for all participants, comorbid conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Anxiety Disorders (Obsessive-Compulsive Disorder, School Phobia) and Mood Disorders were also reported because they have been found to be associated with AS (APA, 2000). ADHD is a disorder characterized by over-activity and inattention, which are frequently noted in individuals diagnosed with AS. Obsessive-Compulsive Disorder (OCD) is a disorder characterized by obsessions, which cause significant anxiety, and with compulsions that function to decrease anxiety. School Phobia is specific phobia that is characterized by significant anxiety provoked by school, often leading to school avoidance. Anxiety Disorders and Mood Disorders have also been associated with AS.

Because of these reported comorbid disorders, the interview data may be a reflection of the adolescent's perceptions due to another disorder or a comorbid diagnosis in addition to their diagnosis of AS. Therefore, the perceptions of the current participants may differ from the perceptions of adolescents who are diagnosed only with AS, with no comorbid conditions. Although parents were not asked about whether or not their children were currently on medication for these co-morbid disorders, any pharmaceutical treatment for these comorbid conditions may also impact the generalizability of the findings to adolescents who are not currently on medication.

Chapter 6

Conclusions

The current study has provided an examination of the self-perceived social competency skills of adolescents diagnosed with AS, as well as their perceptions regarding how others view their social competency skills. Social competence is defined as "the skills and strategies that allow individuals to have meaningful friendships; forge close, emotion-based relationships; productively collaborate with groups, teams, work partners; manage public social settings; and participate in family functioning" (Gutstein & Whitney, 2002, p. 161). For the purposes of the current study, social competency was defined as the ability to have positive interactions with other people, particularly peers.

The qualitative research design utilized in this study allowed for an in-depth exploration of the perceptions of this population relative to social competency skills. The personal accounts of each participant form a foundation for exploration, interpretation and increased understanding of the experiences of this population. The findings reveal that the majority of the participants in the current study reported a positive perception of their social competency skills, specifically their interactions with peers. Although the participants did express the ideas that their diagnosis of AS brought with it a number of weaknesses in the areas of communication and innate social skills, they also reported areas of strength. This self-identified profile of strengths and weaknesses was discussed as an immutable truth. It would be interesting for future researchers to explore the origins of this profile to determine if it was drawn from explanations given to participants by parents or if it evolved through life experiences and self-awareness.

This perception of AS as consisting of a profile of strengths and weakness, in conjunction with other factors such as interests, friendliness/approachability, communication, perception of being misunderstood by others and view of themselves as different, was reported by a number of participants. All of these factors all play a role in the perceived social competency skills of adolescents diagnosed with AS, either in a positive or negative manner. In addition to influencing the social interactions of this population directly, these factors also interact and impact each other. No one factor stands alone in influencing social interactions; rather, there is an ongoing interaction along all the factors that evolves and informs future social interactions. Therefore, each of these 6 factors was reported to play a crucial role in the initiation, maintenance and perception of social interactions with peers.

Although the results of the current study cannot be generalized to all adolescents diagnosed with AS, the findings suggest that despite noted weaknesses, this population largely perceives itself as able to have positive social interactions with peers. Although the types of interactions that they consider positive social interactions with peers may not be seen as developmentally appropriate by adults, they are nonetheless satisfied with these interactions. This knowledge that adolescents with AS can be content with their peer interactions will likely run counter to the thoughts of many parents, teachers and other professionals who feel ongoing interventions are crucial for this population to experience social success. The question would then become, why intervene when the majority of adolescents with AS in the current study reported they are already satisfied with their social competency skills? Should interventions be put into place simply because adolescents with AS have interactions that may appear "atypical" to others?

These questions will need to be explored further because the answers may drive the ways in which future interventions are conceptualized and implemented.

The results of the current study may shed some light on the failure of some social skills intervention programs for adolescents with AS. These programs may meet with limited success if their aim is to address the weaknesses that this population does not self-identify as weaknesses. Skills taught in the course of such a program may not generalize beyond the narrow confines of the intervention if the adolescent does not perceive himself or herself to be lacking the skill in the first place or if the adolescent feels that his or her current level of skill already results in positive social interactions. If the adolescent with AS perceives that he or she is already having positive interactions, the motivation to learn and apply newly learned skills may be minimal in real life situations.

Clearly, this study is only a first step in gaining a better understanding of the experiences of adolescents with AS. Given the findings of the current study, future research effort should explore the self-perceptions of adolescents who have not previously received educational supports or who are not aware of their diagnosis. Researchers may also want to explore the differences between perceptions of adolescents who are on pharmaceutical treatments for comorbid conditions versus those who are not medicated. There are a number of variations that could be explored to gain further information regarding this population.

Another avenue for future research would be to explore the success of intervention programs aimed at self-identified areas of weakness. Previous research indicates that social skill intervention program typically meet with limited success because skills do not generalize to broader, real world situations. If this is due to the

participants' perceptions that they already possess the skills necessary to have positive social interactions, exploring self-identified areas of weakness may help to inform interventions. Adolescents with AS could be asked about the areas they perceive to impact their social interactions negatively; interventions could then be directly targeted at these areas for each individual, with the hope that skills that they are motivated to learn would be more widely generalized.

Based on the experience of speaking with the mothers of the study participants, another avenue for future research would be to explore the experiences of mothers of adolescents diagnosed with AS. During the current study, a number of the mothers of study participants spoke with the researcher about their various experiences as a parent of the child with AS. Their experiences varied, but all had a story to tell about how AS had impacted their lives, from their child's original diagnosis to the present time as a parent of an adolescent. A qualitative exploration of the experiences of this population may aid professionals in understanding the complex familial and group dynamics that occur in the world of AS.

In terms of school psychology, counseling and other professions that work with adolescents with AS, the findings indicate that practitioners should be aware of the unique perspectives and experiences of this population. Participants in the current study expressed the fact that they felt largely misunderstood by adults, even those aware of their diagnosis. This highlights the importance of exploring the individual thoughts and experiences of each student, rather than presuming they are defined by their diagnosis. Knowing what is characteristic of an adolescent with AS will likely not be sufficient in working effectively with this population. By allowing adolescents with AS to share their

own individual perceptions of social competency, practitioners will be able to better focus interventions on self-identified weaknesses.

The results of the current study also indicate that professionals and parents may need to consider the impact of their own perceptions of social competence on the interventions chosen for adolescents with AS. Further exploration is needed, given the possibility that interventions may be put into place simply because adults see the interactions of this population as atypical. If the adolescents perceive their skills to be adequate and are satisfied with their social interactions and the research indicates that social skills interventions are largely ineffective, the continued use of such programs may need to be explored.

The current research has set a foundation for establishing a better understanding of the perceived social competence of adolescents with AS, as well as of their experiences of AS. The results of this study may aid professionals and parents in their understanding of adolescents with AS, but there is much more regarding individuals with AS that needs to be explored. Many participants in this study expressed their frustration with the lack of understanding that exists regarding AS. Hopefully the information gained through this study may lead future researchers to continue to explore and to enrich knowledge in the field for this growing population.

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Appendix A

Parent/Guardian Consent for Adolescent to Participate

<u>INFORMED CONSENT FORM</u>

<u>TITLE OF STUDY</u>

Adolescents with Asperger Syndrome and Self – Perceived Social Competence

<u>TITLE OF STUDY IN LAY TERMS</u>

Adolescents with Asperger Syndrome and How They and Others View Their Social
Interactions and Skills

<u>PURPOSE</u>

The purpose of this research is to find out how adolescents with Asperger Syndrome
(A.S.) understand and view their social interactions as well as their thoughts about how
others see their social skills.

You and your child are being asked to be in this research study because your child is
between the ages of 10 and 17 and has been diagnosed with A.S. If your child is not
between the ages of 10 and 17 and/or is not diagnosed with A.S., your child cannot be in
the study.

<u>INVESTIGATOR(S)</u>

Principal Investigator: Daniel Ingram, PsyD, NCSP	Co-Investigator:
Philadelphia College of Osteopathic Medicine Department: Psychology	Institution: Department:
Address: 4170 City Avenue Philadelphia, PA 19131	Address:
Phone: 215-871-6947	Phone:

Responsible (Student) Investigator: Shawn M. Dolan

The interview your child is being asked to volunteer for is part of a research project.

If you and your child have questions about this research, you and your child can call Dr.
Ingram at (215) 871-6947.

If you and your child have any questions or problems <u>during</u> the study, you and your child can ask Dr. Ingram, who will be available during the entire study. If you and your child want to know more about Dr. Ingram's background, or the rights of research subjects, you and your child can call the PCOM Research Compliance Specialist at (215) 871-6782.

DESCRIPTION OF THE PROCEDURES

If you and your child decide to be in this study, you and your child will be asked to complete separate demographic questionnaires and your child will be asked to complete a one-on-one interview with the student investigator.

The study will take about 45 minutes for each session. There will be two 45 minute sessions over the course of 2 weeks, for a total of 90 minutes of you and your child's time. The sessions will be audiotaped for later transcription.

POTENTIAL BENEFITS

You and your child may not benefit from being in this study. Other people in the future may benefit from what the researchers learn from the study. Parent(s)/guardian(s) may gain a better understanding of their children. Professionals working with adolescents with AS may gain a better understanding of how this population views their social interactions and skills in order to create more effective interventions to address self-reported areas of weakness.

RISKS AND DISCOMFORTS

There are no known risks to your child from being in this study. There will be no negative outcomes if you or your child are not interested in participating in this study or if your son or daughter decides to withdrawal from the project at any time.

ALTERNATIVES

The other choice is to not be in this study at all.

PAYMENT

You and your child will be paid a $10.00 Barnes and Noble gift card for being in this study. The gift card will be given after your child you and your child complete the study.

CONFIDENTIALITY

All information and records relating to your and your child's participation will be kept in a locked file. Only the researchers, members of the Institutional Review Board, and the U.S. Food and Drug Administration 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. At the conclusion of the study, the audiotapes from the interview sessions will be destroyed.

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

If health conditions occur that would make staying in the study possibly dangerous to you and your child, or if other conditions occur that would damage you and your child or your and your child's health, the researchers may take you and your child 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 and your child's willingness to stay in this study, you and your child will be told about it.

INJURY

If you and your child are injured as a result of this research study, you and your child will be provided with immediate necessary care.

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

If you believe that you and your child have suffered injury or illness in the course of this research, you should notify the PCOM Research Compliance Specialist at (215) 871-6782. A review by a committee will be arranged to determine if the injury or illness is a result of your and your child's being in this research. You should also contact the PCOM Research Compliance Specialist if you believe that you and your child have not been told enough about the risks, benefits, or other options, or that you and your child are being pressured to stay in this study against your and your child's wishes.

VOLUNTARY PARTICIPATION

You and your child may refuse to be in this study. You and your child voluntary consent(s) to be in this study with the understanding of the known possible effects or hazards that might occur during this study. Not all the possible effects or the study are known.

You and your child may leave this study <u>at any time</u>.

If you and your child decide(s) to leave the study, there are no steps you and your child will need to take for your and your child's health and safety.

If you and your child drop(s) out of this study, there will be no penalty or loss of benefits to which you and your child are entitled.

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

Signature of Subject:_____

Date: _____/_____/_____   Time:_____ AM/PM

Signature of Witness:_____

Date:_____/_____/_____   Time:_____ AM/PM

Signature of Investigator or Designee_____
                    (circle one)

Date:_____/_____/_____   Time:_____ AM/PM

CONSENT FOR AUDIOTAPING

I voluntarily agree to have my child's voice recorded for later transcription as part of this semi-structured interview. I understand that acceptable measures will be taken to ensure my child's anonymity and that upon completion of the transcription the audiotape of my child's conversation will be destroyed. Furthermore, transcriptions of the audiotape will not be in any way be coded as to identify my child with their responses. I understand that my child or myself may, at any time, request that the recording device be turned off or that the interview be terminated completely without penalty.

_____   _____
(Signature)   (Date)

_____   _____
(Witness)   (Date)

Appendix B

Assent Form for Participation in this Study

Investigators: Shawn Dolan, MA (610-529-0644)

Daniel Ingram, PsyD, NCSP (215-871-6947)

I am being asked to help Ms. Dolan and Dr. Ingram in a project. The goal of this project is to better understand how adolescents with Asperger Syndrome understand social competency and how they perceive their social competency skills.

If I decide to participate, my part of the project will involve being interviewed for 1-2 hours over one to two sessions and answer questions relating to this topic. The interview will be audio-taped and used to determine the results of the study. I will also be asked to fill out a questionnaire. In return, I will receive a $10.00 gift certificate to Barnes and Nobles Booksellers for my time and being a part of this project.

This project has been explained to me and I have been allowed to ask questions about the study. I understand that I do not have to answer any questions if I do not feel comfortable. I can also ask questions throughout the interview if I feel that I do not understand something. I can stop from participating in this study at any time. I have read this form and have been given permission from my parent(s)/guardian(s) to participate in this study and agree to participate.

Participant/Date _____

Phone number where I can be reached _____

Researcher/Date _____

ASSENT FOR AUDIOTAPING

I voluntarily agree to have my voice recorded and later transcribed as part of this interview. I understand that acceptable measures will be taken to make sure that all information I share will be kept confidential and the tape will be destroyed after being transcribed. Additionally, transcriptions of the audiotape will not be linked with my name or identifying information. I understand that I may, at any time, request that the recording device be turned off or that the interview be ended completely without punishment.

_____   _____
                (Signature)   (Date)

_____   _____
                (Witness)   (Date)

Appendix C

Demographic Information –Parent Report

1) What is your child's date of birth?   Month _____ Year _____

2) At what age was he/she first diagnosed? _____

3) Is your son or daughter aware of their diagnosis/diagnoses?   ☐ YES   ☐ NO

4) Has he/she been given any other diagnoses?   ☐ YES   ☐ NO
   If so, please note other diagnoses
   _____

   _____

5) Did he/she receive any Early Intervention services?   ☐ YES   ☐ NO
   If so, please check all that apply:
        ☐ Speech and Language Therapy
        ☐ Occupational Therapy
        ☐ Physical Therapy
        ☐ Sensory Integration Therapy
        ☐ Other:
   _____

6) Does your son or daughter have an Individualized Education Plan (IEP)?
   ☐ YES   ☐ NO

7) Does your son or daughter have a 504 Plan?   ☐ YES   ☐ NO

8) If you answered YES to either question 6 or 7, please describe the program
   _____

   _____

9) Does he/she receive any support services through their school? ☐ YES   ☐ NO
   If so, please check all that apply:
        ☐ Speech and Language Therapy
        ☐ Occupational Therapy
        ☐ Physical Therapy
        ☐ Counseling
        ☐ Other:
   _____

10) Does he/she receive any out of school support services?   ☐YES   ☐NO
   If so, please check all that apply:
     ☐Speech and Language Therapy
     ☐ Occupational Therapy
     ☐ Physical Therapy
     ☐Counseling
     ☐ Social Skills Training/Social Groups
     ☐ Other:_____

11) How many friends does your son or daughter have at school? (Please circle)
            0   1-2   3 or more

12) How many friends does your son or daughter have outside of school (Please

   circle)

            0   1-2   3 or more

13) Are any of their friends also diagnosed with an autism spectrum disorder?

     ☐YES   ☐NO

14) Where has your son or daughter made the majority of their friends?
    Please rank only the top three categories:
     __ School
     __ Neighborhood
     __ Sports Team or Recreational Club (i.e. Boy Scouts)
     __ Community Organizations (i.e. YMCA, church group)
     __ Other: _____

15) What are your son or daughter's interests/hobbies (list and rank):

   _____ (   )

   _____ (   )

   _____ (   )

   _____ (   )

Appendix D

Semi-Structured Interview Script

Introductory Remarks

Hello. I want to thank you for taking the time to sit down with me today and answer some questions. I am interested in hearing about how you think about your interactions with other people, both adults and other adolescents. I will be asking you a number of questions about social competency. For the purpose of this study, social competency will be defined as the ability to have positive interactions with other people, particularly peers. The interview will take approximately 1-2 hours and I will be audio-taping this interview so I can write out the interview at a later date to better understand your thoughts, feelings and views on this topic. When possible, tell me as much information as you can so I can better understand your experience. Remember, if you want to stop the interview at any time, please let me know. Do you have any questions before begin?

Interview Questions

1) Can you think of someone you know that gets along well with other people? Can you tell me about that person? Why do you think they get along well with others?
2) Tell me about how you are like that person?
3) Tell me about how you are different from that person?
4) Tell me about how you get along with your friends and classmates?
5) Tell me about what your parents might say about your interactions with friends/classmates?
6) Tell me about what your teachers might say about your interactions with friends/classmates?
7) What else do you want to tell me?

Clarifying questions
What do you mean by _____?
Tell me more about _____.
Can you give me an example of _____?
Can you tell me about a time when _____?

Now I have a brief questionnaire that I will ask you to complete. Please take your time in answering the questions. Feel free to ask me if you have any questions or need anything explained.

Closing Remarks

Thank you very much for taking the time to speak with me. The information that you shared will be very helpful as I try to understand about how adolescents, like you, think about their social interactions skills or how they interact with others. I hope that you enjoy your Barnes and Nobles gift card and thank you again for you participation.

Appendix E

Demographic Information-Adolescent Report

1) Age (circle): 10   11   12   13   14   15   16   17

2) Grade (circle): 4   5   6   7   8   9   10   11   12

3) Interests/Hobbies (list and rank):

_____ (   )

_____ (   )

_____ (   )

_____ (   )

4) How many friends do you have at school? (Please circle only one answer)

0   1-2   3 or more

5) How many friends do you have outside of school? (Please circle only one answer)

0   1-2   3 or more

6) Do you have a best friend?   ☐ YES   ☐ NO

7) What is your favorite part of school? (Please check only one answer):
☐ Class (Language Arts, Math, Science, Social Studies)
☐ Recess
☐ Lunch
☐ Computers
☐ Gym
☐ Art
☐ Music
☐ Foreign Language
☐ Other: _____

8) What is your least favorite part of school?
       ☐ Class (Language Arts, Math, Science, Social Studies)
       ☐ Recess
       ☐ Lunch
       ☐ Computers
       ☐ Gym
       ☐ Art
       ☐ Music
       ☐ Foreign Language
       ☐ Other: _____

9) Are you involved in any clubs/teams/groups?   ☐ YES   ☐ NO

10) If you answered YES to number 8, what clubs/teams/groups are you involved in?

    _____

    _____

    _____

    _____

    _____

Appendix F

List of Counseling Referrals

PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE

REFERRAL LIST

PCOM Center for Brief Therapy (4190 City Avenue, Philadelphia)

(215) 871-6487

Anxiety and Agoraphobia Treatment Center (112 Bala Avenue, Philadelphia)

(610) 667-6490

Beck Institute (GSB Building, City Line and Belmont Avenue, Suite 700, Philadelphia)

(610) 664-3020

University of Pennsylvania Mood and Anxiety Disorders Section (36th and Market Street, Philadelphia)

(215) 898-4301

You can access additional referrals for treatment in your area by callings the American Psychological Association's referral line at 1 800-964-2000, or the Pennsylvania Psychological Association at 717-232-3817 (www.PaPsy.org) or American Psychiatric Association at 202-682-6000.

Appendix G

Demographic Finding

Adolescent Report

Name	Gender	Age	Grade	# of friends	# of friends outside of school	Best Friend	Interests
Adam	M	14	8	1-2	1-2	Yes	guitar, nature, family, fun
Bart	M	10	5	3 or more	1-2	No	video games, help with cooking, reading
Bob	M	13	8	1-2	1-2	Yes	legos, karate
Charlie	M	14	9	3 or more	1-2	No	football, weightlifting, hunting, fishing
Dan	M	12	6	3 or more	3 or more	undecided	science, bugs, mythology, animals
Ed	M	11	5	1-2	3 or more	Yes	video games, building, computer, TV
Fran	F	11	5	2	1		horses, 4-H, basketball
George	M	13	7	3 or more	3 or more	Yes	video games, basketball, football
Henry	M	14	8	3	3	Yes	video games, park, YMCA, beach
Ian	M	16	10	3 or more	1-2	Yes	helping people, video games, animals, The World
Jazelle	F	10	4	3 or more	3 or more	Yes	swimming, reading,gymnastics, singing
Ken	M	10	4	3 or more	1-2	Yes	fishing, Wii, computer, legos
Laura	F	16	10	3 or more	3 or more	Yes	music, reading, friends, drama
Mike	M	16	10	3 or more	3 or more	Yes	skateboarding, video games, friends, listening to music

* underlined items indicate that parents reported that same interests (57% agreement overall)

Name	Favorite part of school	Least favorite part of school	Member of clubs, teams, groups, etc.
Adam	lunch, gym, music, interaction with best friend	class and boredom	guitar club, wrestling
Bart	computers	class (math)	No
Bob	class	computers	game club, gifted program, ski club
Charlie	lunch	class	football
Dan	class	gym	math, chorus, chess, walking club
Ed	recess	class (social studies)	Astromech builders
Fran	gym	computer, class (math & social studies)	4H horse club, basketball team
George	class	computers	No
Henry	class, lunch, computers, art, tech ed.	music, foreign language	game club, 4H, karate, PVTV
Ian	being around others	math	stage crew (musical)
Jazelle	art	gym	soccer, swimming, gymnastics
Ken	recess, computer, gym	class, art, music, Spanish	No
Laura	class	live classes	drama team, singing group, pipe band
Mike	computers	class	youth group, drama club

Appendix H

Demographic Finding

Parent Report

Name	Age at dx.	Other diagnoses	EI services	IEP (describe)	School supports
Adam	11	Mood dx., ADHD, sibling relational problem	No	Help with school work, addt'l time of needed	OT, counseling
Bart	9	No	S&L, OT	Yes	S&L, OT
Bob	10	No	No	PT emotional support daily	counseling, social skills
Charlie	3	No	S&L	Itinerant S&L, autism coach	autism coach twice a week
Dan	8	No	No	OT, emotional support, gifted	OT, social skills
Ed	8.5	ADHD	No	S&L, OT	S&L, OT
Fran	7	Not yet	No	mininal svcs., going through IEE to redo IEP	Learning Support
George	5	Anxiety disorder	S&L	1:1 aide, extra time for tests, support	S&L
Henry	11	No	No	svcs. have changed a lot, less need for OT and S&L	behavior specialist, recently dropped OT
Ian	9-10	ADHD	S&L, OT	mainstream with emotional support class	counseling
Jazelle	3	NVLD	S&L, OT, PT	Private school, individualized to strengths and needs	S&L, OT, accommodations
Ken	5	ADHD	S&L, OT	S&L, OT, modifications	S&L, OT , counseling
Laura	14	ADD, OCD, Tourettes	No	Yes	Counseling, school support
Mike	14	ADHD, school phobia	No	Yes	Counseling, school support

Name	Supports outside of school	Friends at school	Friends outside of school	Friends on spectrum	Majority of friends
Adam	BSC, psychiatrist	1-2	1-2	No	school and church
Bart	No	3 or more	1-2	No	school
Bob	counseling	3 or more	1-2	Yes	school
Charlie	No	1-2	0	No	school & teams
Dan	counseling	3 or more	3 or more	Yes	school, recreational club, camp
Ed	No	3 or more	3 or more	No	school, neighborhood, family, friends
Fran	counseling, social skills, wrap svcs.	1-2	1-2	No	4H
George	social skills & family therapy in past	1-2	1-2	No	school
Henry	No	1-2	0	Yes	school
Ian	No	1-2	1-2		school, recreational club, community organization
Jazelle	OT, counseling, social skills	3 or more	3 or more	Yes	school, recreational club, community organization
Ken	social skills, private ABA at home	1-2	1-2	Yes	school, social skills
Laura	No	1-2	3 or more	Yes	community organization
Mike	counseling	1-2	3 or more	Yes	community organization