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Adolescent Females with High-Functioning ASD: Self and Mothers' Perspectives of Their

School and Social Experiences

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
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ABSTRACT

Although the prevalence of Autism Spectrum Disorder (ASD) is currently 1 in 68 (Centers for Disease Control, 2015) and research in this area is growing, high-functioning individuals on the spectrum are often overlooked. This is because of their relatively milder symptoms. The recent collapse of Asperger Syndrome (AS) with autism in the most recent version of the Diagnostic and Statistical Manual (DSM-5; APA, 2013) also has obscured the differences that may exist between those with higher vs. lower levels of functioning. Among youth with High-Functioning Autism Spectrum Disorder (HFASD), girls are a particularly understudied and potentially vulnerable group. Previous research has suggested that girls with HFASD may be more affected by their differences from typically developing peers during adolescence than are boys (Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). Other recent findings suggest that girls with HFASD receive less support than boys with HFASD in school (May, Cornish, & Rinehart, 2014). The purpose of this study was to explore the social and school experiences of adolescent females with HFASD from both the girls' and their mothers' perspectives.

The results of the study yielded six themes that emerged from the interviews with four adolescent girls with HFASD and their mothers. Four of the themes were voiced by both the girls and their mothers. Specifically, they both discussed the girls' high levels of interest in imaginary characters, experiences with teachers and peers at school who did not understand them, the need for kind and flexible teachers, and the girls' reluctance to initiate in social interactions. Mothers also discussed two themes that were not mentioned by the girls. All of the mothers expressed

frustration with motivating their daughters in activities unrelated to their interests and described their role as their daughters' protectors. These ideas were not mentioned by the girls. Although results are not expected to generalize to all females with HFASD, the current study adds to the scant literature on this population and offers some insight into the experiences that these girls may face during adolescence.

CHAPTER I: Introduction

Historical Context

Currently, the prevalence of autism spectrum disorders (ASD) is approximately 1 in 68 (Centers for Disease Control, 2015). Although the epidemiology research of high-functioning autism (HFA) is limited, some researchers have proposed that as many as one quarter to one third of ASD diagnoses were classified as Asperger Syndrome (AS) prior to the recent collapse of ASD for diagnostic purposes (Fombonne, 2009). These statistics suggest a strong need for understanding a high-functioning autism population, which has the possibility of becoming overlooked since the release of the Diagnostic and Statistical Manual-5 (DSM-5; APA, 2013).

AS was a condition that was originally reported by Austrian pediatrician, Hans Asperger (1944), who described the syndrome as "autistic psychopathy" (Frith, 1991). This syndrome had been called Asperger Syndrome since Lorna Wing coined the term in 1981 (Wing, 1981). Individuals with AS are considered to have the least severe characteristics of ASD (Whitehouse, Durkin, Jaquet, & Ziatas, 2009). Still, this disorder often results in compromised social functioning and unique behaviors or interests that greatly impair daily functioning. Unlike Autistic Disorder, the syndrome does not include "significant delays or deviance in language acquisition" (American Psychiatric Association, 2000). However, the difference between AS and HFA is questionable (Sanders, 2009). High-functioning autism is a term that appears in the literature and most often refers to individuals who fall under the autism category and possess an IQ above 70, or closer to average cognitive skills (Sanders, 2009). The definition and actual diagnostic criteria of AS according to the DSM-IV-TR (2000) are discussed later in this chapter.

In recent years, there has been controversy surrounding the diagnosis of AS and the possibility of it being consumed under the broader term of ASD in the DSM-5 (Ghaziuddin, 2010; Kaland, 2011). While some researchers suggested that differences existed between AS and HFA, others claimed that the diagnosis of AS was being used inconsistently with the AS criteria in the DSM-IV-TR (Church, Alisanski, & Amanulla, 2000; Tryon, Mayes, Rhodes, & Waldo, 2006). Ghaziuddin (2010) argued for the preservation of AS diagnostic criteria by stating its utility in distinguishing the milder qualitative impairments of the disorder compared to those associated with classic autism in regard to social impairment, idiosyncratic interests, communication style, and age of onset. One of his earlier studies provided evidence for his argument and included 58 participants with AS and 39 participants with autism to examine the qualitative difference in social behavior between the two disorders (Ghaziuddin, 2008). He discovered that 79% of the participants with AS were more likely than the individuals with autism to initiate a social interaction, but they displayed socially inappropriate verbal communication. On the other hand, 82% of the participants with autism were described as acting indifferent in social situations or only briefly responding to questions when asked. Despite such evidence, questioning of the validity of the AS diagnosis persisted due to its strong similarity to HFA (Mayes, Calhoun, & Crites, 2001; Sanders, 2009). The current study allowed for the inclusion of participants having a diagnosis of AS under previous diagnostic criteria.

It has been suggested by psychologist Tony Attwood, who has written extensively about AS, that interventions may work similarly for individuals with AS and HFA (Attwood, 2007). He states that this population will benefit from prevention and intervention strategies that are specifically designed for them, rather than for individuals with autism (Attwood, 2007). Thus, it was my intent to explore specifically females within this subgroup, including individuals with

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AS or HFA, in order to provide more depth to the current research, which should ultimately guide future interventions.

Definition of Asperger Syndrome

The Diagnostic and Statistical Manual of Mental Disorders-4th Edition (DSM-IV; American Psychiatric Association, 1994) began to include AS in 1994. In the DSM-IV-TR, there existed six domains of AS criteria for diagnosis (APA, 2000, p. 84). The domains were as follows:

1) Qualitative impairment in social interaction

2) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities

3) Disturbance causes clinically significant impairments in social, occupational, or other areas of functioning

4) No clinically significant general delay in language

5) No clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior, and curiosity about the environment in childhood

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

Adolescent Females with AS

The current prevalence rate for males with ASD compared to females with ASD is 5:1 (Centers for Disease Control, 2015). The ratio of referrals for females versus males with AS has been documented as 10:1 and this number has been considered an underestimate compared to the gender ratios for individuals with AS (Attwood, 2006). Some of this recognition failure may be partially due to previous diagnostic criteria (Attwood, 2006). Controversy existed over whether

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or not the DSM-IV-TR overlooks autism in girls, and some researchers expressed concerns about this shortcoming of the diagnostic criteria in the DSM-V (Wing, Gould, & Gillberg, 2011). Research suggests that females with ASD exhibit less restricted behaviors and interests than boys with ASD and have significantly more internalizing symptoms (Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). Also, some females with ASD exhibit more severe cognitive impairment in the areas of executive functioning and visual-spatial processing than males on the autism spectrum (Nydén, Hjelmquist, & Gillberg, 2000). The trajectory of social impairment for females with HFASD can look different compared to males with the disorder. Ultimately, the diagnosis among females impacts the attention and support they need within various environments, including the educational system.

Definition of ASD

The Diagnostic and Statistical Manual-V (DSM-V; APA, 2013) now encompasses AS with other past ASD diagnoses under one label. The four domains that frame the criteria for the current diagnosis of ASD are as follows:

1) Persistent deficits in social communication and social interaction across settings, not caused by general developmental delays

2) Restricted, repetitive patterns of behavior, interests, or activities

3) Symptoms present in early childhood, even though they may not become fully manifest prior to social domains later in life

4) Symptoms must limit and impair daily functioning

Based on the literature of youth with ASD, it is assumed that adolescent females within this population would struggle more than adolescent males with ASD. During a time in life when socialization becomes more complex and necessary for success in school, research

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indicates that adolescent females with high functioning autism tend to exhibit greater social impairment than adolescent males with high functioning autism (McLennan, Lord, & Schopler, 1993; Solomon et al., 2012). These females are also more likely to experience comorbid psychopathology compared to males with high functioning autism (Holtmann, Bölte, & Poustka, 2007). All of these challenges can affect how well adolescents perform at school both socially and academically. Knowing more about the unique experiences of this population will ultimately lead to better ways to support their education.

Problem Statement

To date, there has been minimal research concerning girls with ASD in general (Solomon et al., 2012). The problem that this study sought to address was the limited information available regarding the school and social experiences of adolescent females on the higher functioning end of the autism spectrum. The current literature is still lacking in information on how to best serve this population within the realm of education. One might suppose that this level of neglect is due to low diagnostic rates of females with ASD, which may underestimate the actual prevalence rate (Attwood, 2006). The discrepancy between the prevalence rate and referrals of females within this population may be a result of inappropriate diagnostic criteria of ASD for females (Wing et al., 2011). It is only through further research with females with HFA that the reliability and validity of these criteria may improve.

Purpose and Research Questions

There is currently limited research on adolescent girls diagnosed with high-functioning ASD. The current study was one of the first to investigate this by exploring this population's experiences from the perspectives of the girls themselves and their mothers. The purpose of gathering data from multiple sources was to provide the researcher a well-rounded view of the

school and social experiences for adolescent girls with AS. I hoped to draw attention to this particular subject area and gather findings that would lead to future research pertaining to prevention and intervention for this population that could be provided within the educational system.

Research Questions:

1. How do adolescent females with HFASD and their mothers describe what day-to-day life is like for them?

2. What do these girls see as their strengths and challenges?

3. How do they describe their social relationships?

4. How do they describe what school is like for them?

5. What are the best and worst aspects of school for them?

6. How do mothers of girls with HFASD respond to the questions above?

7. What is the degree of similarity between how girls with HFASD and their mothers describe their day-to-day lives, including social relationships and school experiences?

Definition of Terms

Adolescent/Teenager. A person between 12 and 19 years of age.

Asperger Syndrome (AS). A pervasive developmental disorder as defined in the DSM-IV-TR (American Psychiatric Association, 2000).

Autism. A pervasive developmental disorder as defined in the DSM-IV-TR (American Psychiatric Association, 2000).

Autism spectrum disorder (ASD). Prior to the release of the DSM-V, a disorder classified as autism, high functioning autism (HFA), Asperger Syndrome (AS), and Pervasive

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Developmental Disorder-Not Otherwise Specified (PDD-NOS). The DSM-V subsumes all three diagnoses under ASD.

High-functioning autism (HFA). Prior to the release of the DSM-V, individuals on the autism spectrum who are assumed to have a cognitive ability standard score over 70 (Tsatsanis, 2004). For the current study, autism spectrum disorder as defined by the DSM-V and lacking any known significant impairment in intelligence and expressive language.

High-functioning autism spectrum disorder (HFASD). A disorder recognized on the autism spectrum that is associated with typical language and a cognitive score that falls either in or above the borderline range of functioning (Volker, 2012).

Parent. A biological parent or legal guardian.

Scope

This study included four adolescent females with a formal diagnosis of ASD. All participants were between 12 and 19 years of age. The study also targeted the mother of each adolescent participant with ASD. The research included participants residing in two different Southeastern states in the U.S.

Significance of the Study

Research studies have shown the number of children diagnosed with ASD steadily increasing (Kogan et al., 2009). This escalating prevalence rate entails greater need for educational services specifically designed for this population. To date, there is little research pertaining both to how to best serve these students in education and females with high-functioning ASD. In order to effectively educate these students, more research needs to be conducted in order to fill this gap in the literature and gain insight into their school experiences. This study contributed to the current literature by exploring perspectives of adolescent females

with high-functioning ASD and the views of their parents concerning this population's school and social experiences.

CHAPTER II: Literature Review

The information considered in this review will first encompass autism, HFA, and AS, along with their associated characteristics, which were a critical part of the inclusion criteria for the current research and are necessary in understanding the population that was under study. The areas of what was already known about the common characteristics of individuals with ASD, their social experiences, the effects of their social skill impairments, comorbid disorders associated with ASD, and gender differences in the population. The review concludes with an in-depth overview of the limited studies that focus on females with HFASD and the few studies that have examined the school experiences of students with HFASD.

Autism

Autism is a term that was first introduced by Leo Kanner in 1943 when he observed 11 children exhibiting social impairment, repetitive and obsessive behaviors, and echolalia (Kanner, 1943). Although initially deemed similar to childhood schizophrenia, the individuals he referred to demonstrated impairment in socialization and cognitive skills beginning at birth and the amount of social reciprocity in their communications with other people was impaired. The Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR; American Psychiatric Association, 1994) describes autism as a disorder associated with deficits in socialization, communication, and restricted repetitive or stereotyped interests or behaviors. High-functioning autism refers to individuals who fall under the autism category and possess an IQ above 70, or closer to average cognitive skills (Sanders, 2009).

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Asperger Syndrome

According to the DSM-IV-TR, AS was a similar pervasive developmental disorder that was described by social impairments, restricted patterns of behavior or interests, and a lack of language or cognitive delays. AS was a condition that was reported by an Austrian pediatrician named Hans Asperger (1944), who described each individual with the disorder as an "absent-minded professor," which referred to the intensity of their special interests and lack of skills in social environments (Frith, 1991). Asperger noted the disadvantages of their disorder, such as lack of social reciprocity, abnormal speech, and obsessions with objects, as well as potential strengths, including mathematical skills (Frith, 1991).

In 2013, the most recent diagnostic statistical manual (DSM-V; APA, 2013) was published and consumed AS under Autism Spectrum Disorder (ASD). Until recently, much debate surrounded the AS label and whether or not it should be its own disorder in the DSM-V versus being collapsed with autism (Ghaziuddin, 2010; Kaland, 2011). Some researchers maintained that differences exist between AS and HFA (Church, Alisanski, & Amanulla, 2000). On the other hand, other researchers argued for its deletion due to the inconsistent use of DSM-IV-TR criteria for AS (Tryon et al., 2006). Additionally, the validity of AS was questioned due its strong similarity to HFA (Mayes, Calhoun, & Crites, 2001; Sanders, 2009). The current study included female participants with a diagnosis of ASD and without any known intellectual impairments. This allowed the recruitment of individuals who may have been diagnosed with AS or autism as defined under previous or current diagnostic criteria.

Common Characteristics of Individuals with ASD

Theory of mind. Theory of mind is defined as the process of accrediting a mental state to other people (Premack & Woodruff, 1987). Several studies have discovered impairment in

theory of mind for individuals with ASD (Begeer, Bernstein, Wijhe, Scheeren, & Koot, 2012; Demurie, de Corel, & Roeyers, 2011; Spek, Scholte, & Van Berckelaer-Onnes, 2010). The following reviews a few studies relating to how theory of mind is impacted by individuals with ASD.

In comparison to typically developing adolescents and adolescents with ADHD, a study found that adolescents with ASD performed the lowest on mind-reading measures (Demurie et al., 2011). Nineteen adolescents with ASD, 16 adolescents with ADHD, and 18 typically developing adolescents participated in the study and they all ranged in age from 11 to 17 years old. The individuals with ASD and ADHD were recruited from a university psychiatry department and a special school in Ghent, Belgium. There were not any significant differences between the three groups in terms of IQ. The researchers first administered the empathetic accuracy task (Marangoni et al., 1995; Roeyers, Buysse, Ponnet, & Pichal, 2001), where the participants were expected to watch a video and individually write down the thoughts and emotions of the characters at certain intervals. Participants were also administered the "Reading the Mind in the Eyes" Test (Baron-Cohen, Wheelwright, Spong et al., 2001), in which they were asked to choose a mental state term that best illustrated what a person in a photo was thinking or feeling. They were given four options and were also expected to complete a control task, where they tried to identify the person's gender in the picture. Participants completed these tasks for 28 pictures that displayed only the eyes of individual human faces. Next, both the participants and their parents completed a self-report questionnaire, called the Interpersonal Reactivity Index (IRI; Davis, 1983), which measures empathy. The IRI contains a Perspective Taking subscale (propensity to see another person's viewpoint), Empathetic Concern subscale (tendency to feel warmth and compassion for others), Personal Distress subscale (how much others' emotions

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increase one's own level of discomfort), and Fantasy subscale (predisposition to personally feel the actions and emotions of fiction characters). As hypothesized, adolescents with ASD performed the poorest on all of the mind-reading measures administered and obtained the lowest scores on the IRI. Their scores were significantly higher for the Perspective Taking subscale and significantly lower for Personal Distress subscale on the IRI for self-report, compared to their parents' ratings. However, adolescents with ASD on average, self-reported lower IRI scores than the adolescents with ADHD or typical development. Thus, there is reason to believe that they possessed some insight into their communication deficits. On the empathetic accuracy task, it was discovered that adolescents with ASD earned significantly higher scores as their age increased. Future researchers may seek to discover how some of the participants with ASD were able to infer the feelings of the characters in the video for the empathetic accuracy task, while others performed poorly on this task.

In a recent study, Begeer and colleagues (Begeer et al., 2012) were the first researchers to investigate the use of a continuous false belief task, "Sandbox", in children and adolescents diagnosed with HFASD and in an age-matched group of individuals with typical development. Individuals with HFASD frequently perform similarly to typically developing children on classic false belief tasks when they reach approximately 12 years old. Studies that have used advanced theory of mind tasks have not provided consistent results. Also, unlike other measures of false belief difficulties, this particular measure was used to permit responses on a continuum. Therefore, the researchers used the Sandbox task and hypothesized that participants within the HFASD group would score lower on the measure than the comparison group. The sample consisted of 62 children and adolescents in each group, ranging from six to twenty years old. The researchers recruited the participants with HFASD from the Netherlands, specifically, in an

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institution specialized in education for children with autism. The participants with typical development were recruited from primary and high schools in the Netherlands. An experimenter who was uninformed of the experiment's hypotheses presented the Sandbox task by using pictures on a piece of paper and reading a story about a father and his daughter planting flower bulbs in a sandbox. In the false belief condition, the story mentioned that while the father was away, the daughter moved the flower bulb and buried it in a different location within the sandbox. The no false belief condition differed when it was stated that the daughter buried a stone in a different location without moving the flower bulb. Following the interviewer reading the story and asking if the participants had taken a "good look" at the pictures, the paper was flipped over and second part of the story asked where the father would water the flower bulb when he returned. Then the participants were told to draw one cross on the spot they believed was the correct location. Next, the participants were read five mental state stories as part of an advanced theory of mind task. As expected, results indicated that the Sandbox task was a better indicator of individuals with and without HFASD than the advanced Theory of Mind task. Participants with HFASD were more likely to give an egocentric response on the Sandbox task than the participants with typical development. Whereas results from the advanced Theory of Mind task indicated that both groups' performance increased with age, the Sandbox task did not indicate this increase within either group. There was no relation found between participants' IQ and their theory of mind skills. Thus, the researchers suggested that the Sandbox task is a more sensitive measure that can assess the subtle skills of Theory of Mind.

Spek and colleagues (2010) conducted a study in the Netherlands that suggested theory of mind was also impaired within a population of adults between the ages of 18 and 60 years old with HFASD (Spek et al., 2010). They recruited 32 adults with HFA and 29 adults with AS

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from mental health institutions and only allowed individuals without genetic conditions or other medical conditions (e.g., Tourette syndrome) to participate in their study. All participants also were required to have at least an average full-scale intelligence score and verbal intelligence score, which were assessed by the WAIS-III (Wechsler 1997). The neurotypical control group consisted of 32 participants who were recruited from local newspapers and word of mouth. The control individuals were excluded if they had a psychiatric illness or if any of their family members were known to have autism. Parents of the participants were administered the Autism Diagnostic Interview, Revised (ADI-R, Lord et al., 1994), which helped collect developmental information. The researchers also used a semi-structured interview and observations to assess the participants according to DSM-IV-TR criteria for ASD (American Psychiatric Association (APA), 2000). In order to differentiate between autism and AS, they asked further questions based on criteria of Gillberg and Gillberg (1989) and ICD-10 (World Health Organization, 1993). Theory of mind was assessed using three neuropsychological tests and a survey, which were administered to participants individually. The revised version of the Eyes test (Baron-Cohen et al., 2001) consisted of 36 pictures of male and female eye regions and participants were required to choose among four words the best description of each person's thoughts or feelings. The Strange stories test (Happé, 1994) was also administered to the participants and they were read eight stories that involved characters saying things that they did not literally mean. The participants were questioned about the intentions of the characters. The researchers asked the participants to listen and read four more stories that were involved with the Faux-pas test, where two stories contained a faux-pas and two stories did not have a faux-pas (Stone, Baron-Cohen, & Knight, 1998). For each story, the adults were asked whether or not a character in the story said something awkward and if so, they were to answer questions about who said it, what was said

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that was awkward, was there a misconception, and how the character(s) felt. The Empathy Quotient (EQ) questionnaire was also administered to the participants (Baron-Cohen & Wheelwright, 2004). The EQ measured empathy as it related to the skill of recognizing one's own mental state and others' feelings, as well as the ability to demonstrate appropriate emotions. Results from all of the theory of mind tests, except for the Eyes test, indicated that the participants with HFA and AS experienced more difficulties with theory of mind than the participants with neurotypical development. Medium to significant correlations were discovered between the EQ and the Strange stories test, as well as the EQ and the Faux-pas test. Correlations among these three theory of mind tests revealed that the participants on the autism spectrum possessed the ability to identify their own theory of mind skills. Generalization for the results was limited to adults on the autism spectrum with at minimum average verbal intelligence scores. However, the study indicated the EQ may be utilized to help with diagnosis and intervention in a similar population of individuals with HFA or AS.

Comprehension of humor. A group of researchers (Emerich, Creaghead, Grether, Murray, & Grasha, 2003) sought out to discover when compared to typical adolescents, how well adolescents with AS or HFA could comprehend humor. A small sample of eight adolescents (5 males and 3 females) with AS or HFA were recruited from the Autism Society of Cincinnati, as well as from cases of speech-language pathologists in public schools and private practices. Eight more adolescents were recruited from the general population and their development was typical. All participants were individually asked to choose among five humorous endings after either hearing or reading 10 jokes and ten cartoons. If the participants chose to read the body of the jokes or cartoons with their endings, then they were asked to read aloud in order to help the examiner correct any mistakes if they misread. Results showed that the adolescents with autism

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performed significantly poorer than typically developing adolescents when they were presented the joke task, which was the most abstract out of the two tests. They tended to choose the endings that were not related to the story, but were both surprising and humorous. The researchers postulated that these errors were due to impairment in cognitive flexibility. Even though the difference between the two sample groups was not significant for the cartoon tasks, the adolescents with autism tended to choose the straightforward endings on these activities, which were neither surprising nor humorous. These findings overall suggested that they could comprehend surprise and coherence in choosing humorous endings, but they struggled with selecting an ending that included both of these elements. However, generalizing these results would be difficult, given the small sample size and there was much variability among the adolescents with autism. Their poorer performance may have been due to sensing pressure while in the presence of the examiner. Also, IQ was not a controlled variable in this study, which may have contributed to the results.

  Conversation/language. In a study that was conducted in order to examine the conversational difficulties in 29 adolescents with AS and HFA/PDD-NOS compared to 26 adolescents with typical development, youth between 12 and 18 years of age were selected from a database at the Yale Child Study Center (Paul, Orlovski, Marcinko, & Volkmar, 2009). The youth were determined for eligibility based on Verbal IQ scores above 70 and an ASD diagnosis via the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994), as well as the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000).   HFA and PDD-NOS classifications were both identified as one group compared to AS because there was not an overall significant difference between their verbal IQ scores. These two groups were compared to typically development adolescents and the vast majority of the sample consisted of males.

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The ADOS was administered to all three groups in order to examine their conversational strengths and weaknesses. The Pragmatic Rating Scale (PRS; Landa, Piven, Wzorek, Gayle, Chase, & Folstein, 1992) used ADOS videotapes to code normal versus inappropriate conversational behaviors. The results showed that participants within the ASD group exhibited intonation and gaze abnormalities. Additionally, adolescents with ASD struggled with the ability to discuss topics that were relevant to their partners' interests or the current topic being discussed, provide the appropriate type and amount of information based on what the listener requested, and maintain verbal and nonverbal reciprocity. When the researchers examined differences within the ASD group, the only significant differences between the two groups was that the participants with AS were more likely to use language that was overly formal, and the HFA/PDD-NOS group was more likely to exhibit gaze abnormalities. These findings indicated that conversational deficits were common among students with AS and HFA/PDD-NOS, but they were inconsistent and did not appear throughout the entire ADOS administration. This level of inconsistency suggests that individuals with AS or HFA/PDD-NOS have conversational strengths that can be capitalized on during interventions. Future research could examine the same research questions with various methods of data collection, such as classroom observations and teacher rating scales. Also, a larger sample of female adolescents with typical development and under the autism spectrum would help generalize the results toward a broader population.

Circumscribed interests. In a study where the researchers examined various repetitive behaviors in individuals with high-functioning ASD and determined the differences in repetitive behaviors between AS and HFA, participants were recruited from the Child and Adolescent Specialty Clinics at the University of Utah Health Sciences Center, a database that had previously been used for research participants, and from the surrounding community (South,

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Ozonoff, & McMahon, 2005). Autism and AS were diagnosed using DSM-IV-TR criteria and information gathered from parent interviews. The parents were those of 61 child and adolescent participants, including 21 diagnosed with HFA, 19 with AS, and 21 typically developing controls. This sample was comprised of 45 males and 16 females between the ages of 8 and 20. The parents were questioned about their child's repetitive behavior and other functional impairments using the Repetitive Behavior Interview (*RBI*; Turner, 1997) and the Yale Special Interests Interview (*YSII*; South, Klin, & Ozonoff, 1999). The RBI contained questions concerning 50 various repetitive behaviors and asked for specific examples of the behaviors that had been observed. Raters then assigned the observed behaviors into one of four categories: Motor Movements, Object Use, Rigid Routines, and Other Repetitive Behaviors. The fourth category was comprised of behaviors that were not associated with DSM-IV criteria, such as tics, compulsions, and self-injurious behaviors. The YSII contained questions concerning the circumscribed interests of the participants. When compared to other repetitive behaviors that tended to decrease with age (i.e., Object Use, Motor Movements, and Rigid Routines), the severity of circumscribed interests in individuals with AS and HFA tended to increase over time. Parents indicated that their children's repetitive behavior, such as repeatedly discussing a single subject or demonstrating inflexibility to family schedules were aspects of their child's disorder that they felt the most challenged by on a daily basis. Despite the authors' hypothesis that the participants in the AS group would have more circumscribed interests, parents of the children in the HFA group reported similar numbers of circumscribed interests and the differences between the two groups seemed to disappear over time. The only significant difference between the AS and HS group was the higher lifetime severity of Object Use and Rigid Routines for the HFA group. These results imply that differentiating HFA and AS diagnoses may not be useful for

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clinicians in terms of repetitive behaviors. These results should be used with caution since not all autism symptoms were examined in this study and thus, the external validity of AS may be established by exploring other domains.

Self-awareness of ASD characteristics. As part of a larger study that studied the prognosis of males with AS, Cederlund and colleagues examined how much this population comprehends some of the characteristics associated with their diagnosis and how similar their understanding is to that of their parents (Cederlund, Hagberg, & Gillberg, 2010). The researchers recruited participants at the Child Neuropsychiatric Clinic (CNC) in Göteborg, Sweden after reviewing their medical records at the clinic. In order for consideration as a participant, the patients at the clinic were required to be males, possess a clinical diagnosis of AS, have an IQ equal to or above 70, be at least 16 years of age, and follow-up with the researchers within five years or later. The researchers administered the sample of 76 participants and their parents separately seven items from the Asperger Syndrome Diagnostic Interview (ASDI; Gillberg, Gillberg, Rastam, & Wentz, 2001), which involved questions concerning difficulties with social interaction, narrow interests, and routines/rituals. The participants and their parents also completed The Leiter-R-Questionnaires, which yielded information about the participants' skills in the cognitive, social, emotional, and adaptive domains (Roid & Miller, 1997). The researchers administered only the males with AS the Beck Depression Inventory (BDI; Beck & Steer, 1996) in order to measure their amount of depression and the Dysexecutive Syndrome Questionnaire (DEX; Wilson, Alderman, Burgess, Emslie, & Edwards, 1999) to assess their behavior, cognition, personality, and motivation. The Wechsler Adult Intelligence Scale-Third Edition (WAIS-III; Wechsler, 2003) and the DSM-IV Global Assessment of Functioning (GAF; APA, 1994) scale were used to evaluate the participants on inclusion criteria.

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In general, the participants exhibited high self-awareness of their own personal relation to characteristics of AS through self-report ratings that matched similar ratings from their parents. On the other hand, the males in the study reported significantly lower scores than their parents for problems related to peer interaction, social cues, and narrow interests. The BDI predicted all except one of the individuals who possessed a clinical diagnosis of depression, which comprised a small portion of the sample. Also, comparing their data to results from previous studies, the researchers discovered that the males with AS were just as likely to have dyexecutive problems (i.e., daily living skills) as individuals with traumatic brain injury or schizophrenia. Some limitations included the possible bias of the self-assessment portion of the study and the concrete thinking of the participants that may have influenced their answers on the questionnaires. Also, the participants had previously attended a clinic in Sweden and the results may not generalize to male or female individuals with AS in other parts of the world. Varying methods and locations of recruitment and gathering data concerning females with AS should be added to future studies. Still, this study indicates that males with AS have some insight into their difficulties associated with their diagnosis and this may lead to effective designs of educational programs for these individuals.

Social Experiences of Individuals with ASD

Solomon and colleagues (Solomon, Buaminger, & Rogers, 2011) investigated the relationship between abstract reasoning and social functioning in preadolescents with HFASD. They defined abstract reasoning as a component of executive functioning, which involved identifying and forming concepts. Identifying concepts (concept identification) referred to the ability to acknowledge categories of concepts and forming concepts (concept formation) included the initiation of forming schemas in order to organize information. The researchers

investigated these abilities in relation to social behavior. The participants included 20 Israeli children with HFASD and 22 children with typical development. Both groups were between 8 and 12 years old. Each participant with HFASD was required to have a prior clinical diagnosis of autism or AS, verification of this diagnosis by the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994), receptive language scores of at least 80 as determined by the Peabody Picture Vocabulary Test Third Edition (PPVT-III; Dunn & Dunn, 1997), normative reading comprehension levels according to a reading subtest of the Ma'akav (Shany et al., 2003), and a close friend that they had for at least 6 months. Participants of the HFASD group and participants of the typically developing group were matched for maternal education, age, and gender. Both groups participated in the study with a close friend and were videotaped for 40 minutes in a laboratory setting. Each dyad participated in a noncompetitive construction game, where they were expected to jointly construct a marble maze. They also were asked to draw a design together with a box of colored markers and a blank sheet of paper. These two activities were counterbalanced. In order to measure their social functioning, the researchers used the Dyadic Relationships Q-Set (DRQ; Park & Waters, 1989), which contained 55 items that comprised seven dyadic dimensions and used it to code the behavior of the participants during the two activities. These dimensions included positive social orientation, harmony, responsiveness, coordinated play, control, and self-disclosure. The participants and their friends also completed the Friendship Qualities Scale (FQS) about their friendship with each other. The FQS was a self-report measure developed by the researchers that reflected various friendship qualities, which included companionship, security-intimacy and trust, closeness, help, and conflict. Results indicated that the preadolescents with HFASD possessed an overall deficit in concept formation, concept identification, and in sorting descriptions. Lower scores within the

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communication area on the ADI-R were associated with more impairment. The researchers suggested that the impairment in concept identification might represent a developmental delay for individuals with HFASD. Even though friendship intimacy was lower for the participants with HFASD, both groups reported a similar amount of companionship. Abstract reasoning abilities accounted for approximately 20% of the variance for the opinions of relationship quality between friends. Future researchers may want to conduct a similar study with a larger female sample in order to examine whether or not gender has an influence on relationship quality. There might exist other variables, such as personality or family system characteristics that may account for some of the variance. Limitations of this study include the ADI-R's basis on reports of retrospective behavior, rather than reports from a current clinician. Furthermore, one of the qualifications from the study included having had a friend for six months and their ability to attend a study session, which may have led to a sample bias of individuals with HFASD who were more socially adept. Nevertheless, the study does indicate that abstract reasoning abilities may be important to address in social skills training with children on the autism spectrum.

Researchers recently examined the trajectory of maladaptive behaviors that are associated with ASD by concentrating on middle childhood through late adolescence (Anderson, Maye, & Lord, 2011). The sample of this study in particular consisted of individuals who were referred for evaluation at centers for children with developmental delays from various parts of North Carolina and the metropolitan area of Chicago. The sample consisted of 65 children with ASD, 27 children with broader ASD who did not meet diagnosis criteria for autism, and 24 children with other developmental delays. When most of the participants were 9 years old, they were diagnosed by a clinical team that used the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview—Revised (ADI-R; Lord, Rutter, & Le

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Couteur, 1994). At this time, data on the participants verbal IQ and nonverbal IQ were also obtained. All other data from measures were taken when the participants were 9 years old and in four month intervals when the participants were between 13 and 18 years old. Parents of the participants were administered the Aberrant Behavior Checklist (ABC; Aman, 1994), where they rated their child's maladaptive behaviors based on their observations in the past four weeks. They were also given the Pubertal Developmental Scale (PDS; Peterson, Crockett, Richards, & Boxer, 1988) in order to determine the pubertal onset for each participant, questioned about their child's presence or lack of seizure experiences, and asked to report the treatment their child was receiving. Other measures, (i.e., Child Behavior Checklist [CBCL]; Achenbach & Rescorla, 2000; Tenneij & Koot, 2007; and the Developmental Behavior Checklist [DBCL]; Enfield & Tonge, 2002) concerning the participants' internalizing and externalizing mental health were administered to the parents when the participants were 18 years old. Around the same time point, participants deemed more capable were also questioned about their loneliness according to the Asher Loneliness Scale (Asher, Hymel, & Renshaw, 1984). While hyperactivity and irritability tended to decrease from childhood to adolescence in ASD, social withdrawal was shown to increase for some participants with ASD, but only for the participants on the broader autism spectrum. Both seizure onset and puberty onset predicted social withdrawal. In turn, social withdrawal in participants who had greater cognitive abilities and were 18 years old predicted higher levels of loneliness, more depressive symptoms, and more friendship problems. A caveat of these findings is that even though many participants with ASD showed greater social withdrawal as they became older, almost one half of those with autism and two thirds of those considered on the broader spectrum did not. Some limitations of this study include limited generalization of results due to more attrition for families with low SES status and the sample

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captured a specific population given that all of the participants were referred for diagnosis prior to age 3. Still, the findings of this study indicate the need for social interventions provided to children on the autism spectrum through adolescence.

Adults with HFASD also report experiencing social challenges (Müller, Schuler, & Yates, 2008). Müller and colleagues (2008) explored the social experiences and suggestions for social supports from the perspectives of 18 adults with HFASD via semi-structured interviews. 17 of the participants expressed feelings of isolation, which they also reported to increase over time as they became more socially aware of being different than others. Many of the adults shared that they did not have any friends and reported feelings of depression or anxiety as consequences of their isolation from others. The vast majority of the adults suggested that initiating social interactions was a major challenge for them because they either did not know how to initiate or the process of initiating made them anxious. They often commented on how significant facilitated social interactions were for them and many of the participants shared that they utilized mediating objects to help them initiate interactions with others. The participants also indicated that they struggled with various aspects of communicating, such as perceiving sarcasm, implicit messages, interpreting body language, or engaging in spontaneous conversations. Several of the participants stressed the importance of relationships via Internet (e.g., role-playing with others online) or other alternative methods for communication to avoid their challenges in this area. Most of the participants reported a desire for more intimacy with others in relation to romantic relationships and friendships. Nearly all of the participants suggested that they wanted to make contributions to society. Most of them shared that they continuously attempted to gain greater awareness of ASD and their own social difficulties. Many participants discussed how observing others with typical development helped them learn

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how to interact in social situations. In general, adults in the study suggested that social activities that were organized around shared hobbies (e.g., special interest groups) and involved small groups or 1:1 social interactions were essential to improving their social experiences. Most of them shared that congregating with others who had ASD was beneficial due to the opportunities to engage in joint focus activities and encounter other people who could relate to them. Many of the participants stated that having time alone to themselves and having a creative outlet helped them manage the stress they experienced in social situations. Finally, most of the adults emphasized the significance of having support from others that were accepting of their differences, willing to socially initiate for them, and showing a patient and caring demeanor. One limitation of this study was the possibility of participants in the sample having an atypical amount of insight into their social difficulties due to their participation in support groups for individuals with ASD. Also, several participants received late diagnoses and were not provided services targeted toward individuals with autism in school. Younger generations may report different experiences as autism may be diagnosed at earlier ages and individuals on the spectrum may receive earlier interventions. Further research would help determine whether or not adolescents with HFASD share similar perspectives of their social experiences as the adults in this population.

Effects of Social Skill Impairments

In their quest to search for a relationship between depressive symptoms and friendship quality in this population, Whitehouse and colleagues (2009) conducted a study in three different Australian states (Whitehouse et al., 2009). The sample in this study consisted of 35 adolescents with an AS diagnosis and 35 typically developing adolescents. The measures that were administered to all of the participants included the Friendship Quality Questionnaire (FQQ;

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Parker & Asher, 1993), Friendship Motivation Questionnaire (FMQ; Richard & Schneider, 2005), the De Jong-Gierveld Loneliness Scale (De Jong-Gierveld & Kamphuis, 1985), and the Centre for Epidemiological Studies Depression Scale-Children's Version (CES-DC; Weissman, Orvaschel, & Padian, 1980). In addition, the caregivers of both groups of adolescents were questioned about whether or not each adolescent struggled with any of the questionnaires. The caregivers of participants in the AS group were administered a 10-point Likert scale and were asked to rate the quality of friendships that their adolescents reported. Adolescents with AS tended to indicate poorer quality friendships on the questionnaires compared to typically developing adolescents. Similar findings emerged from the caregivers' reports of the participants. Compared to adolescents without AS, the population with AS indicated that they had less motivation to make friends, experienced increased levels of loneliness, and possessed more depressive symptoms. The researchers did not discover a significant relationship between the quality of friendships and depressive symptoms among participants with AS, but frequently having a conflict with a friend or being betrayed by them predicted more depressive symptoms. Feeling lonely mediated this relationship and adolescents with AS had a greater likelihood of having depressive symptoms if their friendships were of low quality and they experienced social isolation. These findings overall indicated the lack of high quality friendships can potentially have on mental health outcomes for adolescents with AS. Despite the reliability check with the caregivers' rating of the participants' friendships, more in-depth information could have been gleaned from interviewing both the adolescents and their caregivers concerning the quality of these friendships. Furthermore, friendship quality was only based on the friendship with whom participant regarded as their best friend. The present study will attempt to gain further insight into the overall friendships and social experiences of females adolescents with AS.

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Adolescents on the autism spectrum have been shown to report ostracism in a manner that is similar to adolescents with typical development (Sebastian, Blakemore, & Charman, 2009). In developing their hypotheses of how ostracism would affect adolescents with and without ASD, researchers used the theoretical framework of Williams's (1997, 2001) theory of Need Threat, which proposes that self-esteem, belonging, control, and one's perception of their own meaningful existence is threatened by ostracism. Twenty-nine male adolescents with ASD and 16 typically developing males were matched for age and IQ. The researchers used deception and informed the participants that the purpose of the research was to examine their ability to visualize mentally. Participants engaged in a computer game which involved passing a ball between other players for three minutes. First, they entered the condition in which they were supposed to feel included, and were passed the ball an equal amount as the other players on the screen. In the next condition where the participants were ostracized, the ball was thrown to them eight times and then thrown to only the other players in the game. All participants were measured on whether or not they were aware of their inclusion or ostracism following each game. Although the entire Need Threat questionnaire (Williams et al., 2000) was only administered after both conditions, but the self-esteem portion was also administered at baseline. The participants completed the mood section of the Need Threat questionnaire and the State/Trait Anxiety Inventory (Spielberger, 1983) at baseline and following each game. Results showed that the adolescents with ASD and typically developing adolescents seemed to know when they were being socially excluded and felt anxiety as a result. The Need Threat model was supported by both groups of adolescents, but adolescents with ASD seemed to have their meaningful existence threatened more than the typically developing adolescents after being ostracized. Their higher scores on this scale indicated that they perceived themselves to be

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"invisible" and viewed their life as "meaningless". However, the mood of the adolescents with ASD did not seem to be impacted by either condition. The authors propose that this latter finding may be due to this population's difficulty with answering abstract questions or identifying their emotions. Thus, it is imperative that future research utilizes other sources (e.g., parents or teachers) in order to gain others' perspectives of this group's change in mood.

Hedley and Young (2006) hypothesized that greater perception of differences between adolescents with AS and their peers, the more depressive symptoms the population with AS would exhibit. The participants of their study consisted of 34 male and 2 female Australian adolescents diagnosed with AS and between the ages of 10 and 16. They were individually administered the Social Comparison Scale (SCS: Allan & Gilbert, 1995; adapted by Dagnan & Sandhu, 1999) and the Children's Depression Inventory (CDI: Kovacs, 1992) at each participant's home. The SCS assessed the participant's perceptions of their own rank and achievement (i.e., better than or worse than other people), social attractiveness (e.g., more or less accepted than others), and group membership (i.e., whether or not they were similar or different than others). The parents of these children each provided a brief medical history of their child. The participants' sense of their own group membership significantly predicted their level of depression symptoms. Specifically, the adolescents with AS were more likely to report symptoms of depression if they perceived dissimilarity between themselves and their peers. However, the correlation discovered does not yield any information concerning the causal relationship between this population's social perceptions and their depressive symptoms. Moreover, the participants were recruited through The Autism South Australia database and several parents indicated that they entered into the study because they were worried that their children might have had depression symptoms. A stronger study would also use a multi-method

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approach of collecting data, instead of relying solely on the CDI as a measure of depression symptoms. Nevertheless, the study indicates that there is a need for practitioners to deliver interventions targeting social skills for adolescents with AS and other ways to assist these individuals with understanding and accepting differences between themselves and other people.

Individuals with ASD and Comorbidity

Mazurek and Kanne (2010) developed a research study that looked at correlations between ASD symptom severity, friendship characteristics, and anxiety/depression within a robust sample of 1,202 children on the autism spectrum between 4 and 17 years of age. The participants were drawn from the Simons Simplex Collection (SSC), which was a study that was based in multiple sites of North America and most (86.4%) of the sample was male. They were administered either the Differential Ability Scales, 2nd Edition (DAS-II; Elliot 2007), Mullen Scales of Early Learning (Mullen; 1995), Wechsler Intelligence Scale for Children, 4th Edition (Wechsler, 1999), or the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 2003) in order to provide IQ scores, which ranged from 39 to 167. The Autism Diagnostic Interview-Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) was administered to the participants' parents. Specifically, Mazurek and Kanne examined the parent report of current friendship status on the ADI-R in order to generate a measure of dyadic friendship. Parent reports were also gathered via the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001), which provided information concerning their children's emotional and behavioral symptoms. Participants participated in the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2002) and a calibrated severity score (CSS) was calculated for each child. As predicted, parent reports on the CBCL indicated significantly higher levels of anxiety/depression symptoms than the CBCL normative sample. The participants with higher IQ scores were more likely to have

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high levels of anxiety/depression symptoms as reported on the CBCL. Also consistent with the researchers' expectations, parents reported that their children with ASD possessed a very small number of friendships. Specifically, the ADI-R indicated that 24.3% of the participants did not have any peer relationships and 15.2% possessed a minimum of one friendship in which they engaged in reciprocity and mutual responsiveness. According to the ADI-R, children and adolescents with higher IQ scores had stronger and more responsive friendships. The ADOS revealed that participants were significantly more likely to have friends if they earned lower scores on ASD symptom severity. An unexpected finding was that children and adolescents who possessed at least one friend and friendship that lacked responsiveness or reciprocity had a greater chance of having higher levels of anxiety and depression. Although significant, several of the correlations in the study were weak. Future research may examine additional variables, such as levels of perspective-taking and self-awareness. Also, a more broad measure of friendship using reports from multiple sources may be helpful in determining what other aspects are related to anxiety/depression symptoms.

Another study investigated social, emotional, and behavioral problems in a sample of 15 children and adolescents with AS between 6 and 18 years old (Schroeder, Weiss, & Bebko, 2011). In order to be included in the study, participants needed to have an average or above average cognitive and language functioning, an AS diagnosis, as well as a lack of a language delay history. Recruitment occurred through the Autism Spectrum Disorders-Canadian American Research Consortium registry and from various agencies that offered services for families of children and adolescents with AS. Researchers administered the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000) to parents of the participants in order to gather data on the participants' social, emotional, and behavioral problems. Parents also participated in

the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994) and the Krug Asperger's Disorder Index (KADI; Krug & Arick, 2003), which gathered information about the participants' behavior and symptoms related to AS. The Wechsler Abbreviated Scale of Intelligence (WASI; The Psychological Corporation, 1999), Peabody Picture Vocabulary Test-III (PPVT-III; Dunn & Dunn, 1997), and the Expressive One-Word Picture Vocabulary Test-2000 Edition (EOWPVT-2000) were administered to the participants to assess their cognitive and language functioning. Parents rated their children and adolescents with AS significantly higher for social, emotional, and behavioral problems than the normative population of the CBCL. Results suggested approximately two-thirds of the sample exhibited clinically significant problems, which typically fell under thought, anxiety, social, affective, and attention problems. Also, internalizing behaviors were shown as significantly more problematic for the participants than externalizing behaviors. Neither intelligence, language ability, nor autism symptoms yielded a significant correlation with the participants' CBCL scores. Weaknesses of the study included its low number of participants and lack of using multiple methods for data collection. Nevertheless, the results suggested that individuals with AS may have a greater risk for internalizing behavior problems.

The main purpose of the study that Ruta and colleagues conducted was to explore certain characteristics (e.g., type, frequency, and severity) of obsessive and compulsive behaviors in children and adolescents with AS, compared to a group of individuals their age with obsessive compulsive disorder (OCD) and a similar group with typical development (Ruta, Mugno, D'Arrigo, Vitiello, & Mazzone, 2010). Secondly, the researchers sought to discover how much having AS predicted the amount of insight or awareness participants with OCD had of their obsessive and compulsive behaviors. Participants were recruited from a university hospital and a

public school in Italy and were between 8 and 15 years of age. Specifically, these individuals more frequently have reported behaviors related to hoarding, repeating, and ordering (Ruta et al., 2010). Individuals with a mental retardation diagnosis, neurological disease, ADHD, or Tic disorder comorbidity were excluded from the study. The Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974) was administered to all of the participants in order to assess their intellectual functioning, while the Children's Yale-Brown Obsessive Compulsive Scale CY-BOCS (Scahill, Riddle, McSwiggin-Hardin, Ort, King, Goodman, Cicchetti, & Leckman, 1997) was used in order to examine what types of obsessive thoughts, rituals, or repetitive behaviors they might have. The CY-BOCS also measured the severity of OCD symptoms and amount of insight the participants possessed. In this study, children and adolescents with AS tended to exhibit more frequent and severe obsessive and compulsive symptoms than their typically developing peers. They were also more likely to engage in hoarding, repeating, and ordering behaviors than individuals with OCD, whereas children and adolescents with OCD were more likely to engage in compulsions relating to contamination, aggression, and checking. The amount of insight that participants with AS or OCD had of their obsessive and compulsive behaviors did not differ and the majority of participants within these two groups indicated fair to poor insight. Limitations of the study include the CY-BOCS intention for use with only children with OCD, the AS participants' struggle with providing explaining their obsessive and compulsive symptoms, and the small sample size that limited generalization of results.

Gender Differences in ASD

    Core characteristics of ASD. Some studies have shown that boys with ASD exhibit more restricted behaviors and interests than girls with ASD (Solomon, Miller, Taylor, Hinshaw,

& Carter, 2012). Seventy-six children and adolescents from 8 to 18 years old participated in the study by Solomon and colleagues (2012), which examined the gender difference in symptoms of ASD and internalizing psychopathology. Twenty females and 20 males with ASD (HFA, AS, and PDD-NOS), as well as 19 typically developing females and 17 typically developing males were included in the sample. The researchers recruited the participants through various local health professionals, state centers, and groups for individuals with ASD. In order to qualify for participation in the study, the individuals had to meet DSM-IV-TR (American Psychiatric Association, 2000) criteria for either Autistic Disorder, AS, or PDD-NOS. They were determined ineligible if they were previously diagnosed with depression, anxiety, ADHD, Fragile X, Tourette's, or seizures. Both the typically developing adolescents and the individuals with ASD were administered the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) and the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). The SCQ was comprised of 40 questions and provided a measure of the participants' social and communication skills. Symptoms related to autism were assessed by parent reports through the Social Responsiveness Scale (SRS; Constantino, 2002), the Children's Communication Checklist-2nd Edition (CCC-2; Bishop, 2003), and the Repetitive Behavior Scale-Revised (RBS-R; Bodfish, Symons, & Lewis, 1999). In order to attain data pertaining to internalizing psychopathology, the participants' parents completed the Behavior Assessment System for Children-2nd Edition (BASC2 subscales: Reynolds & Kamphaus, 2004) and the participants themselves completed the Children's Depression Inventory (CDI; Kovacs, 1992). Results indicated that the males with ASD did not differ in terms of autism symptoms from females with ASD. Similarly, typically developing girls and boys did not differ much from each other on these measures and both groups were shown to have greater social and communication skills

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than the two groups with ASD. However, males with ASD were significantly more likely to exhibit restricted interests than females on the autism spectrum. Also, adolescent females with ASD had significantly more internalizing symptoms compared to the three other groups in the sample. One limitation of the study includes the validity of the measures used for the participants with ASD. For example, it could be argued that most of the items that were used to determine varying levels of restricted interests on the RBS-R related to objects that traditionally interests males, such as trains and dinosaurs. The study may have also been enhanced with additional sources of data, such as observations. Nevertheless, the study indicates that there exists a need for intervention services to support females with ASD and their needs related to internalizing psychopathology.

More recent research has examined gender differences in relation to how ASD symptoms are presented with the DSM-IV-TR (2000) and current DSM-V (APA, 2013) criteria (Hiller, Young, & Weber, 2014). 69 girls and 69 boys with HFASD participated in a study that collected diagnostic information, as well as reports from parents and teachers. Results indicated that girls were more likely to not meet or fairly meet criteria in the restricted interests domain on the DSM-V. Girls demonstrated fewer circumscribed interests than boys and their interests were qualitatively different. Whereas boys tended to obsess with gaming and technology, girls were more likely to show a circumscribed interest that revolved around a specific television program or character. Boys overall had more difficulty with using nonverbal communication and participating in reciprocal conversations. Girls were better at initiating social interactions, but not maintaining friendships. When compared to boys, teachers also voiced fewer concerns with externalizing behavior and social problems. This indicates that girls may show a different

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presentation than boys and further investigation into the experiences of females with ASD may help clinicians with understanding how the disorder manifests in females.

  Executive functioning. Some females with ASD have been shown to exhibit more severe cognitive impairment related to executive functioning and visual-spatial processing compared with males on the autism spectrum (Nydén, Hjelmquist, & Gillberg, 2000). Nydén and colleagues recruited 17 girls and 17 boys between 8 to 12 years of age from a clinic that served individuals with autism and other neuropsychiatric disorders in Göteborg, Sweden. As a comparison group, 17 girls that matched the clinic groups for age and FSIQ over 70 were recruited from regular education classrooms. Out of the two groups from the clinic, five boys and five girls had a pervasive developmental disorder or fell on the autism spectrum. 24 participants were diagnosed with ADHD. Participants were administered measures that assessed their cognitive and visuospatial ability from subtests on the WISC-III (Wechsler, 1992). The researchers used various measures to assess executive functions. The Becker Go-No-Go (Becker, Issac, & Hynd, 1987) and the Becker Conflict paradigm (Mühlenbock & Heiman, 1995) included tasks that required the participants to use motor inhibition on a computer. The Trail Making Test (Reitan, 1958) measured the participant's ability to stop an ongoing response and the Stroop Test (Stroop, 1935) was a measure that the researchers used to test the participants' inference control. The children also completed the Tower of London Test (Shallice, 1982), where their executive functioning was evaluated when they were planning and rearranging beads from one position to another. Their theory of mind skills were assessed by Mental Cartoon Explanation Task (Gallagher, Happé, Brunswick, Fletcher, Frith, & Frith, 2000) and Nonmental Cartoon Explanation Task (Happé, Brownell, & Winner, 1999). These tasks required the participants to indicate the meaning of some cartoons that required mental state attribution and

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some that did not require using theory of mind. Results showed that males in the clinic typically acquired higher scores on measures that tested their visuospatial skills when compared to the females in the clinic and the females from the regular education classrooms. They also seemed less impaired than the girls from the clinic on theory of mind tasks. Also, participants on the autism spectrum scored lower on theory of mind measures than the children with ADHD. Overall, the results indicated that females diagnosed with ASD/ADHD may require more emphasis on social interventions than males with the same diagnoses. However, the significant differences in the study were relatively small and a larger sample of girls with ASD would improve the power of future studies.

   Restricted and repetitive behaviors. Sipes and colleagues studied gender differences within a sample of 390 toddlers between 17 and 36 months of age with an ASD diagnosis (Sipes, Matson, Worley, & Kozlowski, 2011). The caregivers of these children were recruited through an early intervention program in Louisiana that assists children with a developmental delay or medical condition that might result in a developmental delay. The researchers used the Battelle Developmental Inventory, Second Edition (BDI-2; Newborg, 2005) in order to separate the participants by developmental quotient (DQ) and gender, which yielded four different groups (e.g. females with low DQ). The goal of the study was to explore the possible difference in ASD symptoms and whether or not they differed for males and females when DQ was controlled. The Baby and Infant Screen for Children with Autism Traits-Part 1(BISCUIT-Part 1; Matson, Boisjoli, & Wilkins, 2007) was administered to the caregivers in order to measure ASD symptoms related to Socialization/Nonverbal Communication, Repetitive Behavior/Restricted Interests, and Communication. The caregivers also completed the BDI-2, which assessed the participants' developmental levels. According to the results of the study, symptoms of ASD

differed across the four groups. Regardless of gender status, two of the groups (males with average DQ and females with average DQ) were rated as having significantly fewer symptoms than males and females with low DQ. However, females with average DQ were rated by their parents as exhibiting significantly fewer symptoms within the domain of restricted and repetitive behaviors. Other group differences were explained by differences in DQ. The study indicates that the treatment plan for females may look slightly different than males when taking into account restricted and repetitive behaviors.

Comorbidity. Holtmann and colleagues recruited high functioning children and adolescents with ASD and examined sex differences, specifically concerning psychopathology and common deficits associated with ASD in the areas of reciprocal social interaction, communication, and repetitive or stereotyped behaviors (Holtmann et al., 2007). The sample consisted of patients at the Department of Child and Adolescent Psychiatry and participants of a different international project. Participants included 23 females with HFASD and 23 males with matching ASD diagnosis, chronological age, and full-scale IQ participated in the study. Their parents were administered the Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003), the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2001), and the Child Behavior Checklist (CBCL; Achenbach, 1991). The CBCL yields a Total Problems score, as well as syndrome scales that relate to withdrawal, somatic complaints, anxiety/depression, social problems, thought problems, attention problems, delinquent behavior, and aggressive behavior. Results yielded no differences between males and females with regards to the main characteristics of autism (e.g., difficulty with reciprocal social interaction, communication deficits, and repetitive, stereotyped behavior). However, the CBCL revealed that the females with ASD possessed significantly more symptoms of coexisting psychopathology

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than males. The girls in the study particularly experienced more thought, attention, and social problems. One of the limitations of this study includes its use of the CBCL, which only helps identify certain gender differences among individuals with ASD. A qualitative study may help understand these distinctions more in depth and might discover additional insight into how to best serve the social needs of this population. Also, a multi-method approach would strengthen this study, by adding self-ratings, teacher ratings, and observations.

More recent research has yielded similar results that showed girls on the spectrum experience comparable symptoms of autism as boys, but report more anxiety in social interactions (May, Cornish, & Rinehart, 2014). May and colleagues (2014) designed a longitudinal study over a 1-year period to investigate the developmental trajectory of boys and girls with and without HFASD. The children with ASD ranged between 7 and 12 years old and were recruited from a volunteer register, private clinics, and the Center for Developmental Psychology and Psychiatry at Monash University in Australia. The researchers recruited children with typical development from a local school. At Time 1, 32 males and 32 females with HFASD were administered the Wechsler Intelligence Scale for Children IV (WISC-IV-Australian Version; Wechsler, 2005), whereas 30 males and 30 females with typical development were administered the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999). Parents were of the children were administered several questionnaires at both time points, including the Social Responsiveness Scale (SRS; Constantino, 2002), the Children's Communication Checklist-2 (CCC; Bishop, 2003), Repetitive Behavior Questionnaire II (RBQ; Leekam, Tandos, McConachie, Meins, Parkinson, & Wright, Turner, Arnott, Vittorini, & Le Couteur, 2007), Conners-3 (Conners, 2003), Spence Children's Anxiety Scale (Spence, 1998), and the Family Assessment Device questionnaire (Epstein, Baldwin, & Bishop, 1983). Time 2

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included data from parents of 56 children with HFASD and 44 children with typical development. Results indicated that the severity of autism symptoms, externalizing symptoms, and internalizing symptoms for both groups did not change from Time 1 to Time 2. Whereas parent reports for children with HFASD and without HFASD suggested minimal gender differences for both groups, the children with ASD were rated as having higher levels of autism symptoms, inattention, learning problems, executive functioning deficits, aggression, social impairments, and anxiety symptoms. All of the females in the study reportedly exhibited more social phobia symptoms when compared to the males. In the HFASD group, males were reported as showing more intense behaviors related to hyperactivity. The vast majority of children with HFASD attended mainstream private and public schools, but boys with HFASD were significantly more likely than girls to receive support from a teacher's aide. The study may have yielded different results with a greater gap between the two assessment time points. However, results from the study suggest that the gender may relate to the different support that girls and boys with HFASD receive in school. More research in this area may provide better insight into the educational support that girls receive in and outside of school, as well as the specific social phobia symptoms they may experience.

Socialization. Some researchers (McLennan et al., 1993) discovered that some males with high-functioning ASD tended to be more socially impaired in early childhood, while females showed greater impairment in this domain during adolescence. McLennan and colleagues (1993) recruited participants from three large clinics in North Carolina that served individuals with autism and pervasive developmental disorders. The sample involved 21 females with autism who were between 6 and 36 years of age and who possessed IQs over 60. 21 males who were similar in age, IQ, and diagnosis of the females also participated in the study. One

disadvantage to this study was the lack of ethnic diversity within the sample, which included only American Caucasians who had English-speaking parents. Parents of the participants were given the Autism Diagnostic Interview (ADI; Le Couteur et al., 1989), a questionnaire that consisted of more than 100 questions concerning the major characteristics linked to autism. On the ADI, they were asked to describe both past and current behaviors and whether or not specific behaviors (e.g., whether or not their child ever came to them for comfort) had ever occurred. Parents of female participants with autism reported that these girls overall demonstrated early social and communication skills (i.e., initiating social play and seeking comfort) that were less impaired than males with autism who possessed the same age and nonverbal IQ. However, adolescent and adult females with autism were reported as more socially impaired than males, especially in reference to their relationships with peers. The researchers suggested that differences in expectations for girls versus boys for social behavior might have played a role in parent biases. No differences were discovered between male and female participants in the domain of restricted and stereotypical behaviors. This study could be enhanced with a larger variety of informational sources (e.g., observations), in addition to the parent reports that the researchers gathered.

Experiences of Adolescent Females with ASD

One area of research interest, particularly for girls with high-functioning ASD, is their eating habits. Kalyva (2009) sought out to examine the eating behaviors of adolescent females with AS and to compare girls in this population with their mothers' reports of eating problems. The sample in this study consisted of 56 adolescent females with AS and 56 typically developing adolescent females served as the controls. Both groups of adolescents were between 12 and 18 years of age and resided in the country of Greece. In order to be included in the AS group, these

females were required to have a DSM-IV diagnosis of AS specifically made by Local Educational Authorities and a multidisciplinary team. The researchers used the ADI-R (Lord et al., 1994), ADOS (Lord et al., 1989), and reading comprehension subtest on the Greek version of the WISC-III (Georgas et al., 1997) for inclusion criteria. Participants were excluded if they were delayed in cognitive or language domains. Data were collected for five years in Greece and females in the control group attended classes with the girls in the AS group. Both groups were matched on chronological age and BMI. All of the participants and their mothers were administered Eating Attitudes Test-26 (EAT-26, Garner et al., 1982). Results showed that adolescent girls with AS scored higher on the rating for eating problems than typically developing peers. This was indicated by both self-report and reports from the girls' mothers. According to the findings from EAT-26, which was used as a screening tool rather than a diagnostic measure, greater than twenty-five percent of adolescent girls with AS reported eating problems that might be considered as eating disorders. In general, daughters in this study reported more eating problems than their mothers reported. The study indicates that adolescent females with AS may sometimes produce more accurate results than their mothers. Further research should explore this topic in other countries in order to determine whether or not culture plays a role in the eating habits of this population.

In a dissertation, Beteta (2008) explored the academic, home, and social experiences of adolescent females with AS in the northwest region of the United States. Initially, the researcher searched for participants by contacting autism specialists, school districts, and groups within a rural community in Oregon. The sample consisted of four females who were interviewed individually in one sitting that took roughly 45 to 90 minutes to complete. Questions of the semi-structured interviews were tailored for the age category of each female and they were

administered either in a public place or at the participant's home. The researcher also collected artifacts that represented part of the females' identities from each participant and observational data during the interviews and unstructured settings. Informal conversations with the mothers and teachers of the females were also taken into account. Results of the study were categorized into four different themes. The first theme, victimization, was indicated by three of the four participants who had indicated that they had been victims of bullying. All four girls in the sample experienced the second theme, anxiety. Each girl demonstrated their anxiety in various ways, including rocking or flapping, physically distancing themselves from their anxiety trigger, avoiding eye contact, directing their hands to their mouth, banging their head, and yelling or screaming. The causes of anxiety also differed among the participants and consisted of loud noises (e.g., fireworks), people and crowds, breaks in routine, being late, performing in front of others, and needles. Mimicking peers' social behavior and not fully comprehending socialization comprised the third theme of social issues. The author connected this finding to Tony Attwood's (2006) theory of social echolalia. Three of the four participants had age-appropriate interests, which was designated as the fourth theme of the study's findings. The one female who was interested in animé and Power Rangers also lacked the number of social skills that the others displayed. Parent involvement seemed to play a vital role in the lives of all of the participants. The researcher viewed the females' parents as supporters of social and developmental skills, as well as daily independent living skills (e.g. cooking). Although not initially planned, the inclusion of conversations with the participants' mothers was indicated as a crucial component of filling in the gaps where some of the questions were not provided with full responses. Future research would possibly benefit from richer data gathered through a variety of sources, including the participants, their mothers, and their teachers.

Logsden (2010) developed a dissertation study in order to discover the experiences of adolescent females with AS from their own perspectives. Recruitment attempts were made at non-profit agencies, using web sites that included AS support, school districts, AS support groups, and living facilities that served individuals with AS. The three Caucasian females that participated in the study were between 20 and 23 years of age and were diagnosed with AS before they had reached 18 years old. In their own homes, they were each administered a brief demographic questionnaire, the Adjective Checklist (ACL; Gough & Heilbrun, 1983) as a measure of self-concept, and an individual semi-structured interview. In all, these activities took approximately two hours for each girl. The researcher questioned the girls about their interests, school and peer experiences, romantic relationships, self-reflection of AS, concept of female gender, behavior expectations, and self-concept. Behavioral observations of the researcher suggested that all three participants used limited eye contact throughout the interview, two of them tended to fidget, and two of the participants appeared less mature compared to their actual age. Although all of the participants were tested for mental health disorders prior to age six, they were not diagnosed with AS until adolescence. They also possessed comorbid anxiety or depression diagnoses. Vast differences were discovered in how well the participants acknowledged characteristics they had in relation to AS. The female that was most well-versed in AS literature appeared to recognize and accept these attributes more readily. The entire sample perceived socialization and gender roles as challenges. All of the girls reported having at least one friend and they indicated interest in having social relationships. It was discovered that the participants experienced a sense of mistrust in relationships due to previous negative experiences. Two of the females expressed the positive aspects of socializing with other individuals with AS. The girl who seemed to have developed the greatest self-acceptance had

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other friends with AS and one of the girls had a close relationship with her brother, who also had AS. Two of the participants perceived themselves to possess more masculine versus feminine characteristics and desired romantic relationships with people of the same gender. However, some of the descriptions that the females used upon self-reflection involved stereotypical feminine characteristics. A couple of the girls thought that their psychologist benefitted their comprehension of AS and assisted with increasing their self-confidence for social relations. Conversely, the only participant without a psychologist viewed herself as the sole reason for her difficulties and confusion surrounding her identity. Limitations of the study included its small sample size, lack of ethnic diversity, and the absence of male participants included for comparison.

Cridland and colleagues recruited females with ASD between 12 and 17 years old and their mothers from schools and community organizations in Australia to research the experience of girls with ASD during adolescence (Cridland, Jones, Caputi, & Magee, 2014). Three mother-daughter dyads and two other mothers of girls with ASD participated in semi-structured interviews. The mothers in the study unanimously reported that acquiring a diagnosis of ASD for their daughters was a challenge. Most of the mothers suggested that the experience of obtaining a diagnosis for girls was more difficult than it was for boys. The mothers and their daughters reported mixed feelings about the girls' experiences with having a diagnosis that is statistically more common in males. The mothers shared that transitioning to high school, developing and maintaining friendships with adolescent females with typical development, experiencing puberty as females, practicing hygiene routines, and encountering issues pertaining to sexuality and romantic relationships were challenging for their daughters. The mothers in the study also discussed being highly involved in their daughters' lives. They compared how much

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they assisted their daughters with homework, communicated with their daughters' school, planned activities, and helped their daughters maintain proper hygiene to mothers of girls with typical development. The study included girls with an ASD diagnosis in general. Further research is needed to provide information on girls, specifically with high-functioning ASD.

Recent research has examined the social-emotional health of adolescent females with HFASD compared to adolescent females with typical development (Jamison & Schuttler, 2015). Specifically, the sample in the previous study consisted of 23 females with HFASD and 29 adolescent females without HFASD. The girls without HFASD served as peer mentors for the girls with HFASD in an intervention that targeted social skills and self-care. Data were collected from six different intervention groups over four years. The study only included data that were collected prior to the intervention. All of girls with HFASD and the girls with typical development were administered rating scales that included the Social Skills Improvement System (SSIS; Gresham & Elliot, 2008), Harter's Self-Perception Profile for Adolescents (SPPA), and the Youth Quality of Life Instrument—Research Version (YQOL-R). Two fathers and 21 mothers of girls with HFASD completed the SSIS, which was not administered to parents of the girls in the non-HFASD group. In comparison to the girls without HFASD, girls in the HFASD group reported significantly lower levels of social-emotional health in relation to social competence, global self-worth, and quality of life. The girls with HFASD also rated themselves as having significantly more internalizing and externalizing symptoms. Data from parent reports suggested a significant relationship between the girls' ASD symptoms and their levels of social competence. Specifically, ratings from parents indicated that the girls who possessed more intense and severe ASD symptoms had lower levels of social competence. The findings related to the girls without HFASD in the study may have been unique to this population since they were

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all volunteers for an intervention program. Parent-reports for the girls without HFASD may have resulted in different results from these girls' self-reports. A qualitative study that explores the social experiences of adolescent females may yield a better understanding of the girls' and their parents' perspectives of the topics explored in the previous study.

Educational Experiences and HFASD

To date, there exists limited research that pertains to the school experiences of students with ASD and even less studies that target HFASD specifically. Education is of particular interest to the current study and thus, the following studies are included in this review of the literature because they pertain to the school perspectives of these individuals and their parents. The qualitative nature of these recent studies provides a wealth of information concerning the school experiences of this population and further raises the awareness that these students' unique needs should be explored with more research.

School experiences in general. In an earlier study conducted in the United Kingdom, 16 adolescents with AS were interviewed about their school experiences (Connor, 2000). The researcher intended to discover commonalities related to anxiety and stress in this population. After identifying students from either student records or discussing students with their special education coordinators, fifteen boys and one girl from nine different schools were interviewed individually, as well as their respective coordinators. The participants were asked about what school activities they excelled in and enjoyed, the worst things about school, their biggest school challenges, their response to possible problems at school, their experiences in-between classes (e.g., lunch or break), whether or not they had any friends at school and if so, why they liked them, potentially having someone they did not like and why they did not like that person, their best method of learning, how the participant or the school needs to change, and their ambitions

after school. In terms of socialization, these students' self-reports indicated that they lacked confidence in their social abilities. They also expressed that they experienced some performance anxiety in class and anxiety while interacting with peers. During the participants' lunch break, they generally sought out an activity they could do alone. The participants tended to report preference for subjects that were more based on facts and less preference for activities involving whole-group discussion, writing, or those tasks that had vague applications to the real world. Special needs coordinators also discussed their concerns with these adolescents. They mentioned that their students with AS tended to not be socially accepted, were frequently isolated from their peers during lunchtime at school, and were likely to exhibit social vulnerability. The coordinators also noted the challenge of informing school staff of AS characteristics and the reluctance of teachers to modify tasks or assignments for students with AS. They reported on the presence of behaviors changing across settings (e.g., confidence could be viewed differently in a one-on-one setting versus in a group). Overall, the results of the study indicated that there were common challenges that students with AS face in schools and there exists a need for furthering the knowledge of school staff with students diagnosed with AS and their possible educational needs.

Another study conducted in the United Kingdom examined the school experiences of 20 adolescents with AS and adolescents with HFA (Humphrey & Lewis, 2008). The participants' ages ranged from 11 to 17 years of age and they were recruited from four different secondary schools in England. The researchers collected their data through semi-structured interviews, diaries, and artwork about the students' own school experiences. For the diaries, they requested that each of the participants write in a diary that was pre-constructed with prompts to help guide their daily entries. The students were allowed to use pen and paper, type on a computer, or use a

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recording device to document their entries for as long as one month. One of the students constructed drawings of his emotions and how he felt about school. Within this sample, there was a mix of individuals who perceived their diagnostic label as negative, positive, or both negative and positive. The students who viewed their diagnosis negatively indicated a strong desire to be more similar to their peers and many expressed that teachers communicated with them differently from everyone else. While some of the students seemed to appreciate additional support in their classes, they also tended to dislike the visibility of the assistance they received because they believed that it drew more attention to their differences from their classmates. A number of the participants recognized that extra support in school helped them encounter less bullying. Almost all of the participants reported being bullied or teased by their peers regularly. Some of these adolescents identified the importance of support from their peers and friendliness of their classmates. In terms of mental health, this sample experienced anxiety from the environment at school, particularly in response to the unpredictable and less orderly circumstances of secondary school. In order to address these concerns, one of the schools intentionally placed students with AS in certain classes that were perceived as "quiet" and "well-behaved". Other schools offered designated locations for students to relax from the loud sounds or disorder in the schools. The adolescents with AS also expressed that they believed that they had to adapt their own personalities to fit in with their peers. Further exploration of data from various sources (e.g., observations, teacher and parent interviews) would strengthen the aforementioned findings.

Social experiences at school. Wainscot and colleagues broadly studied the experiences of students with AS/HFA at school and sought out to discover how they spent their time in and out of class, where they spent their school breaks (e.g., lunch), how much they enjoyed school,

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their perceptions of their friendships, and their amount of physical activity (Wainscot, Naylor, Sutcliffe, Tantam, & Williams, 2008). The researchers recruited participants between the ages of 11 to 18 through Special Education Needs Coordinators (SENCOs) in 10 different schools within Sheffield and Rotherham, UK. The SENCOs identified students that could be included in a group formed for students with an AS/HFA diagnosis and students that qualified for a comparison group, which consisted of students who were not documented as having a special education need. A total of 57 students participated in the study, of which 2 were female. Researchers met with each participant at the beginning of a school day for approximately 10 minutes in order to provide the student a pedometer and obtain consent. At the conclusion of the same school day, the researchers took a maximum of 30 minutes and conducted a structured interview, where they individually questioned the participants about their social experiences during throughout the day. For example, the students were asked about what they did, where they were, and whom they were with during lunch and breaks. The results supported the researchers' hypotheses that the students with AS/HFA interacted less with their friends and their classmates than the comparison group. Most of the participants without a special education need, compared to the students with AS/HFA, reported spending more time outside during lunch and breaks. The researchers further hypothesized that this finding might have been due to their desire to steer clear of places that involved more communication with others, more physical activities, and greater likelihood of being bullied without supervision. No significant differences were found between the groups with regards to their amount of enjoyment in school. The students with AS/HFA reported having a significant lower number of friends and talked to fewer classmates than the other groups. However, the groups were equally likely to report having a best friend in the school. On the other hand, the students with AS/HFA were more likely to

report being bullied, ignored, and disliked by their classmates. Another hypothesis confirmed by the researchers was that these participants were significantly less active than those in the comparison groups. Caution should be used with using the results of this study due its high reliance on self-report, diagnosis information provided by the school, and the fact that much of the interview surrounded around social experiences for that particular school day. The proposed study will explore similar research questions through a triangulation method of data collection and with a specific concentration on the social experiences of females with AS/HFA.

In a descriptive study that examined the developmental course of 39 boys and 1 girl with AS between 3 and 15 years old, medical charts were collected, as well as standardized test scores, parent reports, teacher reports, and observations (Church et al., 2000). Data were gathered for participants ranging from preschool, elementary school, middle school, and high school. Results showed that the lack of social skills was a salient theme from preschool through high school. These participants began to feel different than their peers in middle school and consequently felt sad, anxious, and rejected. Most of the adolescents with AS desired peer group membership, but did not possess the social skills to fit in with a group. Even with social skill training, this population experienced frustration, confusion, anxiety, and occasionally inappropriate behavior as a result of their social difficulties. It was common for the participants to have only one or two friends and these friendships were usually formed by a mutual interest (e.g., computer games). These relationships were characterized as being superficial in nature. Most of the adolescents in this study desired to spend time with their family or other adults rather than their same-aged peers. Besides social difficulties, both teachers and parents expressed concern about the lack of academic motivation in adolescents when it came to subjects in which they did not take a particular interest. Also, rigidity in thinking and obsessive-compulsive

behaviors remained throughout the participants' childhood and adolescence. There are a number of limitations that should have been addressed in this article. First, the sample size decreased as each age level was examined and high school data were available for only five of the participants. Also, there was one girl included in the sample.

Kasari and colleagues (2011) recently examined the relationship between playground observations, as well as teacher, peer, and self-reports of 60 children with HFASD and their peer relationships (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011). They hypothesized that students who remained on the outside of their social networks would have the least amount of social skills according to teacher reports. In order to meet eligibility criteria for participation in the study, participants needed to have received an ASD diagnosis from a licensed psychologist, met ASD criteria according to the ADI-R and the ADOS, immersed in a general education classroom for no less than 80% of their time at school, were between age 6 to 11, in grade 1 to 5, and possessed at least an IQ score of 65. Exclusion criteria included having a comorbid disorder. The sample consisted of 60 children with ASD and 815 children of typical development. Sixteen of the 66 children had an AS diagnosis. This study was conducted in the greater Los Angeles area and the researchers recruited participants from various classrooms in 30 different schools. In terms of diversity, the ASD sample was made up of participants from various ethnic backgrounds (46.7% Caucasian, 5% African American, 21.7% Latino, 16.7% Asian, and 10% Other) and 90% of the sample was male. The typically developing children were randomly selected from the classrooms of each participant with ASD and matched the participants with ASD on gender, age, grade, and classroom. Participants were assessed using the *Friendship Quality Scale* (FSQ; Bukowski et al., 1994), *Playground Observation of Peer Engagement* (POPE; Kasari et al., 2005), an original Teacher Perception Measure, and an original Social

Networks and Friendship survey. Individuals with autism were shown to exhibit less reciprocity in their friendships and to be peripheral to social networks within their classrooms. Specifically, 18% of the sample of ASD children and 64% of typically developing children demonstrated reciprocity in their friendships at school (Kasari, 2011). Surprisingly, popularity ratings by peers and the presence or absence of a reciprocal friendship did not predict the amount children with ASD engaged with their peers on the playground. The children who had aides were more likely to be unengaged with their peers on and off of the playground. Both the participants with ASD and without ASD were similarly rejected from their peers. A strength of the study is that the researchers used multiple sources and methods for gathering data. However, the study lacked background and observational data of typically developing peers. Certain variables, such as ethnicity, may have influenced the results of the study. From the results, the researchers further hypothesized that children with ASD would have more success with their peers if they were provided social interventions on the playground.

Parents have suggested that their children with AS are especially vulnerable to bullying due to their lack of skills in the social domain, gullibility, and overreaction to others' provoking gestures (Sofronoff, Dark, & Stone, 2011). The purpose of this study was to determine the psychometric properties of an instrument measuring social vulnerability, explore the relationship between social vulnerability and bullying, and to see whether or not characteristics common to those with AS predict bullying. Participants in this study consisted of parents of children with AS who were between 6 and 16 years old. All of these children attended a mainstream school in a large urban area within Australia. The Social Vulnerability Scale (SVS; Stone & Sofronoff, 2006) was administered and completed for 133 of these children, of which 115 were male. Parents of 92 children with AS also answered survey questions concerning demographics,

behavioral characteristics of AS, anxiety, anger, social skills, bullying, and behavior problems. An additional sample that completed the SVS only consisted of 23 parents of 15 male and 8 female children of typical development. Results suggested favorable internal validity for the SVS and parents reported higher levels of social vulnerability in children with AS. The authors of this study postulated a positive relationship between social vulnerability and common ASD characteristics, such as deficits in theory of mind and social intelligence. Anxiety, anger, and behavior problems were associated with higher levels of social vulnerability, which was predicted by low levels of social skills. According to the parents of children with AS, their children experienced more anger, anxiety, and behavior problems than the parents of typically developing children. The results of this study also revealed a strong and positive relationship between social vulnerability and bullying for children with AS. Even though all of the factors under study predicted peer victimization, social vulnerability emerged as a single significant predictor of bullying. Parents particularly reported verbal teasing as a problem for their children with AS. Results would have yielded greater reliability with a larger sample size of the parents of typically developing children, different sources of data, and longitudinal measures. Still, the results of this study indicate a greater need for interventions targeted social intelligence of students with AS and widespread education of the negative effects of verbal bullying.

Support at school. White and colleagues (2007) examined the educational placements and school services provided to students with high-functioning ASD (White, Scahill, Klin, Koenig, & Volkmar, 2007). The participants were recruited from 25 various states in the U.S. 101 children and young adults from ages 5 through 21 were administered the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999) and one of three different intellectual measures that included the Wechsler Intelligence Scale for Children (Wechsler,

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1991), Wechsler Adult Intelligence Scale-Third Edition (WAIS-III; Wechsler, 1997), and the Wechsler Adult Intelligence Scale-Revised (WAIS-R; Wechsler, 1981). Parents of the individuals with ASD were administered the Autism Diagnostic Interview-Revised (Lord, Rutter, & LeCouteur, 1994), the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984), and a questionnaire that was compiled by the researchers of the study and related to the participants with ASD and their educational history. In order to qualify as a participant, the individuals needed an overall IQ score of at least 70 or higher, a clinical diagnosis of ASD that both the ADI-R and ADOS supported, and enrollment in a public school. Results indicated that the participants with autism, versus PDD-NOS or AS had a higher probability of being involved in special education. The participants who performed lower on the IQ tests, exhibited more severe symptoms on the ADOS within the socialization and communication domains, and had lower communication scores on the Vineland were more likely to be enrolled in special education versus regular education classes. It was discovered that the participants often followed the curriculum according to how they were originally placed (e.g., in regular versus special education) in school. The participants who transferred to less inclusive settings were scored fairly higher on the ADI-R for social impairment. According to results from the Vineland, the students that transferred to more inclusive settings or to regular education tended to show greater deficits in social skills versus participants who remained in special education. The participants that were enrolled in special education through middle school scored lower on IQ tests, overall adaptive behavior, and demonstrated greater impairment in communication and more repetitive behavior than the participants who remained in regular education. The parents of the participants reported speech and language therapy as the most common service delivered to their children in the schools, whereas school services targeting social skills was reported much less frequently.

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Unfortunately, a weakness in this study is its sole reliance on parent-report for data collection on the school services that were provided to the participants with ASD. Some of the parents may not have recognized all of the services that their children were receiving at school. Nevertheless, the results indicate that there is a need for more social interventions included in school services when socialization is one of the areas in which students with ASD tend to struggle the most.

Other researchers have examined parents' perspectives of their children's quality of life with AS in Canadian schools (Brewin, Renwick, & Schormans, 2008). Nine parents, including 6 mothers and 3 fathers, were recruited from a larger study. These participants had children with AS between 4 and 13 years of age. Two of the nine parents had daughters with AS. The researchers used semi-structured interviews, which typically lasted from one to two hours. The participants were questioned about the positive influences the particular schools had on their children, who was helpful at their school, and what their sons' or daughters' main needs were in relation to AS. One of the major themes that emerged from this study was the concept of teachers not acknowledging the students with AS and their disabilities. Parents suggested providing social skills training in schools and more after-school activities that involve the special interests of their children. Additionally, they mentioned that school personnel need to undergo training in order to learn how to communicate with individuals with AS. The parents also advocated for the school providing more support specifically for children with AS and better communication with other ecological resources, such as the community and therapists. The participants expressed concern about their children's difficulties with transitioning, meeting new people, and straying from routine. A few limitations of the study include its small sample of parents with females diagnosed with AS, the lack of diversity in the sample that was generally comprised of middle-class parents from an urban location, and how the research was gathered

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from one source of information. However, the results of the study indicate that teachers and other school staff should receive training on how to best serve students with AS, schools should provide social skills training, and students with AS may need additional assistance with making transitions.

The results of the previous study are consistent with the findings from more recent research, in which parents of students on the autism spectrum attending school in the United Kingdom suggested that school personnel should receive more training in interacting with this population and provide greater home-school communication (Dann, 2011). The researcher specifically explored how students on the autism spectrum experienced transitions. Six adolescents with autism (including one female), six parents, and eighteen staff members at their schools participated in the study. Data collection took place when the students were in middle school and approximately four months later when they were in high school. Semi-structured interviews were conducted with the parents and students separately, while focus groups were used for the school staff members. Questions asked of the parents and the educators during the first session related to previous educational experiences of the students with autism, their current experiences, and the expectations that the students had of their transition. During the second session, these two groups of participants were asked to make comparisons of the students' current and past experiences and how their transitions related to their expectations. The students themselves were more broadly asked during both sessions about their school experiences. In addition to the suggestions for more training to school staff and home-school communication, it was discovered that having a designated location for students to escape to when they were overwhelmed or experienced sensory overload, having more structure and organization in a school, and being able to develop relationships with school personnel was beneficial for students

entering mainstream secondary school. Several of these findings would help schools determine how to best serve the needs of children and adolescents on the spectrum. One major strength of the study was the triangulation of sources that the researcher used to gather data. However, the lack of diversity within the sample of student participants makes it difficult to generalize the results to females and adolescents with high functioning autism or AS.

School experiences of girls with HFASD. A recent study explored the school experiences of three girls with HFASD in the United Kingdom (Moyse & Porter, 2014). Data collection involved observations of the girls at school across various settings and semi-structured interviews with each girl's mother, classroom teacher, and the school's special education coordinator. The girls themselves were invited to participate in different activities that were led by the researcher. For two of the younger girls who were seven and eight years old, these activities included walking around school and taking pictures of locations that they liked. During discussions with the two girls and the eleven-year-old girl, the researcher retrieved information about their experiences through visual diagrams and drawings. All three of the girls struggled with unspoken social expectations in the classroom. For example, two of the girls often blurted out answers because did not seem to comprehend when the teachers were directing questions to the entire class. Observations also revealed inconsistent class rules and infrequent checks for comprehension. Two of the girls were observed struggling to work collaboratively and interact with their peers, yet they were not often supported during these situations. The teachers allowed the girls to stay inside during break or leave lunch early, which enabled the girls to avoid peer interactions. Overall, mothers reported their daughter's impairment as more severe when compared to interviews with their teachers. Further research in needed to examine

whether these findings replicate for girls with HFASD in other geographical locations and to determine if adolescent females share similar experiences.

With knowledge of the aforementioned characteristics of females with HFASD and their experiences in the school setting, the current study explored the experiences of adolescent females with HFASD from the perspectives of the girls themselves and their mothers. The studies reviewed in this literature review often lacked a variety of data sources, which further validated findings in the current study. Also, the world of adolescent females with HFASD was an area that warranted further exploration. The current literature indicated that this population may present symptoms of autism differently from males and exhibit different forms of comorbid psychopathology. The proposed study attempted to address the specific needs of adolescent females with HFASD in order to help provide practitioners a better idea of how to provide services specifically for this population.

CHAPTER III: Method

Purpose

The purpose of this study was to explore the perspectives of adolescent females with HFASD and their mothers with regard to their social and school experiences. The following research questions were used to guide the study:

Research Questions

1. How do adolescent females with HFASD and their mothers describe what day-to-day life is like for them?

2. What do these girls see as their strengths and challenges?

3. How do they describe their social relationships?

4. How do they describe what school is like for them?

5. What are the best and worst aspects of school for them?

6. How do mothers of girls with HFASD respond to the questions above?

7. What is the degree of similarity between how girls with HFASD and their mothers describe their day-to-day lives, including social relationships and school experiences?

Research Design

Due to the limited number of studies focused on adolescent females with HFASD, a qualitative design was used in the current study in order to add a deeper understanding of this population and reduce the current gap in the literature. Specifically, a qualitative study was chosen to capture how adolescent females experience daily life. As Giorgi (1997) suggests, a qualitative approach concentrates on life at a conscious level and how it is perceived based on

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one's own life experiences, rather than reality. In order to accomplish this in the current study, a semi-structured interview format was used with the females with ASD and their parents.

Data were gathered from mothers and daughters to allow me to provide a broader spectrum of information of females with ASD. As indicated in the literature review, individuals with ASD may report certain challenges related to their diagnosis as less severe than their parents (Cederlund et al., 2010). In this study, I also interviewed the mothers of the females with ASD to allow for greater understanding of how mother-daughter perspectives align.

Ethical Issues

Ethical issues related to human subject participation were addressed by adhering to all regulations within the University of South Florida IRB procedures. Since this particular population may have struggled with executive processes, experienced difficulty in social situations, and consisted of minors, special consideration were taken into account when interviewing these participants by balancing their comfort level and the acquisition of information requested. My major professor and I consciously used language in the consent and assent forms that were deemed developmentally appropriate. Consent forms were distributed to the mothers and assent forms were distributed to the girls at the start of each interview. At the beginning of the interview, I notified the participants that they could either pause or stop the interview process at any time. I also told each participant that I would stop the interview at any time if she became upset and I would immediately notify the mother if she informed the researcher that she was a danger to herself or someone else. However, none of the participants indicated signs of distress or danger to themselves or others. When data were collected, all identifiable information was replaced with pseudonyms. All consent and assent forms with signatures for the study resided in locked file cabinets and transcripts were protected via the use

of passwords on my computer. Signed information will be destroyed following a period of 5 years.

Study Population and Sample

  Recruitment. The Center for Autism & Related Disabilities (CARD) in Tampa, FL agreed to help locate potential research participants through use of their e-mail list serve. This facility is one of seven regional CARD locations across the state of Florida and is located on the campus of the University of South Florida. It provides several services, including home-based consultation, collaboration with parents and professionals, group training, community site visits, research and resource dissemination, and the distribution of community support information. CARD offers services to children and adults who have an ASD, described by an evaluator to possess "autistic-like" behavior, a dual sensory impairment, or have a sensory impairment with other disabilities. Proof of a diagnosis is required in order to receive services from CARD. Approximately 225 females with an ASD diagnosis in the Tampa Bay area were on CARD's email list at the time of recruitment. These females were from six different counties in the Greater Tampa Bay region. An invitation explaining the purpose of the study was sent in an email blast from the CARD facility in Tampa, Florida. Families who were interested in the study were expected to contact my major professor or me via phone or e-mail. Once contacted, I conducted a screening over the phone to confirm that the girls and their mothers met inclusion criteria.

  Snowball sampling was utilized in addition to CARD's email blast. This technique is one of the most popular methods of sampling in qualitative research and has the potential of recruiting individuals who would otherwise be excluded from research (Noy, 2008). For the current study, I asked the enrolled participants to voluntarily contact other members of the

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community who might be interested in participating. From there, potential participants would have my information and my major professor's contact information if they desired to call or email me.

Social media served as another resource for recruiting individuals to participate in the current study. Previous research has stated that the social media website, Facebook, may be effective for recruiting participants from low-prevalence populations due to its increasing amount of users (King, O'Rourke, & DeLongis, 2014). CARD posted the recruitment information on their Facebook page. My major professor and I also posted the recruitment flyer on our personal Facebook pages in order to broaden the search for potential participants.

Finally, my major professor and I contacted local therapists in North Carolina and Florida and asked them to voluntarily distribute the informational recruitment flyer for the current study. Similar to the other methods of recruitment that were used, anyone who was interested in participating in the study was then expected to contact us.

Sample selection. In order to capture the perspectives of female adolescents with HFASD and their mothers' perspectives of their day-to-day experiences, a purposeful sampling methodology was used. Four to six adolescents and a mother of each female with HFASD were targeted for participation. Five mothers in total contacted the researcher or her major professor and their daughters met inclusion criteria, but one mother and daughter decided to not participate prior to between the recruitment and consent process. Four participants were included in the current study. The following served as inclusion criteria:

1. Female

2. Diagnosed with ASD by a health professional

3. Between 12 and 19 years of age

4. Parental permission for participation if under age 18

5. Enrolled in a school within a formal setting (e.g., public or private school)

6. Lacking any known significant impairment in intelligence and expressive language (other than the pragmatic deficits often found among youth with milder forms of autism)

7. Living at least 50% of the time with a mother within the states of Florida or North Carolina.

Mothers were defined as any female biological or adoptive parent or legal guardian of the adolescent female participant with HFASD.

Participants. Recruitment resulted in four adolescent girls with HFASD and their mothers. Table 1 shows the participants' assigned pseudonyms, the age of diagnosis for the girls, the mothers' and their daughters' ages, the girls' current grade, the self-identified race for each girl, and the location in which each girl was from.

Table 1

Participant Demographics

Participant Pseudonyms	Age at Diagnosis	Daughter's Age at Time of Interview	Mother's Age at Time of Interview	Current Grade	Self-Identified Race	Location
Alison & Antoinette	4	19	50	12	Bi-Racial	Tampa, FL
Brittany & Brenda	14	16	56	11	White	Durham, NC
Caitlin & Connie	4	14	50	8	White	Durham, NC
Destiny & Donna	8	13	38	9	White	Graham, NC

Alison & Antoinette. Antoinette contacted me after discovering my recruitment flyer posting from CARD, and the interview sessions with her and her daughter took place in her office at work. Alison and her mother lived together in Florida, where Alison attended a charter school that specifically serves high school students with special needs. Alison received special education support at school under an IEP plan. Outside of school, Alison was provided services from CARD (e.g., classroom observations and consultation with teachers), attended a social group for young adults with ASD, and participated in drama therapy. I initially wondered about the extent of Alison's verbal abilities when she spoke very little during the assent process and exhibited an apathetic demeanor with minimal eye contact. When I began the first interview by asking her to tell me about herself, she struggled to respond and then only provided brief responses when I posed the question in different ways. After I asked her about what she likes to do and the sketchbook she brought with her to the first interview, she appeared much more eager to participate throughout the rest of the interviewing process. Antoinette readily shared her story and during informal conversation with me acknowledged the little research that was available for girls on the autism spectrum.

Brittany & Brenda. Brittany lived with her mother, father, and younger brother in Durham, North Carolina. Interviews with Brittany and Brenda took place inside their home after Brenda discovered my recruitment flyer from her local autism support group. Brittany's support at school had shifted from an IEP to a 504 Plan and she currently attended a project-based learning charter school. Her 504 Plan included extended time on tests and monthly meetings with her special education teacher to discuss how she is doing in school. Brenda stated that Brittany currently does not receive support outside of school because Brittany does not want it despite multiple attempts from Brenda to engage her in social activities. Unlike Alison, Brittany

responded more verbally during the assent process, although she did not ask any further questions about the current study or why she was participating. Both Brittany and Brenda appeared forthcoming with their responses throughout their entire interviews. Brittany appeared to have the most insightful responses compared to the other girls who participated. She was the only one who mentioned her diagnosis and she briefly suggested that it possibly affected her socially. Brenda seemed to have the highest academic expectations for her daughter; they both discussed Brittany's future plans of attaining a Ph.D. in Anthropology.

Caitlin & Connie. Connie learned about my study from email listservs that were sent from the Goodwill Community Foundation (GCF) Family Support Services and Durham Autism Society. I conducted Caitlin's and Connie's interviews in their home where they lived with Caitlin's father and her younger sister in Durham, North Carolina. Although Caitlin had most recently attended a private school, Connie expected Caitlin to soon enroll in a charter school that would assist Caitlin with going out into the community and finding a job following high school graduation. Connie stated that Caitlin's most recent private school did not include any supportive services because "it's not required". Connie shared that Caitlin had also previously attended public school, where she had an IEP with speech-language therapy, received instruction in a separate setting for part of the school day, was provided assistance from a resource teacher in an inclusion classroom, and occupational therapy on a consult basis. Connie reported that Caitlin did not currently receive any outside therapies or services due to financial reasons, but she previously received speech language therapy for help with pragmatic language and Connie worked with a Relationship Development Intervention (RDI) consultant to help address Caitlin's social and behavioral challenges. Caitlin seemed to struggle the most socially compared to the other girls who were interviewed. Upon initially meeting Caitlin, she sat down awkwardly close

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to me as she showed me her stuffed animal from one of her favorite books. During the assent process with Caitlin, she promptly agreed to participate in the study and then returned to discussing her favorite book and stuffed animal. Both Caitlin and Connie eagerly responded to the interview questions, although Caitlin's responses often focused on her circumscribed interests.

  Destiny & Donna. Destiny and Donna participated in interviews with me at their home in Graham, North Carolina. Destiny lived with her mother, father, and four siblings. Donna had heard about my study from a friend. Similar to Brittany, Destiny had transitioned from an IEP to a 504 Plan and she currently attended a charter school. Destiny's 504 Plan included support with pulling her out of class for fire drills and permission to fidget with something or read a book following tests, as well as help with organization. Destiny did not currently receive any support outside of school. I thought that establishing rapport with Destiny was challenging, and although she assented to participating in the current study, she did not seem interested in the research or why she was participating. Destiny provided brief responses to the initial interview questions but elaborated more on her current social and school experiences. Like the other mothers who participated in the current study, Donna readily provided detailed responses to her interview questions.

Data Collection

  Semi-structured interviews. My major professor and I formulated open-ended questions in order to gather information that pertained to the purpose of the research study, which was to explore the perspectives of adolescent females with HFASD and their mothers in relation to their school and social experiences. Although numerous questions were prepared for the interviews with the girls and their mothers, a natural flow of conversation and establishment of rapport were

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desired. At times, it was necessary to include probes within the interviews, where the researcher asked additional questions on a topic that was not thoroughly explained with a question.

Seidman (2013) recommends conducting a series of interviews rather than collecting qualitative data in a single session with each participant. I conducted two interviews with each participant. This approach to interviewing allowed myself time to listen to each participant discuss her experiences, establish rapport between the interviewer and the participant, and provide a chance for the participant to reflect on the meaning of her experience. Additionally, a previous researcher who interviewed female adolescents with AS reported minimal responses from the participants was possibly due to the brief amount of time that was provided for establishing rapport with the girls (Beteta, 2008). In the first interview, I asked the participants to discuss their general experiences and interests. Specifically, they were asked to describe themselves for someone who did not know them, chat about some of the activities they did for fun, describe their favorite things to do, and discuss some of their strengths and weaknesses. The first interview ended with the researcher explaining to the participants that they would have the opportunity at the next meeting to share a sample or an artifact (e.g., short story or drawing), which would allow them to reflect on what their experiences meant to them. The second interview focused on each participant's social life and school experiences. At the beginning of the second interview, I provided each participant time to share an artifact and discuss its importance. Two of the girls spontaneously shared artifacts during both interviews and the researcher allowed them time to discuss these items when the conversation flowed in that direction. The remainder of the second interview consisted of asking the participants to discuss how they got along with other teenagers, their definition of a friend, details about their friends, their thoughts about dating, how they saw themselves as similar to/different than other teenagers

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their age, what advice they would offer a new student at their school, some of the best/worst things about school, their favorite teacher, how they would change their school to make it better, and what they would like to happen in their future after high school. In general, the interviews with the adolescent females attempted to capture the participants' understanding of their own experiences.

While I sought to gather information based on the participants' own perspectives of their life experiences, it was useful to determine the consistency of the reports from the females with HFASD and the views of their mothers. In an attempt to clearly distinguish the participants' perspectives from those of their parents, semi-structured interviews with the mother of each participant were conducted separately from the females with HFASD. I conducted two interviews with the mothers, similar to the girls' interviews. The mothers participated in the interviews following the girls' interviews to ensure that their perspective would not influence the way that the researcher interviewed the girls. Prior to beginning the first interview, the mothers completed a demographics questionnaire. During the first interview, I asked each mother about her daughter's favorite things to do, how she sees her daughter similar to/different than other teenagers her age, what she viewed as some of her daughter's strengths/challenges, what advice she would provide to another parent who has a daughter with similar challenges, and how much her daughter knew about her diagnosis. The second set of interview questions asked each mother to describe how her daughter got along with other teenagers, some of the positive/negative social experiences her daughter had, her daughter's current friendships, what additional support her daughter received in and outside of school, her daughter's best teacher, how her daughter's education could be improved, and what she saw for her daughter's future after high school.

Following both sets of interviews, each girl and each mother were provided an incentive, which consisted of a $10 Target gift card.

All of these interviews were conducted at a central location that was accessible by both the participants and me. Three of the mother-daughter dyads were interviewed in their homes and one mother and her daughter were interviewed in the mother's office at work. A tape recorder was used and field notes were taken in order to ensure reliability and validity of the data. The field notes included my observations, such as the participants' eye contact, body language, and conversational flow. I also noted brief initial thoughts of the interview content. The audio recordings ensured that each participant's consciousness, rather than that of the researcher's, was captured accurately (Seidman, 2013). I then transcribed all of the interviews verbatim. Finally, in order to protect the anonymity of each participant, a pseudonym was used to replace names during the transcription process.

Memo writing was a bracketing method that was conducted in order to identify my potential personal biases (Tufford & Newman, 2012). The memos consisted of my theoretical notes before, during, and after data collection. In order to not disturb the interview, the notes during the interview took place directly following each interview session. I kept these notes in an interviewing journal, which helped distinguish between my preconceived thoughts or ideas and the results of the research (Chenail, 2011).

Data Analysis

Data were analyzed by using a thematic analysis approach to search for patterns in responses across interviews and followed the guidelines suggested by Braun and Clarke (2006). As recommended, I repeatedly read over the transcripts, generated codes from the transcripts,

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and explored possible themes from the data. The steps that Braun and Clarke (2006) suggested and those that were taken to analyze the data are as follows:

1) Become familiar with the data and transcribe verbal data

2) Generate initial codes

3) Search for themes

4) Review themes

5) Define and name themes

6) Produce the report

As both Braun and Clark (2006) and Seidman (2013) suggested, the first step of manually transcribing the interviews verbatim helped me become familiar with the content of the data that was gathered. I then marked within the text what was perceived as interesting and took notes on thoughts that emerged (Braun & Clark, 2006). The second step consisted of generating initial codes for the data and creating potential themes that I captured from the patterns of responses within the transcripts. Next, I analyzed and sorted the codes within broader themes. The third step also involved distinguishing main themes from possible sub-themes and labeling other codes as miscellaneous. During review of the themes in the fourth step of analyzing the data, I re-read all of the coded data and explored possible patterns. I then re-read the entire data set to determine the validity of the themes that were discovered. In the fifth step, I defined and refined themes, identified the purpose of each theme, and determined how each theme related to the broader themes of the research. I completed the data analysis process in the sixth step, which involved writing up the analysis and selecting extracts from the data to demonstrate the prevalence of themes. Data were presented with rich descriptions of the themes and how they related to the participants' experiences.

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CHAPTER IV: Results

In this chapter, I describe the themes that emerged in the data analysis of the interviews with mothers and daughters, providing quotes and examples from each participant and her mother to illustrate the themes I found. In the next chapter (Chapter 5, Discussion), I explain how each of the themes maps on to the research questions. Overall, six themes emerged through the data analysis. Table 2 displays the name of each theme, a description of the theme, which research questions were related to the theme, and how many mothers and daughters discussed the theme in their interviews.

Table 2

Theme Descriptions

Theme Name	Theme Description	Related to Research Questions	Daughters Discussing This Theme	Mothers Discussing This Theme
Imaginary characters as a focal point of interest	Girls have high levels of interest in imaginary characters in books, cartoons, and other forms of media. Interest takes the form of talking about these characters, drawing them, writing about them, and playing games online focused on them.	1, 2, 3, and 5	All	All
Misunderstood at school	Girls encountered individuals in schools (including teachers and peers) who did not understand their special needs. Problems included lack of teacher understanding of ASD in both public and private schools; bullying by peers; and social isolation leading to multiple school changes.	4	Alison Brittany Destiny	All
Mother as protector	Mothers responded to their daughters' social and educational challenges by assuming the role of their protectors. In this role, they facilitated social interactions for their daughters and were actively engaged in supporting their daughters' educational progress through regular monitoring and intervention.	3 and 4	None	All
Can't motivate her in any way	Mothers described frustration with not being able to motivate their daughters to engage in activities outside of their daughter's restricted interests.	2 and 4	None	All
Need for kind, nurturing, flexible teachers	Mothers described the best teachers for their daughters as being nurturing, flexible, and engaged with their daughters outside of school. Girls described their best teachers as kind.	5	Alison Brittany Destiny	All
Reluctant to initiate social interactions but not necessarily uninterested	Girls did not make plans to engage with other youth socially, but most were willing to go on social outings if invited by another or organized by mothers.	2 and 3	Alison Brittany Caitlin	All

Central Themes Emerging From the Interviews

    Imaginary characters as a focal point of interest. The first theme that I identified in my data analysis was imaginary characters as a focal point of interest. All of the girls had high levels of interest in imaginary characters in books, cartoons, and other forms of media. Their interest took the form of talking about these characters, reading about them, drawing them, and playing games online with them. One girl also had a stuffed animal of her favorite character that she carried around with her. The interest in imaginary characters was noted by all of the girls and their mothers and appeared to play a significant role in their daily lives. The girls were engaged with these characters during their own personal time and in social activities as well. Although all girls showed this interest, the level of interest varied across the four girls. Below I show how the theme was expressed for each of the participants.

    Alison. Alison initially appeared hesitant to participate in the first interview and she did not speak much at all during the assent process. Once she had told me that she liked to draw and I asked her about it, she took out a sketchbook of character ideas for stories she had written. Alison discussed her characters and stories in depth and she was much more forthcoming with her responses to remainder of the interview process. During the second interview, Alison shared her collection of 164 figurines that matched a binder full of cards of *My Little Pony* characters. Alison also engages in role-playing with other people in an online community known as *DeviantArt* with her original characters and characters from the cartoon, *Xiaolin Showdown*. When asked about what she sees as her strengths and weaknesses, her answers remained on the topic of her interest in imaginary characters. In describing her strengths, she noted, "And, sometimes, I draw like, a character, but there will always be something very, very small that's different..." In day-to-day life, Alison described her interactions with friends as revolving around

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making "improv movies" that involve characters she and her friends create. Antoinette, Alison's mother, noted that Alison takes her stuffed animal, Sonic (a character from *Sonic the Hedgehog* cartoon), with her when she is anxious about interacting with other people. Alison brought Sonic to her interview with me. Imaginary characters also surfaced when Alison spoke about her future, which she noted would involve making a movie of her original characters with a friend. Antoinette expects that her daughter will likely work in a shop that involves animation.

Brittany. Although Brittany and her mother, Brenda, indicated that Brittany had a less intense interest in fantasy and developing imaginary characters, it still seemed to play a role in Brittany's life. Similar to Alison, Brittany shared a sketchbook of her own original characters from fantasy novels that she writes and other characters from cartoons, such as *Steven Universe*. Brittany spends much of her free time writing novels and reading books associated with science fiction and fantasy. According to Brenda, "[Brittany] writes novels for the heck of it" and "...what she draws when she has free time, it's like all animé, kind of that look." One of the few social activities that Brittany engages in other than organized activities (e.g., Girl Scouts or Fencing) is an annual animé convention that she attends with a friend where they dress up as animé characters. One of her future desires is to publish one of her books.

Caitlin. Caitlin's fascination with imaginary characters seemed to revolve around more intense and narrow interests. Similar to Alison, Caitlin carried a stuffed animal, a character from one of her favorite books (*The Phantom Tollbooth*) during her interviews. She also shared that she enjoys joining online communities like *DeviantArt* to research fantasy-related interests, including the *Oz* book series. Caitlin's artifacts included (1) a picture of a character from *The Phantom Tollbooth* that she had printed from the online community, *FanFiction*, (2) and *Calvin and Hobbes* comic strips. Connie, Caitlin's mother, voiced her concern about the intensity of

Caitlin's interests related to fantasy and suggested that they provide a strong challenge for her in other aspects of her daily life, including the lack of social interactions with other teenagers at school. Connie stated: "She just talked to the adults because she could get them to be flexible for her and listen to her stories and respond." When questioned about her school experiences, Caitlin shared that her favorite teachers recognized references to either *The Phantom Tollbooth* or *Calvin and Hobbes*.

Destiny. Similar to Brittany, Destiny's interest in fantasy and imaginary characters appeared less intense compared to those expressed by Alison and Caitlin. Destiny's artifact was a sketchbook and she shared that she enjoyed drawing both animé and original characters. According to Destiny and Donna, animé is also a common interest that Destiny shares with her friends. When describing her daughter's friends, Donna shared, "Um, they have similar interests, and, so [Destiny] can talk about, animé with them, at, nauseum." When asked about her interests involving animé, Destiny said: "I'll draw, watch it, hum the theme song over and over until it's out of my head." Destiny also commented that she likes reading fantasy novels, and her mother stated that Destiny enjoys reading manga.

Misunderstood at school. The difficulty of finding a good school fit for the girls was a topic that was frequently discussed, mostly by the four mothers. Three of the four girls currently attended charter schools and the fourth girl was scheduled to start attending a charter school in the near future. All of the girls had switched school settings (e.g., traditional public school to charter school) at least once. The two girls who were currently served under special education and seemed to have the greatest academic challenges had shifted between schools the most (at least four times). Whereas the girls themselves tended to share how they adjusted socially to the

different schools, the mothers also commented on the disparity of resources and problematic teacher interactions across the various school settings.

Alison. When questioned about her school experiences, Alison mentioned five different schools, but she expressed her loathing of one middle school in particular as she stated, "I hated it in every way, and my mom hated it just as much as I did." Alison further explained that she witnessed several negative behaviors from her peers at the school, saying; "The kids, like the outside kids, or the kids that don't have special needs class, were bad to the bone." Antoinette mentioned that in third grade, Alison began having more behavior difficulties as her class work became more challenging. She explained that Alison would exhibit frequent tantrums involving kicking and screaming and the assistant principal was often called to remove Alison from her classroom. When it was time for Alison to go to middle school, Antoinette noted: "...they put her in the school where the middle school behavior school was...she got bullying not only from students but teachers too." Conversely, both Alison and Antoinette expressed satisfaction with the charter school that Alison currently attends, which is exclusively for high school students with special needs who will be earning a certificate of completion rather than a regular high school diploma. Antoinette explained that her daughter's current school integrates social skills into their curriculum and Alison "has made such progress" with drama therapy, which is led by the school counselor. Antoinette stated, "The best thing we ever did was move here."

Brittany. Brittany transitioned from private school to a charter school. Both of her schools emphasized project-based learning primarily for students with typical development. Similar to Alison, Brittany seemed to notice the difference between her interactions with peers at the different schools. In reference to her private school experience, Brittany shared, "Everyone kinda had, cliques, I guess...I was sort of the lone wolf of the school." She indicated

that her current school offers more social opportunities through group projects, and there is less time to focus on anything other than academics. Brenda shared her frustration with the lack of resources at Brittany's previous school noting, "She went to private school. They have nothing." Therefore, there were several services, such as speech therapy and social skills classes, which Brenda sought out outside of school for Brittany when she was younger. She later noted that Brittany's current school does not offer social skills classes either. Brenda suggested that the difference between the population in private and charter school had an impact on how her daughter was recognized for her academic success. She said:

> I think it's been helpful getting positive reinforcement from the school...that has helped her. Sometimes I think that when she was in the private school and she was one of...just kind of average...middle of the road...she wasn't, like she's smart, she wasn't, uber uber smart... I think that it's been to be in a school where people are like, 'Hey, you're really smart.'

Brenda also reflected on the school setting in relation to Brittany's pathway to her diagnosis, which she received in eighth grade. Brenda stated, "I'll always kind of wonder...if she had been in public school, would she have been identified earlier?"

Caitlin. Throughout her school career, Caitlin experienced multiple moves through public, private, and homeschool settings. Connie noted that Caitlin recently asked her, "Why can't I ever stay at one school for more than a year?" Connie thought that public school worked for Caitlin "when it was the right teacher." Connie said the private school setting served a mix of students with autism and behavioral needs, but it lacked supportive services, such as help with social skills. Referring to private school, Connie also said, "the academics weren't geared toward where she really needed to be, too much emphasis on the stuff she'd already mastered"

and "they weren't socially helping them...build and scaffold relationships." Connie indicated that homeschooling has the advantage of individualized instruction, but is not the best thing for Caitlin's social development. Connie noted that in hindsight, "I think she would've been more successful had she stayed at the first [public school] and rode through the issues" and changes in school settings have "made it harder for [Caitlin]." Connie is currently hoping that Caitlin will soon move to a charter school that assists the students with going out into their local community and prepares them for jobs following high school graduation.

Destiny. Destiny also attended private, traditional public, and charter schools. According to Destiny and Donna, the main difference between the school settings was how they affected her Destiny socially. Both Destiny and Donna indicated that Destiny struggled with making friends until she started attending the charter school. Destiny stated: "So, I could see myself as fairly normal for my school...but not everywhere else." She also said, "...we're one of those schools where it's like, if you don't fit in everywhere else, you will fit in really well there." Donna indicated that she could be more involved and present in the private and charter schools versus the public school. She said that in public school, "you're not quite as welcomed in the classroom." Donna stated that ever since Destiny started going to her current charter school, she no longer had difficulty with making friends. Donna said:

> They've [the students] got, one thing or another that makes them just a little quirky. There's a reason why they chose to go to a small, charter school, and it's not just for people with autism, it has nothing to do with that. It's just...they tend to fit in better there, because of smaller classroom sizes, and she found her people very quickly.

Mother as protector. While discussing the social interactions and education of their daughters, each mother revealed various ways in which they were involved in their daughters'

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daily lives. These mothers seemed particularly invested in their daughters' educational and social experiences.

Alison. Antoinette, who works for an organization serving individuals with ASD, suggested that she and her coworkers were quite involved with Alison's school experiences. Antoinette noted that her coworkers "made recommendations and consulted with the teachers and stuff and I, just because...I'm in the field...they're good with taking my suggestions as well." Antoinette mentioned that she has tried to help Alison with her social anxiety and eye contact. She shared that teachers have attempted to force Alison to make eye contact and Antoinette said, "I kind of even taught her that strategy of oh, look at their nose, or look at their chin, or look at their forehead, cause they're kind of in that general vicinity." Antoinette also stated that she routinely asks her daughter about her experiences and will provide her examples of socially appropriate behavior, as in the following description:

> I'm always...with her...we kind of go through her day and it just started like years ago, and it's kind of like routine now. Where...she kind of tells me about her day and then, if there's hang-ups or problems...we kind of talk through those, and I always try to tell her, 'Well, maybe you should have done it like this. Maybe next time you should say this.'

Brittany. Brenda expressed her frustration with attempting to help Brittany with her social skills, such as arranging a social meeting with another girl her age, taking her to social skills classes, and going with her to talk to a therapist. Brenda stated, "I feel like I've tried multiple times and different things and it hasn't worked." She also shared that she frequently provides Brittany reminders about school. Brenda indicated that although Brittany's teachers see Brittany as an organized student, she believes that is largely due to the support that she provides Brittany. Brenda commented,

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I feel like I wind up nagging her a lot, like, 'Did you do that? You said you'd do that. Did you do it yet? You need to get that done. Have you thought about that? You really need to get started.'

Caitlin. Connie also seemed heavily involved in her daughter's education and social interactions. In addition to homeschooling Caitlin on and off, Connie reported that she observed Caitlin's class when she was enrolled in a formal school. Connie said, "I'd sit in class and watch and I was like...she just lost all of that...because it wasn't visual enough and it wasn't... active enough." Connie also constantly seeks out opportunities to help Caitlin improve her social skills. She noted: "We're always searching for something that works and work with her interests and, like I said, something to get her, physically involved and that kind of stuff." In order to help her daughter with her social skills, Connie organized a group for girls on the spectrum that included her daughter; led Caitlin's Girl Scout troupe; enrolled Caitlin in various social activities (e.g., dancing, swimming, theatre, etc.); engaged in training courses for parents of children with autism; worked with a Relationship Development Intervention consultant; and took Caitlin to social skills classes.

Destiny. Destiny and her mother openly acknowledged Donna's involvement in her daughter's education. When questioned about the worst things at school for her, Destiny said: "Like Mom has forced me to go back in and ask for a redo on assignments and I'm quite thankful for that, but it does get annoying when she springs it on you..." In reference to school, Donna said, "[Destiny] doesn't like me to even try to be involved, but we have to." Donna said that she often collaborates with other parents and orchestrates activities for her daughter to play with other kids. She commented that she currently remains involved with the parents of Destiny's friends. Donna stated:

The parents are involved, more heavily than other parents probably would...you know where we're, texting each other, making sure these kids are going to where they are supposed to and, doing a lot of the behind the scenes stuff. They don't really know how much we've, initiated and worked on this for them? But because they don't have a lot of, um, experience, with this kind of, um, situation, we've kind of, in the background, been emailing each other?

Can't motivate her in any way. The mothers in particular expressed their concern about their daughters' lack of motivation in relation to activities that were unrelated to their interests. Reports from the mothers suggested that the daughters' resistance affected areas of life such as their education, participation in extracurricular activities, family involvement, and future plans for after high school.

Alison. Antoinette shared that Alison used to refuse to complete classwork when she did not want to do it. She indicated that Alison could do more in school if she had more extrinsic motivation. Antoinette said:

Of course she's in a special ed program, so the demand is not as, high as what it is for typical students, but by far, she always, is, the top one in her class as far as academics and stuff...so my, only regret is like, that she's not still on a standard curriculum...because sometimes I still think that she probably, could have done it. You know? If, they had, not quit, pushing her to do it.

Antoinette also briefly mentioned Alison's lack of motivation in relation to her daughter's future. She stated that she does not envision her daughter as willing to work in a typical job setting. She said: "It'd definitely would have to be in her interests that's the only thing, or she's... not gonna do it."

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Brittany. Brenda discussed her daughter's lack of motivation in relation to school assignments that do not interest her and extracurricular activities. She provided an example of when she received a call from school when Brittany refused to complete an assignment. Brenda said: "She pretty much told the teacher she won't going to do it, she wasn't interested in it, she wasn't going to write it." Brenda also suggested that Brittany lacks motivation when competing in extracurricular activities. Brenda noted:

> Like she is on the cross-country team, but she doesn't really care about her split. She doesn't want work to run any faster. You know, those kinds of things don't, motivate her. Which kind of drives me crazy.

Brenda also expressed her concern that Brittany was not building her resume for college. Brenda stated: "Like even if I say, 'This is important. You need to kind of like expand things, because, you know, you're gonna need more than that, for college.' Like she still won't try to do that."

Caitlin. Similar to Brenda, Connie mentioned Caitlin's lack of motivation in relation to school. Connie stated:

> I mean school has been a challenge because if it's not motivating to her, if it's not interesting, she doesn't...give it her attention and that sorta thing...you know it's like, there's the future-ready and there's the occupational course of study, and she's actually pretty smart, if she's attending and interested in something...she's always gonna end up not being, you know, in that group, in that, academic, college, kind of group because, she's just, doesn't feel like attending to the things that don't interest her.

Connie indicated that Caitlin's interests also make it difficult to motivate her outside of school. For example, Connie described:

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She went through a phase where you couldn't even walk outside, 'cause that was nature, gasps, the air was bad and, you know, (laughs), it's like...that kinda limits her, in some respects, in terms of...her...interests and what she's willing to kinda go and reach out, branch out and do.

In relation to Caitlin's future, Connie stated: "She really only wants to do work about stuff that she's passionate about."

Destiny. Donna discussed her daughter's lack of motivation in and outside of school as one of Destiny's biggest challenges. Donna said: "I can't motivate [Destiny] in any way." She further explained that it was challenging for her to get Destiny to complete her homework and study. She stated, "...if I say there's an exam on Friday, you know, we need to study for this, it doesn't...matter." Donna also expressed some frustration with Destiny's lack of interest in family involvement and helping out around the house. On the other hand, Donna acknowledged that when Destiny's motivation to learn about her own interests as a strength. Donna stated:

She will find an interest and then take it to an extreme that...you and I probably wouldn't.
She...liked a book that had a lot of Greek mythology in it, and so, she then, started
studying Greek mythology on her own, pulling books out of the library, reading about it,
and in fifth grade read *The Odyssey*, which most kids don't read until college or high
school...because it interested her. Now, if I had told her, 'You should read this,' she
would've, screamed and, thrown a fit, been very difficult, but, her ability to...do what she
wants when she wants it is...a strength, because...it powers her on.

Need for kind, nurturing, flexible teachers. When most of the girls and their mothers were asked to discuss interactions with teachers, they tended to agree that the best teachers were

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kind, nurturing, and flexible. Three of the four mothers also shared the opinion that the best teachers were invested in their daughters' lives in and outside of their own classrooms.

Alison. Both Alison and Antoinette suggested that Alison's best teachers had a kind demeanor. When asked what made a teacher her favorite, Alison stated: "You know, she wasn't that strict." Throughout discussions about Alison's school experiences and interactions with teachers, Antoinette repeatedly mentioned that Alison's best teachers were less strict and more supportive in nature. She also mentioned how Alison's best teacher kept in touch with Alison after she was her teacher and interacted with her outside of school. Antoinette stated: "...she would come and get her, and you know, take her for ice cream or, you know, or [say], 'Oh, come drop [Alison] off by my house.'..." Antoinette described Alison's best teacher as "like family."

Brittany. While Brittany described her best teachers as those who were "really good at explaining things, and, getting you to understand," Brenda said that two of her daughter's best teachers were "nurturing." She further explained, "I think he also made her believe that she was smart and that she could do things," while other teachers "were frustrated with her" and "kinda annoyed." Brenda noted that the other teacher who she thought was best "would constantly tell her she was...talented." Brenda commented that one of Brittany's best teachers remained connected with Brittany after she was her teacher. Brenda stated: "...even when she got into middle school and she would see her, she'd give her a hug, talk to her about...what she was doing and what not."

Caitlin. Connie also suggested that her daughter's best teachers had a nurturing demeanor. She said that the greatest teachers would allow Caitlin to go into another room or give her time to calm down if needed, whereas other teachers "were very reactive" and would cause her behavior to worsen. Connie suggested that patience and kindness were valuable

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characteristics that teachers should have when they work with individuals on the autism spectrum. When asked how Caitlin's education could be improved, Connie mentioned having more teachers who have a "kind demeanor."

Destiny. Both Destiny and Donna indicated that Destiny's best teachers shared a caring personality. When Destiny described one of her favorite teachers, she said: "she was just really nice" and "more lenient." Donna discussed her daughter's best teacher as follows:

She comes to dinner. She emails us with exciting news. We love her...she's like one of my kids.

Donna indicated that Destiny's best teacher also continued to remain in Destiny's life and she stated that her teacher would "kinda facilitate the teachers" that Destiny had later in her education.

Reluctant to initiate social interactions but not necessarily uninterested. Most of the daughters and all of the mothers suggested that the girls were reluctant to initiate social interactions. The girls' challenges with initiating social interactions included feeling shy until they became more familiar with someone, needing someone else to take the initiative to meet for social interactions, and simply not attempting to interact with others their age.

Alison. Alison and Antoinette indicated that Alison was hesitant to engage in social interactions. Alison noted that her mother would say that she was initially shy but would eventually warm up with other people. Antoinette said: "Like a safety blanket, she has to have something to show you, or share or, she can't like, initiate." She shared that Alison carries her stuffed animal, Sonic (a character from *Sonic the Hedgehog* cartoon) with her to help her initiate social interactions. Upon meeting Alison, she was very quiet and seemed apathetic about participating in the beginning of the initial interview. Although she had her *Sonic* stuffed animal

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and artifacts related to her interests to both interviews, she only began to warm up toward me when I encouraged her to share the items that she had brought.

Brittany. Brittany and Brenda both acknowledged Brittany's difficulty with initiating social interactions with other teenagers. Brittany stated:

> I guess if I had to say anything about my personality and my social experiences...if someone wants to, meet up, it has to kinda be their initiative. I don't really know how to go about, like, setting up, playdates or social outings or, anything like that.

Brenda shared a similar perspective of her daughter's social interactions when she reported: "She doesn't initiate doing things...with other kids."

Caitlin. Caitlin and Connie also seemed to share similar perspectives on Caitlin's lack of initiation of social interactions with other teenagers. When asked how she gets along with other teenagers, Caitlin stated: "Oh, that's a real tough one, because I actually really don't." Caitlin further explained, "I never tried." Connie noted that she would ask Caitlin daily whether or not she talked to any other students, and Caitlin would respond that she had not.

Destiny. Although Destiny did not seem to want to discuss her past social experiences, Donna indicated that initiating social interactions was a challenge until recently. Donna said that up until sixth grade, Destiny did not have many friends. Donna commented,

> She had one friend, and it was...tentative. It was...she never really kind of understood how to be a friend. So she really just only did stuff with her if...I kind of got involved and...set it up.

Donna noted that she still helps initiates some of Destiny's activities with other teenagers by collaborating with other parents.

CHAPTER V: Discussion

The purpose of this study was to explore the perspectives of adolescent females with HFASD and their mothers in relation to their social relationships and school experiences. The first research question focused on how adolescent females with HFASD and their mothers described what day-to-day life was like for them. The remaining research questions related to the girls' strengths and weaknesses, social relationships, school experiences, the best and worst things about school for them, and the comparison between the daughter's responses and their mother's. In this chapter, I address my interpretation of the findings and how they relate to the current literature. I also describe limitations of the study, as well as implications for educators, future researchers, and parents.

Day-to-Day Life for Girls with HFASD

In conducting this research, I wanted to talk to girls with HFASD and their mothers about the kinds of things that were important to the girls and how they lived their lives day-to-day. In analyzing the interviews, I found one theme in particular emerged as a central focus in the girls' lives: imaginary characters as a focal point of interest.

In talking about their day-to-day lives, the girls in this study and their mothers described how much imaginary characters were a focal point of interest in their lives. For example, these characters were mentioned while Alison discussed her strengths and weaknesses, social interactions in and outside of school, and future plans following high school graduation. This particular interest also emerged multiple times throughout interviews with the other girls. All of the girls seemed to engage in activities or social interactions that involved imaginary characters

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whenever they had free time at school and during their personal time outside of school. In addition to reports from the girls and their mothers, the artifacts that the girls presented indicated that they often incorporated these characters in artistic activities, such as drawing and writing stories. This finding dovetails with a previous study in which all of the adolescent females with HFASD demonstrated artistic and creative interests (Beteta, 2008).

Imaginary characters may be more important to girls on the spectrum than boys. Recent research has shown that boys with HFASD tend to have different restricted interests than girls with HFASD (Hiller, Young, & Weber, 2014). In the Hiller et al. study, boys engaged in more activities related to stereotypical play with objects (e.g., lining up toys) and electronic media (e.g., playing video games), whereas females showed more obsessive behavior in relation to a specific television show or character. When discussing their interests, the girls in the current study often provided descriptive details about how the imaginary characters related to different stories that they had either written or read about. Future research would need to examine whether or not girls have a stronger interest in the development of characters when compared to boys, who may be more drawn to the use of action and visual effects in electronic media.

An interesting question that emerges from the focus on imaginary characters is whether this is perhaps a "safer" way of interacting with others. It is known that individuals with HFASD often want to engage in social relationships, but that they may struggle with anxiety around the unpredictable nature of human interaction (Müller et al., 2008). Perhaps engagement with imaginary characters provides an opportunity to "connect" without the typical challenges associated with human interactions. The girls in this study often engaged in social interactions that involved imaginary characters through playing games online and role-playing on the Internet. One of the mothers noted that she thought this alternate method of communication with

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others was helpful to her daughter. This dovetails with the finding that adults with HFASD have suggested that having a different way to communicate with others other than in person or on the phone allows them to escape from some of the challenges they experience in conversation (e.g., comprehending implicit meanings behind one's tone of voice; Müller et al., 2008).

Strengths and Challenges of Girls with HFASD

The second research question pertained to what the girls perceived as their strengths and challenges. The theme imaginary characters as a focal point of interest resurfaced when each girl discussed her strengths, such as reading, writing, drawing, and playing video games. Three of the four girls suggested that their strengths included drawing in particular, and they shared drawings of imaginary characters as artifacts. The mothers also acknowledged their daughters' areas of interests as strengths because they were motivating for them. Perhaps the girls discovered their focus of imaginary characters through their strong reading abilities. All four mothers shared reading as an area of strength for the girls and two of the mothers discussed how shocked they were when they learned their daughters learned how to read by age three.

In terms of challenges, all of the mothers viewed the girls' lack of motivation in activities unrelated to their interests as challenges for their daughters in planning their future, completing schoolwork, and participating in extracurricular activities. The mothers mainly focused on the struggle to motivate their daughters in education, which will be discussed later in this chapter reviewing the girls' school experiences. Donna additionally mentioned her inability to motivate Destiny to be more involved with her family. She also attributed Destiny's lack of family involvement to her diagnosis and Donna shared her belief that individuals with ASD only responded to motivators that directly helped or hindered their own goals. Donna's experience

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related to previous research where parents indicated that the lack of flexibility in individuals with HFASD negatively impacted their family (South et al., 2005).

Both mothers and daughters voiced the girls' reluctance to initiate social interactions as a challenge. Alison and Antoinette acknowledged Alison's hesitation in meeting new people, which can be challenging for individuals with HFASD in general (Brewin, 2008). Alison brought a *Sonic the Hedgehog* stuffed animal to her interview sessions and Antoinette reported that Alison often brought an object related to her interests to help ease her anxiety when encountering new people. In a previous study, adults with HFASD reported bringing objects to help them engage in social interactions (Müller et al., 2008).

Three of the four mothers shared incidents where the girls were involved in social activities that occurred generally only when organized by others. The girls' reluctance to initiate in social interactions presented as a barrier to independently organizing social outings. This finding may not be unique to adolescent females with HFASD. Adults with HFASD have also reported initiating social interactions as a challenge and how it was important that others facilitated social interactions for them (Müller et al., 2008). Despite their social challenges, the girls in the study seemed interested in interacting with others and the reasons behind their hesitation with initiating may vary among individual perspectives. For example, Brittany indicated that her reluctance was due to not knowing how to set up social outings or play dates, whereas Brenda suggested that Brittany does not initiate social interactions as a result of experiencing past rejection from peers. The lack of social skills and peer rejection may lead to a lack of self-confidence in one's social abilities, which has been shown in adolescents with HFASD (Connor, 2000). Thus, the girls may have felt the effects of peer rejection earlier in life

due to their social impairments, which has caused them to be more reluctant to initiate interactions with others in adolescence.

Social Relationships of Girls with HFASD

How the girls with HFASD described their social relationships seemed to often involve socializing with others about their interests in relation to imaginary characters. As mentioned previously in this chapter, the girls' focus on imaginary characters may provide them different opportunities to engage in social interactions that involve fewer communication challenges. During required face-to-face interactions, the girls seemed to prefer conversations with imaginary characters as a focal point of interest. This finding was not surprising, considering adolescents with HFASD are known to exhibit difficulty during conversation when a current topic is irrelevant to their own interests (Paul et al., 2009).

A recent study suggested that as the severity of ASD symptoms in adolescent females increased, their levels of social competence decreased (Jamison & Schuttler, 2015). The current study seems to support this claim in relation to restricted interests. Caitlin demonstrated the most narrow and intense interests in relation to imaginary characters and seemed to encounter the most difficulty with social interactions. The books, *The Phantom Tollbooth* and *Oz,* and the comic strip, *Calvin and Hobbes* were the three stories that she mainly focused on. Caitlin also seemed the most socially impaired when compared to the other three girls in the study. Upon first meeting Caitlin, she sat abnormally close to the researcher and petted the researcher's arm with her pet stuffed tiger, "Leslie", which was a character from *The Phantom Tollbooth.* Caitlin also made spontaneous references to her favorite stories during her interviews without offering an explanation. For example, she responded to a question about how she is like other teenagers by stating, "I would probably look a lot like another girl my age...If, one cheek of hers was purple

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and the other was red, her chin blue, her forehead yellow, and her nose bright green." The researcher later realized that Caitlin was referencing *Scraps*, a character from the *Oz* book series.

The theme of mother as protector also was heard in all of the mothers' interviews in relation to the girls' social relationships. The mothers reported their involvement in relation to arranging or encouraging social activities outside of school for their daughters. Mothers attempted to help their daughters interact with other people their age by providing their daughters advice on socially appropriate behavior, encouraging them to participate in social skills classes, and planning social outings with other parents and their children who were the same age as their daughter. It appeared that they did not necessarily have a desire to serve as a protector for their daughter in social relationships, but rather responded as necessary to the girls' social impairments. This supports previous literature that has shown mothers of adolescent girls with HFASD as highly involved in their daughters' social lives (Beteta, 2008).

School Experiences for Girls with HFASD

The girls and their mothers described their school experiences in relation to being misunderstood by peers, which resonates with current literature that suggests adolescents with HFASD tend to face social rejection and/or bullying from their peers at school (Connor, 2000; Humphrey & Lewis, 2008; Wainscot et al., 2008). All four mothers in the current study reported that their daughters had experienced bullying in a school setting. Destiny was the only daughter who had mentioned that she was bullied at her previous school. She also seemed very confident in her belief that she would currently be experiencing bullying if she was not at her current school, where the people are "ok with differences". The other girls in the study may not have mentioned their experiences with bullying as a result of preferring not to reflect on these negative experiences. On the other hand, Antoinette and Brenda mentioned occasions where

their daughters did not realize when they were being bullied. Adolescent and young adult males with HFASD tend to report less problems with social interactions than their parents (Cederlund et al., 2010).

Destiny and one of the girls who did not mention bullying expressed that they felt either a lack of friendship or social isolation from their peers at school. Destiny briefly shared that she did not have many friends at her previous school and said that she chose not to remember it when probed further. Donna further elaborated that prior to enrolling at her current charter school in sixth grade, Destiny did not "find anyone who kind of accepted her." Even though Destiny did not mention this lack of acceptance at her previous school, previous research indicated that adolescents with ASD often realize when they are being socially excluded and consequently feel anxiety (Sebastian et al., 2009). Brittany referred to herself as the "lone wolf" at one of her previous schools and commented on how the social cliques at her old school made it difficult for her to socialize with other students. It was difficult to determine how Brittany felt about her isolation from peers, which is related to more depressive symptoms in adolescents with HFASD when combined with lower friendship quality (Whitehouse et al., 2009).

The girls in the study also seemed to be misunderstood by adults in school, in addition to the students. Individuals with ASD often encounter teachers who do not seem to comprehend their diagnosis or fully meet their needs (Brewin et al., 2008; Dann, 2011; Moyse & Porter, 2015). All of the mothers in the current study discussed incidents with either individual teachers or administrators who they felt did not understand their daughters' needs. Antoinette shared that Alison was bullied by teachers at one school and some teachers have tried to force Alison to make eye contact with them. Antoinette said that making eye contact made Alison anxious, even with her own mother. Alison expressed her frustration with teachers who did not understand

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how she was listening and paying attention without making eye contact. Educators may in general misunderstand triggers for social anxiety, which is more common in girls than boys with HFASD (May, Cornish, & Rinehart, 2014).

Teachers' and administrators' lack of awareness in the impairments of the girls with HFASD also appeared to affect the mothers' experience with receiving appropriate services for their daughters in the schools. Donna reported how difficult it was to get Destiny an IEP in school because educators "said she was too smart for an IEP", even though she struggled with socialization and sensory behaviors. Brenda also expressed her frustration that her daughters' school did not appear to recognize Brittany's challenges, even though Brenda felt that she was constantly helping her at home. Some of these experiences with being misunderstood may be unique to females, as recent research has suggested that boys with HFASD receive more support at school than girls on the spectrum, even when they share similar cognitive abilities and behavior problems (May, Cornish, & Rinehart, 2014).

The mothers' reports also indicated a lack of appropriate social skills training in the schools, which is supported in the literature on educational experiences of youth with HFASD (Brewin et al., 2008; White et al., 2007). Only Antoinette shared that her daughter received help with social skills, which was incorporated in the curriculum of her current school. Brenda stated that neither Brittany's previous nor her current school offered assistance in this area and Donna did not suggest that Destiny ever had help with social skills in an educational setting. Connie shared concerns that the school Caitlin attended only offered social skills classes to younger students or shared social stories that were specifically targeted toward students with more behavioral difficulties.

Two of the girls seemed to have eventually found a school that seemed to work really well for them both socially and academically. These girls who had discovered appropriate social and educational opportunities attended charter schools where the school population appeared more accepting of their differences. Antoinette stated that the vast majority of Alison's peers at her current school have autism. In addition to making friends with peers who share similar interests, Antoinette enthusiastically discussed the social skills resources at Alison's current school. Similarly, Donna and Destiny shared their deep appreciation of Destiny's current school, where they described the school population as a mixture of students who are "different", but do not necessarily have diagnoses. Donna also shared her relief that the parents of the students at Destiny's current school seemed to possess a better understanding of autism. Further research is needed in this area to better understand the characteristics of certain schools that make them the best fit for individuals in this population.

All of mothers also reported struggling to motivate their daughters to engage in school activities unrelated to their interests. This is consistent with previous research in which both teachers and parents discussed their concern about the lack of academic motivation in adolescents with HFASD (Wainscot et al., 2008). The girls' degree of intensity in their interests also may have played a role in how motivated they were in school. Alison and Caitlin seemed to have the most intense focus on their interests due to how much and how often they discussed imaginary characters. They also required the most support in school and received special education services, whereas Brittany and Destiny had a 504 Plan. Antoinette and Connie both suggested that their daughters were capable of more success in school. When their thoughts are so often focused on their own interests, it may be difficult for these girls to switch their thinking to educational subjects. Research has indicated that girls with HFASD tend to have less

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cognitive flexibility than boys (Memari, Ziaee, Shayestehfar, Ghanouni, Mansournia, & Moshayedi, 2013). In the previous study, lower cognitive flexibility was also more common in participants with lower educational levels, whereas small differences were shown between age groups.

All four mothers also discussed their role as protector when they described their daughters' school experiences and previous research has revealed high levels of parental involvement from mothers of adolescent females with ASD (Cridland et al., 2014). In the current study, mothers' involvement in their daughter's education included providing the daughter socially appropriate ways to interact with her teacher, sending coworkers to the daughter's school to observe and provide recommendations, observing the daughter's classes, encouraging the daughter to complete her homework, helping the daughter with organization, frequent school visits to advocate for their daughter's' needs, inviting teachers over for dinner to get their daughter the support that was not provided by the school administration, and making an effort to be physically present at school via volunteering, substituting, and chaperoning school field trips.

Best and worst aspects of school for girls with HFASD. Overall, mixed responses emerged when the girls and their mothers were questioned about the best and worst aspects of school for them. When asked what were the best things about school for them, the daughter's responses included leisure-related activities (e.g., class parties and recess), classes with their favorite subjects, lenient teachers, and nonjudgmental peers. The worst aspects of school from the girls' reports included witnessing negative behavior (e.g., peers bullying other students) of their peers, feeling stressed when they did not understand something, learning about any academic subject unrelated to their interests, redoing assignments after their mother finds out about a low grade, and finishing assignments before anyone else in English class.

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The theme need for kind, nurturing, and flexible teachers served as an indicator of what made the best teachers from the mothers and their daughters' perspectives. All four mothers suggested that their daughters' best teachers were nurturing and flexible, whereas the daughters generally described their teachers as "kind". Antoinette suggested that the strict nature of teachers who generally work with students with behavioral difficulties is ineffective with students on the autism spectrum in general. Three of the mothers also shared incidences where these teachers demonstrated levels of involvement beyond what is typical and were involved with the girls outside of the classroom. A nurturing and flexible demeanor worked best for these girls, but this finding may be unique to the current study.

Comparison Between Girls' and Mothers' Responses to Interview Questions

Upon initially examining the data from all the interviews, I recognized some congruence between the girls and their mothers in the patterns of their responses. The girls and their mothers similarly reported the girls' focus on imaginary characters and their difficulty in initiating social interactions. Other themes demonstrated more differences between how the girls and their mothers discussed them. Misunderstood at school was a theme that most of the girls discussed in relation to their social experiences at school, whereas the mothers added how their daughters were also misunderstood by educators. The girls often reported their favorite teachers as "kind", whereas the mothers further elaborated that their daughters' best teachers had a nurturing and flexible demeanor. The main differences between the girls' and their mothers' responses revolved around the themes can't motivate her in any way and mother as protector.

The girls' difficulty with being motivated to engage in activities unrelated to their interests was mentioned by all of the mothers and none of the daughters. This experience may have been unique to them versus the girls themselves because they could more easily delineate

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between real life versus fantasy, which related to the girls' interest in imaginary characters. The mothers discussed struggling to motivate their daughters as one of the biggest ongoing barriers that they continue to face, whereas other reported challenges (e.g., sensory problems) have decreased from childhood to adolescence.

While interviewing the mothers, I was astounded by how devoted they were to their daughters' lives. Much of their role as a protector seemed to go unnoticed by the girls in the study. The results of this study support current research that suggests parental involvement plays a significant role in the lives of adolescent females with HFASD (Beteta, 2008; Cridland et al., 2014). Although the mothers described how much they were involved with their daughters' education and school experiences, none of them expressed how their role as a protector impacted themselves. Previous research has suggested that mothers of adolescent females with ASD exhibit feelings of exhaustion and less time to devote to other aspects in life (e.g., career and social activities), but also acknowledge the positive aspects of seeing their daughters progress over time and learning more about their diagnosis (Cridland et al., 2014).

Overall, it was challenging to obtain clear answers to the interview questions from the girls with HFASD when compared to their mothers. For example, the daughters tended to describe their favorite teachers as "kind," whereas the mothers elaborated much more on what made the best teachers desirable. Similar findings were reported in a past qualitative study, where the researcher reflected on the comparison of responses between adolescent females with AS and their mothers (Beteta, 2008). The past study suggested that the age of the females and their developmental delay may have affected the participants' responses. Other research indicates that adolescents with HFASD tend to exhibit difficulty with engaging in conversations that focus on others' interests and providing the appropriate amount of information when

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requested (Paul et al., 2009). Another possibility may be that the girls' responses were affected by social anxiety, which is sometimes felt by adolescents with HFASD (Connor, 2000). However, the girls in the current study appeared to eventually become at ease with the researcher during the first interview.

Limitations

As this is a qualitative study with a small number of participants, the results of this research are not expected to generalize to all girls' experiences with HFASD. The perspectives of these girls and their mothers may or may not be shared by others who were not interviewed. Also, the sample of participants was somewhat homogeneous with regards to geographical location and race. Participants were recruited from only two different states in the Southeastern United States and experiences may vary by location. Three of the girls in the study reported their ethnicity as Caucasian and one of the girls was reportedly biracial. Cultural influences may affect the girls' school and social experiences.

A limitation in the methodology of the current study was that the primary measures, the interview guides for the girls and their mothers, included questions that were created for the current study. There is not any reliability or validity data to support these measures. *Member checks* would further validate the findings by asking the participants to review the data and interpretations that were reported (Lincoln & Guba, 1985).

I reflected on whether or not the mothers who participated in the study were a reflection of who would participate in qualitative research. Recruitment methods included flyers and list-serves distributed by organizations that delivered services to individuals with autism. Therefore, the mothers in the study possibly represented parents who are more likely to seek out opportunities for their daughters with HFASD. It is likely that mothers who are more involved

in their daughters' lives are also more willing to participate in interviews and encourage their daughters to share their experiences with researchers. The experiences of girls with HFASD may be very different if they have parents who are less involved.

Implications for Educators

The interests of the girls with HFASD in the current study seemed to play a significant role in their daily school and social experiences. The intensity of the girls' interests appeared related to their levels of academic motivation. As suggested by one of the mothers, these girls may be more motivated to learn when lessons are modified to include their interests. Future research would need to investigate the effect of incorporating students' interests in the classroom and how this strategy affects academic motivation of students. The girls' interests also emerged when discussing their friendships and general social interactions. Educators may consider providing girls with HFASD more opportunities to interact with other students who share similar interests, which may help improve the girls' levels of confidence through more experience with successful social interactions.

The experience of the girls being misunderstood at school is an important finding, given that in previous research, teachers' understanding of HFASD and the quality of peer interactions affected the quality of life in individuals within this population (Brewin et al., 2008). This study specifically demonstrates the need for more educators' training to help them appropriately interact with girls with HFASD and recognize the challenges of this population. As indicated by all of the mothers, a nurturing and flexible demeanor seems to work best for these students. Future research would need to further how teachers can be more effective when working with girls with HFASD. The mothers' reports of the lack of social skills training provided in schools also suggests that more services need to be provided in this area.

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In addition to working on professional development to promote a better understanding of girls with HFASD and providing more opportunities for social skills training, the current study suggests that educators also should address how these girls are treated by their peers. Bullying and social isolation were reported in relation to social interactions, specifically in the school setting. Educators may consider providing developmentally appropriate lessons on HFASD to students so that they have a better understanding this population and are more sensitive to the treatment of their peers.

Implications for Parents

Findings from the current study suggest that mothers of girls with HFASD play a significant role in protecting their daughters both socially and academically. While parents may expect to be more directly involved than others whose children are typically developing, they may also consider resources outside of school for additional assistance. For example, two of the mothers described their experience with getting help from community-based organizations that serve individuals on the autism spectrum as helpful. These beneficial services specifically included structured teaching in early intervention classes, a transition to middle school workshop, parenting classes, and consultation with teachers following classroom observations. Parents of girls with HFASD may also anticipate difficulty when searching for a school that fits their daughters' needs. The results of this study suggest that traditional public schools may not be equipped to adequately address this population's social and academic development.

Implications for Researchers

After reflecting on my experience with interviewing this population, there are a number of considerations that may specifically benefit future research. All of the girls in the current study appeared to become more relaxed and comfortable when I allowed them to discuss their

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interests. I would suggest that future researchers initially establish rapport with participants by allowing them time to share what they like to do at the beginning of their interviews. The artifacts that the girls brought with them helped me understand how they incorporated their interests into their day-to-day lives and the girls appeared to enjoy sharing these artifacts. The mothers in the current study seemed more eager to talk to me, as each mother readily spoke about her daughter's experiences throughout both interviews.

The current study examined the school and social experiences of girls with HFASD from only the perceptives of the girls and their mothers. Reports from teachers and other family members (e.g., fathers and siblings), as well as behavioral observations might unveil different perspectives of what day-to-day life is like for this population.

Conclusions

The current study provides a glimpse into the school and social experiences of girls with HFASD. Much of the dialogue with the girls and their mothers related to the girls' interests, which seemed to affect their social interactions and motivation to engage in other activities, especially related to school. Although discovering restricted and narrow interests in the study was not surprising considering the girls' diagnosis, replication of findings in future research may suggest imaginary characters as focal point of interest that is specific to girls on the autism spectrum. Being misunderstood by teachers and peers seemed to relate to the unexpected trend of multiple changes across school settings and mothers suggested the need for more nurturing and flexible teachers within the school system. The misunderstanding at school by educators and peers indicate a need for more teacher training and promotions of ASD awareness for students in the school setting. As expected, the females in the study struggled with socialization and these specific participants tended to exhibit difficulty with the process of initiating social interactions.

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This suggests that future research should focus on the effectiveness of social skills interventions with a particular interest in how they affect the initiation of social interactions.

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APPENDIX A

Approval from CARD

USF UNIVERSITY OF SOUTH FLORIDA
COLLEGE OF BEHAVIORAL
& COMMUNITY SCIENCES

August 12, 2014

Dear Ms. Land,

I have reviewed your research proposal for your study entitled, "Adolescent Females with High-Functioning ASD: Self and Mothers' Perceptions of Their School and Social Experiences". Contingent on IRB approval, we will assist your recruitment efforts by posting an approved flyer on the ASDnet website as well as having CARD post it through our social media on one date, to be determined based on your recruitment timeline.

I understand the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the University of South Florida IRB. Please contact me upon receiving IRB approval and we will work with you to determine next steps in your recruitment process.

Sincerely,

Dr. Karen A. Berkman, Executive Director

Informed Consent for Mothers & Parental Permission

Informed Consent to Participate in Research

Information to Consider Before Taking Part in this Research Study

IRB Study # 18518

You and your daughter are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you; additionally, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you and your daughter to take part in a research study called:

Adolescent Females with High-Functioning ASD: Self and Mothers' Perceptions of Their School and Social Experiences

The person who is in charge of this research study is Lindsey Land, M.A. This person is called the Principal Investigator and is being guided in this research by her Faculty Advisor, Linda Raffaele Mendez, Ph.D., in order to fulfill the requirement for an Educational Specialist (Ed.S.) degree. However, other research staff may be involved and can act on behalf of the person in charge.

The research will be conducted at an agreed upon location between yourself and researcher.

Purpose of the study

The purpose of this study is to:

- Explore the perception of adolescent females with High-Functioning Autism Spectrum Disorder (HFASD) and their mothers with regard to how they experience adolescence, with a particular focus on social relationships and school. This information will add to the research on females with HFASD and their school and social experiences.

Study Procedures

If you take part in this study, you and your daughter will be asked to:

- *Participate in two interviews separate from each other and lasting approximately thirty minutes to an hour each that will ask you and your daughter about personal questions regarding your daughter's school and social experiences.*
- *The interviews will be conducted in two visits and each visit will be one to two weeks apart. During the first visit we will ask you and your daughter general questions about your daughter and what she likes to do. In the second interview, we will ask you and your daughter about the school and social experiences your daughter has had. Your daughter will also be encouraged to share an artifact (e.g., drawing or short story) during the second interview in order to further demonstrate her hobbies or interests.*
- *The interviews will take place at an agreed upon time and location by yourself and the researcher.*
- *The interviews will be audio recorded so that other members of the study staff can help turn the interviews into written transcripts. The information on the tape will not be identifiable. The recordings will be maintained until they are converted to transcripts by the research staff. The recordings will be digital. Once the audiotapes have been transcribed, the audio recordings will be deleted. The transcripts will be kept for a minimum of five years after the close of the study.*

Total Number of Participants

Approximately four to six pairs of mothers and daughters will take part in this study.

Alternatives

You do not have to participate in this research study.

Benefits

The potential benefits of participating in this research study include:
The benefit to you of participating in this study is to give you an opportunity to share your story with a researcher who is interested in documenting your journey.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

This study will ask you and your daughter to think about school and social events. There is a possibility that you or your daughter could become emotional or upset when talking about these subjects. Participants may choose not to respond to questions that make them uncomfortable.

Compensation

If you complete all of the study visits, you and your daughter will be provided an incentive, which will consist of a $10 Target gift card. If you stop participating before the study is over, the payment you receive will be based on the amount of time you were in the study. Specifically, if you stop after one interview, then you will be provided a $5 Target gift card.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator and her faculty advisor.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Office for Human Research Protection (OHRP) and the Department of Health and Human Services.
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Lindsey Land, M.A. at (910) 840-7324.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent for my daughter and I to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

_____   _____
Signature of Person Taking Part in Study   Date

_____
Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:
- What the study is about;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

_____   _____
Signature of Person Obtaining Informed Consent   Date

_____
Printed Name of Person Obtaining Informed Consent

Informed Consent for Females with HFASD if 18 or older

USF
UNIVERSITY OF SOUTH FLORIDA

Informed Consent to Participate in Research

Information to Consider Before Taking Part in this Research Study

IRB Study # 18518

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you; additionally, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

Adolescent Females with High-Functioning ASD: Self and Mothers' Perceptions of Their School and Social Experiences

The person who is in charge of this research study is Lindsey Land, M.A. This person is called the Principal Investigator and is being guided in this research by her Faculty Advisor, Linda Raffaele Mendez, Ph.D., in order to fulfill the requirement for an Educational Specialist (Ed.S.) degree. However, other research staff may be involved and can act on behalf of the person in charge.

The research will be conducted at an agreed upon location between yourself and the researcher.

Purpose of the study

The purpose of this study is to:

- Explore the perception of adolescent females with High-Functioning Autism Spectrum Disorder (HFASD) and their mothers with regard to how they experience adolescence, with a particular focus on social relationships and school. This information will add to the research on females with HFASD and their school and social experiences.

Study Procedures

If you take part in this study, you will be asked to:

- *Participate in two interviews lasting approximately thirty minutes to an hour each that will ask you about personal questions regarding your school and social experiences.*
- *The interviews will be conducted in two visits and each visit will be one to two weeks apart. During the first visit we will ask you general questions about yourself and what you like to do. In the second interview, we will ask you about school and social experiences. You will also be encouraged to share an artifact (e.g., drawing or short story) during the second interview in order to further demonstrate your hobbies or interests.*
- *The interviews will take place at an agreed upon time and location by yourself and the researcher.*
- *The interviews will be audio recorded so that other members of the study staff can help turn the interviews into written transcripts. The information on the tape will not be identifiable. The recordings will be maintained until they are converted to transcripts by the research staff. The recordings will be digital. Once the audiotapes have been transcribed, the audio recordings will be deleted. The transcripts will be kept for a minimum of five years after the close of the study.*

Total Number of Participants

Approximately four to six pairs of mothers and daughters will take part in this study.

Alternatives

You do not have to participate in this research study.

Benefits

The potential benefits of participating in this research study include:
The benefit to you of participating in this study is to give you an opportunity to share your story with a researcher who is interested in documenting your journey.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

This study will ask you to think about school and social events. There is a possibility that you could become emotional or upset when talking about these subjects. Participants may choose not to respond to questions that make them uncomfortable.

Compensation

If you complete all of the study visits, you will be provided an incentive, which will consist of a $10 Target gift card. If you stop participating before the study is over, the payment you receive will be based on the amount of time you were in the study. Specifically, if you stop after one interview, then you will be provided a $5 Target gift card.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator and her faculty advisor.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Office for Human Research Protection (OHRP) and the Department of Health and Human Services.
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

*However, if you tell us that you or someone else is in danger, we will share your information with your parents so that they can better help you.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, call Lindsey Land, M.A. at (910) 840-7324.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

_____   _____
Signature of Person Taking Part in Study   Date

_____
Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:
- What the study is about;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

_____   _____
Signature of Person Obtaining Informed Consent   Date

_____
Printed Name of Person Obtaining Informed Consent

APPENDIX D

Assent for Females with HFASD if Under 18

USF

UNIVERSITY OF SOUTH FLORIDA

Assent to Participate in Research

Information for Persons under the Age of 18 Who Are Being Asked To Take Part in Research

IRB Study # 18518

Title of study: Adolescent Females with High-Functioning ASD: Self and Mothers' Perceptions of Their School and Social Experiences

Why am I being asked to take part in this research?
You are being asked to take part in a research study about female teenagers and their school and social experiences. You are being asked to take part in this research study because you are a female teenager with High-Functioning Autism Spectrum Disorder (HFASD). If you take part in this study, you and your mother will be one of about four to six pairs of mothers and daughters to participate at this site.

Who is doing this study?
The person in charge of this study is Lindsey Land, M.A. However, other research staff may be involved and can act on behalf of the person in charge.

What is the purpose of this study?
By doing this study, we hope to learn about the experiences of female teenagers with HFASD and their mothers with regard to how they experience adolescence, with a particular focus on social relationships and school.

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Where is the study going to take place and how long will it last?
The study will be take place at a location that is agreed upon by you, your mother, and the researcher. You will be asked to participate in two visits, which will take about thirty minutes to one hour. The total amount of time you will be asked to volunteer for this study is approximately two hours over the next two to three weeks.

What will you be asked to do?
- *Participate in two interviews lasting approximately thirty minutes to an hour each that will ask you about personal questions regarding your school and social experiences.*
- *The interviews will take place in two visits and each visit will be one to two weeks apart. During the first visit we will ask you general questions about yourself and what you like to do. In the second interview, we will ask you about school and social experiences. You will also be encouraged to share an artifact (e.g., drawing or short story) during the second interview in order to further demonstrate your hobbies or interests.*
- *The interviews will take place at an agreed upon time and location by yourself, your mother, and the researcher.*
- *The interviews will be audio recorded so that other members of the study staff can help turn the interviews into written transcripts. The information on the tape will not be identifiable. The recordings will be maintained until they are converted to transcripts by the research staff. The recordings will be digital. Once the audiotapes have been transcribed, the audio recordings will be deleted. The transcripts will be kept for a minimum of five years after the close of the study.*

What things might happen if you participate?
To the best of our knowledge, your participation in this study will not harm you.

Although we have made every effort to try and make sure this doesn't happen, you may find some questions we ask may upset you. If so, we will tell you and your parents or guardian about other people who may be able to help you with these feelings.

In addition to the things that we have already talked about, listed above, you may experience something uncomfortable that we do not know about at this time.

Is there benefit to me for participating?
The benefit to you of participating in this study is to give you an opportunity to share your story with a researcher who is interested in what you have to say.

What other choices do I have if I do not participate?
You have the alternative to choose not to participate in this research study.

Do I have to take part in this study?
You should talk with your parents or guardian and others about taking part in this research study. If you do not want to take part in the study, that is your decision. You should take part in this study because you want to volunteer.

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Will I receive any compensation for taking part in this study?
You and your mother will receive a $10 Target gift card for taking part in this study. If you stop participating before the study is over, the payment you receive will be based on the amount of time you were in the study. Specifically, if you stop after one interview, then you will be provided a $5 Target gift card.

Who will see the information about me?
Your information will be added to the information from other people taking part in the study so no one will know who you are. However, if you tell us that you or someone else is in danger, we will share your information with your parents so that they can better help you.

Can I change my mind and quit?
If you decide to take part in the study you still have the right to change your mind later. No one will think badly of you if you decide to stop participating. Also, the people who are running this study may need for you to stop. If this happens, they will tell you when to stop and why.

What if I have questions?
You can ask questions about this study at any time by contacting me (Lindsey Land) at lindseyland@mail.usf.edu and the USF IRB at (813)-974-5638. You can also talk with your parents, guardian or other adults about this study. You can talk with the person who is asking you to volunteer. If you think of other questions later, you can ask them.

<div align="center">

Assent to Participate

</div>

I understand what the person conducting this study is asking me to do. I have thought about this and agree to take part in this study. I have received a copy of this form to take with me.

_____ _____
Name of person agreeing to take part in the study   Date

_____
Signature of person agreeing to take part in the study

_____ _____
Name of person providing information (assent) to subject   Date

Recruitment Flyer

Do You Have an Adolescent Daughter (Age 13 to 19) with High Functioning Autism Spectrum Disorder (ASD)?
If so, we'd like to hear your story and hers.

Who: Mothers living in the states of Florida or North Carolina and their adolescent daughters (12-19 years old) with high-functioning ASD. We are looking for girls who have expressive language skills that would allow them to share their experiences in a face-to-face interview.

When: Whatever time is best for you. You and your daughter will participate in two (2) individual interviews lasting approximately 30-60 minutes each.

Where: Interviews will take place in a private location agreed upon with the interviewer.

Why: We are conducting a study of the life experiences of girls with Autism Spectrum Disorder from their own and their mothers' perspectives. We are particularly interested in the girls' experiences in school. This research study is being conducted by a graduate student researcher (Lindsey Land) from the University of South Florida.

Note: What you and your daughter share with us is confidential. It will not be linked directly with you when we publish our findings. You and your daughter will choose a fake name for the interviews, and we will use that name to refer to you when we write up the study.

Incentive: After completing the two (2) interviews, each mother and each daughter will receive a $10 Target gift card.

Research Contact: If you have any questions, please contact Lindsey Land, M.A. at (910) 840-7324 or lindseyland@mail.usf.edu or Dr. Linda Raffaele Mendez at (813) 974-1255 or Raffaele@usf.edu.

APPENDIX F

Phone Script

Hello, I appreciate your interest in our research study. Let me share with you some further details about the study. I am interested in learning more about whether or not the interview that I have created will adequately capture your daughter's school and social experiences. I would greatly appreciate you and your daughter taking the time to speak with me in a series of separate interviews (2 for each mother and daughter). I expect each interview to take approximately thirty minutes to one hour and greatly value your knowledge and opinions. There are no right or wrong answers; I am simply interested in hearing about your daughter's experiences. You are encouraged to stop the interview at any time if you are uncomfortable or wish to end your participation. You may also decline to answer any questions you chose and we will simply move on to the next question. All information you share with me in the interview will be kept confidential. This means that everything you tell me will be kept private. The only exception to this is if your daughter tells us that she is in danger, at which time we will inform you directly. In any writing or reporting of your experiences, no names will be used and it will be impossible to tell what your specific comments are when I write up my report. If you are still interested, there are a few questions that I would like to ask you now.

Inclusion Criteria Checklist

☐ Female is between 12 and 19 years of age

☐ English is their primary language spoken

☐ Female has received a diagnosis on the Autism Spectrum by a medical doctor or professional with similar training in assessing and diagnosing Autism Spectrum Disorders
   Child's Diagnosis: _____
   Diagnosed by: _____
   Where: _____
   At what age: _____

☐ Female adolescent with Autism Spectrum Disorder lacks any known significant impairment in intelligence and expressive language (other than pragmatic deficits)

☐ Enrolled in a school within a formal setting (e.g., public or private school)

☐ Mother lives with their child at least 50% of the time within Florida or North Carolina

☐ Mother's age is between 30 and 65 years old

APPENDIX G

Demographics Questionnaire

1. My birth date: _____- _____- _____
            (month)   (day)   (year)

2. My daughter's birth date: _____- _____- _____
            (month)   (day)   (year)

3. My Race/Ethnic Identity: _____

4. My daughter's Race/Ethnic Identity: _____

5. City where currently living: _____

6. My daughter is in grade: 6   7   8   9   10   11   12
                               Other: _____

7. Are there any additional educational services (e.g., special education or 504 plan) that your daughter receives? If so, please explain.

   _____

   _____

   _____

   _____

8. If there are any outside therapies or services (e.g., Speech) that your daughter receives, please include them here:

   _____

   _____

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Examples of Possible Artifacts

Examples of Possible Artifacts

Sometimes it is easier to share samples or artifacts that demonstrate your hobbies or interests to describe yourself. If you would like, please bring an artifact that you would like to share at our <u>next meeting</u>. Below are several examples of possible artifacts.

- ➢ Yearbook

- ➢ Pictures

- ➢ Scrapbook/scrap box

- ➢ Corkboard

- ➢ Mementos

- ➢ Awards

- ➢ Drawing

- ➢ Music

- ➢ Movies/books

APPENDIX I

Girls' Interview Guide

<u>1st Interview</u>:
I will be asking you a series of questions about your interests and your experiences with school and peers.

1. Tell me about yourself.
2. What do you like to do?
3. What do you not like to do?
4. What are some activities that you do for fun?
5. What are your favorite things to do?
6. What are some of your strengths or things you do best?
7. What are some of your weaknesses or things you wish you did better?
8. Sometimes it is easier to share samples or artifacts that demonstrate your hobbies or interests to describe yourself. If you would like, please bring an artifact that you would like to share at our next meeting.

<u>2nd Interview:</u>
9. Tell me about how you get along with other teenagers.
10. What does it mean to be a friend?
11. Tell me about your friends.
12. Tell me how you feel about dating.
13. How do you see yourself as similar to other teenagers your age?
14. How do you see yourself as different from other teenagers your age?
15. Imagine I was a new student at your school. What advice would you give me?
16. Describe some of the best things about school for you.
17. Describe some of the worst things about school for you.
18. Describe your favorite teacher and why that person is your favorite.
19. How would you change your school to make it better?
20. What would you like to happen in your future after high school?

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APPENDIX J

Mothers' Interview Guide

<u>1st Interview:</u>
1. Tell me about your daughter's favorite things to do.
2. How do you see your daughter as similar to other kids her age?
3. How do you see your daughter as different from other kids her age?
4. What do you view as some of your daughter's strengths?
5. What do you view as some of your daughter's challenges?
6. What advice would you give to another parent who has a daughter with similar challenges?
7. How much does your daughter know about her diagnosis?

<u>2nd Interview</u>:
8. Tell me about how your daughter currently gets along with other teenagers.
9. What are some positive social experiences that your daughter has had?
10. What are some negative social experiences that your daughter has had?
11. Describe your daughter's current friendships.
12. What additional support does your daughter receive in and outside of school?
13. Tell me about the best teacher your daughter has ever had and what makes him or her the best.
14. How could your daughter's education be improved?
15. What do you see for your daughter's future after high school?

APPENDIX K

University of South Florida Institutional Review Board Approval

USF
UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

August 26, 2014

Lindsey Land
Educational and Psychological Studies
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**
IRB#: Pro00018518
Title: Adolescent Females with High-Functioning ASD: Self and Mothers' Perceptions of Their
School and Social Experiences

Study Approval Period: 8/26/2014 to 8/26/2015

Dear Ms. Land:

On 8/26/2014, the Institutional Review Board (IRB) reviewed and **APPROVED** the above
application and all documents outlined below.

Approved Item(s):
Protocol Document(s):

Thesis Proposal
This study involving data pertaining to children falls under 45 CFR 46.404 – Research not
involving greater than minimal risk.

Consent/Assent Document(s)*:
Assent for Females with HFASD if Under 18.docx.pdf
Informed Consent for Females with HFASD if 18 or older.docx.pdf
Parental Permission & Mothers Informed Consent.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the
"Attachments" tab. Please note, these consent/assent document(s) are only valid during the
approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which
includes activities that (1) present no more than minimal risk to human subjects, and (2) involve

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APPENDIX L

University of South Florida Institutional Review Board Continuing Review

USF
UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
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12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

8/10/2015

Lindsey Land, M.A.
USF Department of Educational and Psychological Studies
4202 E. Fowler Ave EDU 105
Tampa, FL 33620-5650

RE: **Expedited Approval for Continuing Review**
IRB#: CR1_Pro00018518
Title: Adolescent Females with High-Functioning ASD: Self and Mothers' Perceptions of Their School and Social Experiences

Study Approval Period: 8/26/2015 to 8/26/2016

Dear Ms. Land:

On 8/10/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within including those outlined below.

Approved Item(s):
Protocol Document(s):
Thesis Proposal, version 4, 5.20.15

Consent/Assent Document(s)*:
Assent for Females with HFASD if Under 18.docx.pdf
Informed Consent for Females with HFASD if 18 or older.docx.pdf
Parental Permission & Mothers Informed Consent.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab on the main study's workspace. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s) and replace the previously approved versions.