

Predicting Parenting Stress by the Symptomatology of Children with High Functioning  
Autism Spectrum Disorder

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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Education (School Psychology).

Chapel Hill  
2010

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## **Abstract**

Rebecca Elaine Matthews: Predicting Parenting Stress by the Symptomatology of Children with High Functioning Autism Spectrum Disorder  
(Under the direction of Steve Knotek, Ph.D. and Janey Sturtz McMillen, Ph.D.)

Parents of children with disabilities often possess higher stress levels than parents of typically developing children. Much research has focused on parents of children with autism. However, we know little about parents of children with high functioning autism spectrum disorders (HFASD). In order to better understand how to serve this population, it is important to understand which specific child traits and behaviors affect parenting stress in these families.

This study seeks to explore a number of questions regarding stress in parents of children with HFASD. The research questions explored in this dissertation are as follows: (1) Do parents of children with HFASD experience higher levels of stress than the normative population? (2) Do the social difficulties of children with HFASD predict higher parenting stress? (3) Do the communication difficulties of children with HFASD predict higher parenting stress? (4) Do the restricted, repetitive, and/or stereotyped behaviors, interests, and activities of children with HFASD predict higher parenting stress? (5) Is the total HFASD symptomatology of children with HFASD a significant predictor of parenting stress? (6) Are behavior problems of children with HFASD a significant predictor of parenting stress? (7) Does social support moderate the relationship between child characteristics and parenting stress?

This study consisted of 55 children with HFASD and one of their parents. Parents completed self-report measures on parental stress levels and social support as well as measures on child characteristics related to behavior and the symptomatology of autism spectrum disorders. Scores on these measures were used as variables in hierarchical linear regression models.

The results of these analyses suggest that: (1) parents of children with HFASD experience higher stress levels than parents in the normative population (2) greater difficulties with social skills and behavior problems among children with HFASD are associated with higher parenting stress (3) communication difficulties and stereotyped behavior do not predict higher parenting stress (4) higher levels of total HFASD symptomatology are associated with increased parenting stress (5) social support does not moderate any of the other variables' effects on parenting stress. Limitations of this dissertation and implications for practice are discussed.

To my mother, Elaine Matthews, who always demanded that I believe in myself.

## **Acknowledgements**

This dissertation is truly a product of many. First, thank you to my dissertation advisor, Janey McMillen for all the time and energy you invested in me and my work. You have mastered the art of setting firm deadlines and offering encouragement. Thank you for being my mentor and friend. Thank you to my dissertation chair, Steve Knotek for always believing I could achieve this goal. Thank you to the rest of my committee for your time and invaluable help. Thank you to Melissa DeRosier for providing me with a place to see my graduate training come alive in the real world. Thank you to Justin Parker for validating my anxiety and for always providing the exact words I need to hear. Thank you to Teresa Marie Vestal for your friendship and quick wit. Thank you to Don Adams, for teaching me so much about myself, for providing a sounding board for my successes and screw ups, and for always having faith in my talent.

To Adam, thank you for dragging me to the computer every Saturday and Sunday for months. Thank you for pushing me to finish and for knowing exactly what I needed along the way. Thank you to the Holland family – for being my biggest fans.

Thank you to my family, Elaine, Larry, and Eric, for the pride you took in all of my small steps towards this final product. You all were so good at recognizing the good days to ask about my progress and the days when those questions were left unasked. To Eric, the kid for whom learning never appeared hard, thank you for never making me feel like I could not do everything that you could and thank you for being patient when trying to teach me math. To Dad, thank you for helping me find so many other arenas where I could be successful and

for always expressing your pride in me. To mom, thank you for teaching me that I am smart, especially when public school made that hard to recognize. Thank you for sending me out into the world with very little fear.

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## **Chapter One:**

### **Introduction**

Although once considered a rare disorder, reports of people receiving services for autism have significantly increased in the last 20 years (CDC, 2001; CDC, 2007; Eaves & Ho, 2004; Fombonne, 2003; Lord et al., 2006; Pinto-Martin & Levy, 2004; Rice et al., 2007; Wiggins, Baio, & Rice, 2006). Population based studies conducted before 1985 reported prevalence rates of autism to be 0.4 to 0.5 per 1,000 children (CDC, 2005; US Census Bureau, 2004). In 2009, the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) Network released data findings showing average prevalence rates of Autism Spectrum Disorders of approximately 1 in 110 children (CDC, 2009). Some attribute this increase to the broadening concept of autism rather than a true increase in the number of children developing the disorder (Fombonne, 2003; Hyman, Rodier, & Davidson, 2001). Regardless of the reason for increased prevalence rates, there are more children and families seeking intervention services for the varying symptoms of autism and other sequela.

Parents of children with autism experience increased levels of stress compared to children with other disabilities (Baker et al., 2003; Bristol & Schopler, 1984; Donovan, 1988; Dumas, Wolf, Fisman, & Culligan, 1991; Higgins, Bailey, & Pearce, 2005; Sivberg, 2006; Weiss, 2002; Yirmiya & Shaked, 2005). In order to explain this difference, researchers have begun examining the effects of symptoms specific to children with autism on parenting stress (Freeman, Perry, & Factor, 1991; Hastings & Johnson, 2001; Kasari & Sigman, 1997;

Konstantareas & Homatidis, 1989; Ornstein-Davis & Carter, 2008). However, no studies were found that examine the impact of symptoms specific to children with higher functioning forms of autism on parenting stress. The current paper will provide a brief history and overview of autism and higher functioning forms of autism, followed by a study examining the relationships between the core symptoms specific to children with higher functioning forms of autism and parenting stress.

The review of the literature begins with a description of autism, including prevalence rates, symptoms, and deficits associated with the disorder. The varying disorders classified as autism spectrum disorders will be presented with the diagnostic criteria for each, as well as the continuing disagreement about terminology, and the inclusion of these disorders as a continuum of symptoms. The review of the literature then examines stress levels of parents with children with disabilities, specifically, autism and high functioning autism spectrum disorders. This section begins with a discussion comparing the stress levels of parents with children with other disabilities and parents of children with autism spectrum disorders. Next, the effects of specific symptoms of autism spectrum disorders on parenting stress will be explored. This section will also include a discussion on child characteristics that affect parenting stress such as behavior problems and cognitive functioning as well as the role of social support and relationship with parenting stress. The next section will conclude with a review of literature on the findings of the few studies that have examined stress of parents with children with high functioning autism spectrum disorders. Following the review of the literature, the statement of the problem and the research questions will be addressed.

Parental stress levels are related to child adjustment and intervention outcomes (Bittsika & Sharpley, 2000; Harris, 1994; Osborne, McHugh, Saunders, & Reed 2008; Robbins, Dunlap,

& Plienis, 1991) and are therefore important for mental health professionals to consider when working with children with high functioning autism spectrum disorders and their families. As mental health professionals design interventions for children with high functioning autism spectrum disorders, it is imperative to not only target the skill deficits unique to autism, but to also focus on behaviors or skill deficits that most negatively affect parents. This study seeks to establish that parents of children with High Functioning Autism Spectrum Disorders (HFASD) do indeed experience levels of parenting stress higher than parents with typically developing children. The term HFASD will be used in this study to represent children who meet DSM-IV-TR criteria for Autistic Disorder, PDD-NOS, or Asperger's syndrome, but have normal intellectual functioning and passable command of language skills (APA, 2000; Ozonoff et al., 2002). This study will also examine child symptoms of HFASD and their predictive power on parenting stress. The final question of this study will examine the moderating effect of social support on HFASD symptomatology to predict parenting stress. Chapters Three, Four, and Five describe the research aims and methodologies of the study.

## **Chapter Two:**

### **Review of the Literature**

Autism is a neurobiological disorder that impairs a person's ability to communicate with and relate to others, is characterized by rigid routines or repetitive behaviors that negatively impact the person's daily life, and occurs in all racial, ethnic, and social groups (Department of Health and Human Services, National Institutes of Health, & National Institute of Mental Health, 2005). Although the exact origin of autism is not yet known, current research suggests the disorder is biological in nature and several possible causes have been determined. Evidence points to underlying brain dysfunction, given that individuals with autism display a range of cognitive functioning with 25% to 50% of people having mental retardation and 50% of individuals with autism having abnormal EEGs (CDC, 2007; Gillberg & Coleman, 1992; Trottier, Srivastava, & Walker, 1999). The CDC (2007) reported that males are more likely to be affected than females, with an average prevalence ratio of 4.3 males to one female. Research suggests autism has a genetic component, with results showing that siblings of individuals with autism have a 3% to 8% chance of also having autism compared to the prevalence rate of the general population of 1% (Volkmar, Chawarska, & Klin, 2005).

#### **History of Autism**

The term autism was coined by Leo Kanner, in 1943, when he was researching 11 young children he described as "socially aloof and indifferent, who were mute or had echolalia and idiosyncratic speech, were intensely resistant to change in their own repetitive

routines, and who had isolated skills in visuo-spatial or rote memory tasks against a background of general delay in learning” (Wing, 1997). In 1966, Victor Lotter completed the first ever epidemiological study of autism, using the two distinctive features Kanner named most important to the disorder, social aloofness and indifference to others, and resistance to change in elaborate repetitive routines (Wing, 1997).

### **History of Asperger’s Syndrome**

One year after Kanner’s research, Hans Asperger, an Austrian pediatrician, described another pattern of behavior in older children and adolescents (Wing, 1997). While the details of Kanner’s and Asperger’s descriptions of their research population were different, there were obvious similarities in their behavior observations. The children Asperger described displayed naïve and inappropriate social interactions, good speech, but used it for monologues on their own special interests, had poor intonation and body language, were absorbed in their circumscribed interests, and often had poor motor coordination (Wing, 1997). They had a range of intelligence from borderline to superior, and often had specific learning difficulties (Wing, 1997). Because Asperger wrote his original paper in German around the time of World War II, it was not widely read in English speaking countries until 1981 (Ozonoff, Dawson, & McPartland, 2002). English neuropsychologist, Uta Frith, translated the paper into English and Dr. Lorna Wing, a researcher from the Institute of Psychiatry in London, summarized it in English (Ozonoff et al., 2002). The similar yet unique descriptions of the two sets of children by Kanner and Asperger are the basis for the diagnoses now referred to as autism and Asperger’s syndrome (Autistic Disorder in the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000).

In 1980, autism was included in the Diagnostic and Statistical Manual, 3<sup>rd</sup> edition (DSM-III) for the first time under a new class of conditions called Pervasive Developmental Disorders (PDD; American Psychiatric Association, 1980). PDDs are developmental disorders affecting multiple areas of development such as communication, social skills, behavior, cognition, and sometimes motor skills (Ozonoff et al., 2002). Presently, the DSM-IV-TR continues to group autism and Asperger's syndrome under the category PDD, along with three other disorders: Pervasive Developmental Disorder-Not Otherwise Specified, Rett's Disorder, and Childhood Disintegrative Disorder (APA, 2000).

### **Autism Spectrum Disorders**

In 1979, researchers Wing and Gould studied a group of children who had an array of disabilities and any feature of autism (Wing, 1997). The broad range of abilities found among these children led to their hypothesis that autism exists on a "wide spectrum of autistic conditions" (Wing, 1997). In 1992, Rutter and Schopler suggested using the term "autistic spectrum disorders" to replace the too generic label, Pervasive Developmental Disorder. Currently, most autism researchers use the term Autism Spectrum Disorder (ASD) to describe the pattern of behaviors among children who experience difficulty in multiple domains of development including social, communication, behavior, and cognition (Ozonoff et al., 2002). Individuals with ASD can be diagnosed with one of five disorders: (a) Autistic Disorder, (b) Asperger's syndrome, (c) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), (d) Rett's Disorder, or (e) Childhood Disintegrative Disorder. For the purposes of this study, Rett's Disorder and Childhood Disintegrative Disorder will be excluded, because they differ from autism in pattern of onset, course, and outcome.



Due to the range in cognitive, social, communication, and behavior patterns among children with ASD, considerable debate exists on the differences between High Functioning Autism (HFA) and Asperger's syndrome; there are generally two camps on this issue. The first argues that Asperger's syndrome is a less severe form of ASD (Baron-Cohen & Hammer, 1997; Manijiviona & Prior, 1999; Wing, 1988). The second group suggests that Asperger's syndrome is, in fact, a separate disorder with clinical and neurobehavioral differences (Rinehart, Bradshaw, Brereton, & Tonge, 2002). The DSM-IV description aligns with the second argument and requires that autism must be ruled out in order to diagnose someone with Asperger's syndrome (APA, 2000).

### **High Functioning Autism Spectrum Disorders**

Rinehart et al. (2002) refer to two subtypes of ASDs that align with the debate between Asperger's syndrome and HFA: "low functioning autism" and "high functioning autism". These distinctions are based on intellectual functioning and possible causes (Note that these distinctions are not made in the DSM-IV; Rinehart et al., 2002). The low functioning type is classified by below average intelligence (i.e., IQ below 70) and may be more likely caused by an acquired or genetically determined source, while the high functioning type is characterized by average intellectual functioning (i.e., IQ above 70), and the absence of "identifiable brain damage, neurological findings, or biological markers" (Rinehart et al., 2002). Prevalence rates estimate that 50% to 75% of individuals with autism have normal intellectual functioning (i.e., IQ above 70; CDC, 2007).

This higher functioning subset of ASD has emerged in the autism literature within the last 20 years and is generally referred to as High Functioning Autism Spectrum Disorder (HFASD). This includes children who meet DSM-IV criteria for Autistic Disorder, PDD-

NOS, or Asperger's syndrome, but have normal intellectual functioning and passable command of language skills (APA, 2000; Ozonoff et al., 2002). HFASD includes the term High Functioning Autism (HFA), despite it not being listed as its own diagnosis in the DSM-IV. Just as debate exists regarding the inclusion of Asperger's syndrome and autism on one or separate spectrums, diagnostic debate exists as to inclusion of the three above mentioned diagnoses under the broader term HFASD (Klin, Pauls, Schultz, & Volkmar, 2005; Lee, 2009; Miller & Ozonoff, 2000). Because all three disorders are similar in their relative strengths in both the cognitive and language aspects that distinguish these children from those with ASD, their strengths can make differential diagnoses complicated (Kasari & Rotheram-Fuller, 2005). Due to the similarities of their relative strengths, many researchers have chosen to include children with these three diagnoses in their interventions (LeGoff, 2004; Solomon, Goodlin-Jones, & Anders, 2004). The main foci of this study will be children with High Functioning Autism Spectrum Disorders and their parents.

#### **DSM-IV-TR Criteria: Autistic Disorder and High Functioning Autism**

The DSM-IV-TR describes Autistic Disorder with the following criteria: (a) a qualitative impairment in social interaction, (b) qualitative impairments in communication, and (c) restricted repetitive and stereotyped patterns of behavior, interests, and activities (APA, 2000). Delays or abnormal functioning must exist in at least one of the following areas with onset prior to age three years: (a) social interaction, (b) language as used in social communication, or (c) symbolic or imaginative play. This study is concerned with the higher functioning population diagnosed as having Autistic Disorder, people with High Functioning Autism (HFA). HFA is not recognized as a stand-alone disorder by the DSM-IV-TR and does not have its own diagnostic criteria (McLaughlin-Cheng, 1998). Children with HFA are

diagnosed with Autistic Disorder in the DSM-IV-TR and have normal intellectual functioning and language skills commensurate to their chronological age (Ozonoff et al., 2002).

### **DSM-IV-TR Criteria: Asperger's Syndrome**

In order to be diagnosed with Asperger's syndrome, an individual must display qualitative impairment in social interaction and restricted repetitive and stereotyped patterns of behavior, interests, and activities. These conditions must cause clinically significant impairment in social, occupational, or other important areas of functioning. To receive a diagnosis of Asperger's syndrome, an individual cannot have had significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years), clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood (APA, 2000). Although individuals with Asperger's syndrome do not have language impairments, language acquisition is not necessarily normal (Toth & King, 2008). Individuals with Asperger's syndrome may exhibit deficits in pragmatic (i.e., social use of) language or use of overly formal or repetitive language (Toth & King, 2008). Gillberg, Cederlund, Lamber, and Zeijlon (2006) estimated the prevalence of Asperger's syndrome to be 9.2 in 10,000.

### **DSM-IV-TR Criteria: Pervasive Developmental Disorder–Not Otherwise Specified**

Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS) belongs to the same class of conditions (PDD) as Autistic Disorder and Asperger's syndrome in the DSM-IV-TR (APA, 2000). This category is used when an individual displays severe and pervasive impairment in the development of reciprocal interaction and impairment in verbal

or nonverbal communication skills or presents with stereotyped behavior, interests, and activities (APA, 2000). Gillberg et al. (2006) have estimated prevalence rates for PDD-NOS to be 23.5 in 10,000.

### **Difficulties for Children with HFASD**

No two children with HFASD are exactly alike in the way their symptoms present in their daily functioning, just as no child will display all the features of HFASD. The following section will describe the symptoms most common among children with HFASD.

**Difficulties in social interaction.** One of the essential deficits characteristic of children with HFASD is in social interactions or social skills. Gresham and Elliot (1990) defined social skills as “socially acceptable learned behaviors that enable a person to interact effectively with others and to avoid socially unacceptable responses”. Neece and Baker (2008) have provided examples of social skills such as sharing, helping, initiating relationships, requesting help, giving compliments, and saying ‘please’ and ‘thank you’. These skills enable children to have successful relationships with peers and family members (Neece & Baker, 2008). For children with HFASD, social impairments may include the use of nonverbal behaviors and peer relationships, a lack of spontaneous enjoyment-sharing with other people, and social or emotional reciprocity (APA, 2000). Children may have difficulty initiating or joining in activities with other children, developing peer relationships, taking the perspective of another person, and using nonverbal behaviors such as eye-to-eye gaze, facial expressions, body postures, and gestures to regulate social interaction (APA, 2000). They may make odd or inappropriate comments, and have difficulty expressing empathy (APA, 2000; Bellini & Hopf, 2007; Epstein, Saltzman-Benaiah, O’Hare, Goll, & Tuck, 2008). Because of these social skill deficits, children with HFASD may become isolated or bullied,

resulting in social anxiety, depression, isolation, and other negative outcomes (Bellini, 2006; Tantam, 2000).

**Difficulties in communication.** The second deficit that characterizes HFASD is the presence of impairment in communication. Although difficulty with communication is a requirement for the diagnosis of Autistic Disorder in the DSM-IV-TR (2000), these impairments are not necessarily found in all children with HFASD. This impairment may manifest as a delay in verbal language, impairment in the ability to initiate or sustain a conversation with others, stereotyped and repetitive use of language or idiosyncratic language, dominating conversations with topics of personal interests, difficulty understanding expressions, and a lack of varied, spontaneous make-believe play or social imitative play as developmentally appropriate (APA, 2000).

**Restricted repetitive and stereotyped patterns of behavior, interests, and activities.** Children with HFASD display restricted repetitive and stereotyped patterns of behavior, interests, and activities. These may be abnormal either in intensity or focus. Children with HFASD may be inflexible with specific, nonfunctional routines or rituals. They may display stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements) or have a persistent preoccupation with parts of objects (APA, 2000).

**Exceptions in difficulties of children with Asperger's syndrome.** The diagnostic criteria for Asperger's syndrome are different from those of autism in the area of communication. To receive a diagnosis of Asperger's syndrome, a child must not have a clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years). Having significant delays in cognitive

development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood also preclude one from receiving the Asperger's syndrome diagnosis.

### **Summary of Deficits Experienced by Children with HFASD**

Children with HFASD may have difficulty establishing and maintaining interpersonal relationships with others as well as communicating with peers, siblings, and adults (Bellini & Hopf, 2007; Epstein et al., 2008). Processing and integrating information from the environment and participating in new environments may present significant barriers for children with HFASD (Bellini & Hopf, 2007). They may struggle to share enjoyment or initiate interactions with others, take another's perspective, and infer the interests of others (Bellini & Hopf, 2007). If left untreated, these impairments can lead to poor academic achievement, social failure and peer rejection, anxiety, depression, substance abuse, and other forms of psychopathology (Bellini, 2006, La Greca & Lopez, 1998; Tantam, 2000). Despite the aforementioned deficits, children with HFASD usually demonstrate at least average or above average levels of cognitive ability. While children with HFASD exhibit relative strengths in cognitive ability and language, their significant social deficits, restricted and repetitive interests and behaviors, and poor social-pragmatic communication frequently interfere with family functioning.

### **Parenting Stress**

Abidin (1995) defined parenting stress as the parent's internal response to the relationship between the parent and the child. It is the combination of the demands of parenting with the parent's perception of the accessibility and availability of resources (Abidin, 1995). While it is expected that all parents experience stress as their children

develop, the presence of certain factors, such as difficult child characteristics or a disability, can increase stress levels (Mash & Johnston, 1990).

**Parenting stress and children with developmental disabilities.** Extensive research efforts have detailed the elevated levels of stress associated with parenting children with physical, learning, and developmental disabilities (Cameron, Dobson, & Day, 1991; Cameron & Orr, 1989; Dumas et al., 1991; Fuller & Rankin, 1994; Innocenti, Huh, & Boyce, 1992; Kazak & Marvin, 1984; Konstantareas & Homatidis, 1989). Parents of children with developmental disabilities experience increased stress and are consequently at an elevated risk for psychological distress (Wolf, Noh, Fisman, & Speechly, 1989). Evidence indicates that stress experienced by parents has a major impact on the parent-child system (Abidin, 1983; Mash & Johnston, 1983, 1990). Without proper treatment, chronic parenting stress can increase the likelihood of a parent committing child abuse and neglect (Wolfe, 1993, 1994), as well as poor mental health outcomes for the parent such as depression (Benson & Karlof, 2009).

**Parenting stress and ASD symptomatology.** Parenting stress has been a frequently researched aspect among families of a child with ASD. Children with autism present stress for parents related to difficulties with communication, behavior, social skills and isolation, self-care, and lack of community understanding. When compared to parents of children with intellectual or other developmental disabilities, research shows that parents of children with ASD experience more psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic symptoms (Baker et al., 2003; Bristol & Schopler, 1984; Donovan, 1988; Dumas et al., 1991; Higgins et al., 2005; Sivberg, 2006; Weiss, 2002; Yirmiya & Shaked, 2005). Boyd (2002) suggested higher stress

levels in parents are associated with the child's specific disability. In another study comparing young children with autism to children with other developmental problems, the parents of the children with autism reported feeling their child was harder to care for than most same-aged children, being bothered by things their child did, and giving up more of their life than expected to meet their child's needs (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Sanders and Morgan (1997) reported higher levels of stress in parents of children with autism when compared to parents of children with Down syndrome. These results were true for both mothers and fathers. In summary, parents of children with ASD have been reported to experience more stress than parents of children with other developmental disabilities, suggesting the need to identify the specific factors associated with this increase.

Researchers have found the severity of ASD symptomatology to be positively associated with parental stress (Hastings & Johnson, 2001; Kasari & Sigman 1997; Konstantareas & Homatidis 1989; Freeman et al., 1991; Tobing & Glenwick, 2002). More specifically, the presence of symptoms such as hyperirritability, self-injurious behaviors, cognitive level of functioning, presence of seizures, and dysmorphic features were found to be highly associated with more parenting stress (Lecavalier, Leone, & Wiltz, 2006). The following literature review will explore evidence supporting the need to better understand characteristics associated with children with ASD (i.e., difficulty with social skills, restricted repetitive and stereotyped patterns of behavior, and communication difficulties) and their effect on parenting stress. Other parent and child factors shown to affect parenting stress among parents with children with ASD will also be described.



*Parenting stress associated with ASD and social skills.* One of the major deficits in children with ASD is difficulty with social or interpersonal relationships. In a study investigating the associations between parenting stress, the specific symptoms of ASD, and social competence, researchers found the most consistent predictor of parenting stress for both mothers and fathers was the child's delays/deficits in social skills (Ornstein-Davis & Carter, 2008). In the same study, mothers who reported lower levels of child social relatedness also reported higher overall stress (Ornstein-Davis & Carter, 2008). Kasari and Sigman (1997) examined the responsiveness of children with autism in their study and found children who were more responsive in their interactions with the experimenters had parents who reported lower levels of parenting stress.

Because most studies on parents of children with autism focus on young children, additional research is needed to describe the developmental and social transitions that begin during middle childhood and early adolescence. Moving through middle childhood, a number of significant social changes occur that are vitally important to a child's social skills and social relationships. As children's social relationships change from more casual and fleeting to more stable, rigid, and restricted relationships, it becomes more evident who does and does not belong to particular social groups (DeRosier, 2007). As youth struggle to be accepted socially, social pressures intensify and affect youth's social comfort (Brown, 1990; O'Brien & Bierman, 1988). As children reach adolescence, their social interactions become more conversation-based rather than play- or activity-based (DeRosier, 2007). The social skills needed to develop and maintain these relationships are difficult for most children with autism (e.g., support, validation, sharing intimate thoughts and feelings, being sensitive to the needs of others). In sum, this transition stage from childhood to adolescence is likely a time

when children with HFASD begin to receive higher levels of negative feedback from their peers for their lack of social skills. As these children receive this negative feedback, parents may become more aware of their children's deficits and feel increased levels of stress.

Some studies have found that mothers of older children with autism are likely to be more adversely affected than those with younger children (Gray & Holden, 1992; Holroyd, Brown, Wikler & Simmons, 1975; Konstantareas & Homatidis, 1989). Bebko, Konstantareas, and Springer (1987) also found that with older children, although parents reported less severe symptoms, they remained just as stressed as parents with younger children. In a study with parents of children with Asperger's syndrome or Nonverbal Learning Disability, higher pessimism was positively correlated with the child's age, suggesting that parents were more pessimistic if they had an older child (Little, 2002). Little (2002) has suggested that parent's pessimism may increase because the social deficits of children with Asperger's syndrome become more obvious as the child gets older.

In addition to the social changes occurring during middle childhood, the age at which children with HFASD are diagnosed may lend weight to the argument to study parenting stress of children between the ages of eight and twelve. Children who are diagnosed with autism and have average or higher IQs are generally identified at a later age than those with cognitive impairments (Shattuck et al., 2009). Shattuck et al. (2009) found a median age for children with autism and a cognitive impairment to be 5.1, while the median age for children with ASD and IQ higher than 70, was 7.1 (Shattuck, et al, 2009). It is possible that the age at which children with HFASD are diagnosed or length of time between the onset of ASD symptoms and the diagnosis and treatment affects the stress levels of parents of children of

HFASD. In sum, parents of children with HFASD may experience high levels of stress that are unique to their age or developmental levels and should be explored further.

***Parenting stress associated with ASD and restricted repetitive and stereotyped patterns of behavior, interests, and activities.*** Another core symptom of ASD that may contribute to heightened stress experienced by parents is the child's restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. Learning to cope with and adjust to the challenges associated with parenting a child with ASD, such as their need for sameness and ritualistic behaviors, has been shown to be a significant source of stress for parents (Twoy, Connelly, & Novak, 2007). Konstantareas and Homatidis (1992) reported the self-injurious behaviors displayed by children with autism were the best predictors of higher stress levels for parents. In another study by Konstantareas (1991), parents were found to be distressed by different expressions of their child's autism behaviors. Mothers of children in this study were most distressed by more visible, immediate, and embarrassing behaviors such as stereotypical and bizarre use of their bodies. Finally, Lecavalier et al. (2006) conducted a multiple regression analysis and found that after conduct problems and lack of prosocial behaviors, self-isolated/ritualistic behaviors (i.e., shy, ritualistic, isolating, odd, and repetitive behaviors) were the most strongly associated with caregiver stress. While these behaviors have been found to increase stress for parents, when compared to other core ASD symptoms, these behaviors may be less stressful for parents than others, such as social difficulties. For example, Bebko et al. (1987) found a child's difficulty with change was the least stressful for parents among all the symptoms associated with ASD.

***Parenting stress associated with ASD and communication.*** Communication difficulties and their relationship to parenting stress have not been studied as extensively as

other characteristics of ASD. In a study of parents of children with developmental disabilities, not including autism, the findings clearly demonstrated a statistically significant and strongly negative relationship between the level of total parenting stress and the child's ability to communicate (Ello & Donovan, 2005). In 1987, Bebko et al. found a similar relationship between parenting stress and communication among families with children with autism. They examined the relationship of the core autism features to parents' stress and found that verbal expression difficulties were one of the most stressful features of the child's disability for both mothers and fathers. However, more recently, Ornstein-Davis and Carter (2008) examined the core deficits associated with ASD and found autism specific communication skills were not salient predictors of stress for mothers and were only associated with fathers' perceptions of child difficulty. They did, however, suggest that since parents of very young children were sampled, parents of young children as a group may not have clear expectations for appropriate language development and thus may not have attributed their stress to their child's difficulties in communication (Ornstein-Davis & Carter, 2008). Konstantareas (1991) found that fathers of children with autism were more stressed by their inability to communicate than mothers.

**Parenting stress associated with ASD and behavior problems.** Although behavior problems, such as aggression or impulsivity, are not necessary for a diagnosis of ASD, they are common among children on the autism spectrum (Brereton, Tonge, & Einfeld, 2006; Gadow, Devincent, Pomeroy, & Azizian, 2005). The association between parenting stress and behaviors displayed by children with ASD has a solid research base. Several studies with parents of children with ASD have found the child's behavior or conduct problems were most strongly related to parent stress, rather than other autism symptoms, severity of

developmental delay, or adaptive skills (Bromley, Hare, Davison, & Emerson, 2004; Hastings et al., 2005; Lecavalier et al., 2006). In 2004, a study examining parenting stress among mothers of children with intellectual disabilities (23 of 74 had ASD), found high rates of child problem behaviors combined with limited prosocial behaviors were associated with higher parenting stress (Beck, Hastings, & Daley, 2004). In a study examining the associations between parenting stress (both mother and father) and characteristics of autism, mothers were found to be impacted more by problematic behaviors than social deficits (Ornstein-Davis & Carter, 2008). The same study examined behavior problems that were not characteristics of ASD and found an association with parental stress (Ornstein-Davis & Carter, 2008). Ornstein-Davis and Carter (2008) also found that for fathers, externalizing behaviors that may be difficult to manage or which draw negative attention in public were the primary non-core autism behavior that was associated with stress. Konstantareas and Papageorgiou (2006) also examined parenting stress in relationship to characteristics of children with autism. This study found the child's general activity level was a highly significant predictor of stress followed by the child's mood and ASD symptoms as the next best predictors of parenting stress. These findings suggest a significant relationship between parenting stress and behavior problems among children with ASD. Assessing this relationship, in addition to the effects of ASD core symptoms, is especially important given these findings.

**Parenting stress associated with ASD and cognitive functioning.** Another factor often mentioned in the literature on ASD and parenting stress is the child's level of cognitive functioning. Studies exploring the contributions of children's core autism behaviors to parents' stress found uneven cognitive abilities were among the autism related symptoms that

were most stressful for mothers and fathers of school aged children (Bebko et al., 1987; Koegel et al., 1992). This particular deficit is likely related to a parent's concern over the potential for their child to be dependent and need lifelong care due to the restrictions cognitive limitations can present (Koegel et al., 1992). Another study suggests mothers of children with both autism and cognitive limitations may experience higher levels of stress due to the child's potential for long-term dependency (Robbins et al., 1991). However, more recent studies have found contradicting evidence such as the study by Ornstein-Davis and Carter (2008) who found that verbal functioning was not a salient predictor of stress for mothers or fathers.

**Parenting stress and social support.** As Abidin (1995) suggests in his description of parenting stress, the parents' perception of their access to resources of support is vital to balance the demands of children with disabilities or behavior problems. Social support can be defined as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support (Dunst, Trivette, & Cross, 1986). Formal and informal services provided by professionals or organizations that the family finds useful are also considered social support (Boyd, 2002).

Boyd (2002) suggests the characteristics associated with the child are one of the primary factors in leading a parent to seek social support to alleviate stress. The best predictors of a family seeking out social support are the child's behavior problems, dependency on the caregivers, and need for assistance with self-help skills (Boyd, 2002). Families with children with ASD and behavioral difficulties feel increased external pressure to seek social support due to the child's behavior and ASD symptoms (Boyd, 2002).

Many studies have documented the link between parenting stress and social support for parents of children with disabilities and these findings have been duplicated for parents of children with ASD. Boyd (2002) examined two studies of mother's stress and social support networks. These studies found mothers with larger social support networks experienced lower stress levels, while mothers with little social support had high levels of stress. Sharpley, Bitsika, and Efremidis (1997) found social support is undoubtedly valuable to parents of children with autism and even more so when immediate family members giving support are knowledgeable of the child's difficulties. This study also found that for parents without access to family members providing child care, higher levels of depression, anxiety, daily level of stress, and frequency of being stretched beyond their limits were reported (Sharpley et al., 1997). In a study by Tway et al. (2007), parents of children with ASD evidenced resiliency in adapting to the challenges of caring for and raising a child with autism. The families reported using social support systems within the family's social network as a part of their coping strategy. Social support may in fact influence the effects of the level of child disability on parenting stress (Plant & Sanders, 2007). In summary, these findings suggest social support can affect stress levels experienced by parents of children with ASD and will therefore be examined as a moderator in this study.

**Parenting stress and negative child outcomes.** Just as child characteristics, such as behavior problems or symptoms of autism, can have a critical impact on a parent's environment, aspects of the parents can interact with the characteristics of the child. Parents of children with ASD who have high levels of stress are not only at risk for their own poor mental health outcomes, but they may also contribute to increased difficulties experienced by their children. In a study investigating the effectiveness of early and intensive intervention

services for children with ASD in reducing parenting stress, evidence was found linking elevated parenting stress to fewer gains made by the child (Osborne et al., 2008). Studies seeking to improve the core characteristics of ASD in children have found that parenting stress is associated with fewer improvements (Gabriels, Hill, Pierce, Rogers, & Wehner, 2001). Not only can parenting stress impact gains made by the child in interventions, parenting stress may also increase the child's behavior problems. Baker and colleagues (2003) studied parenting stress over a one-year period and found that maladaptive child behavior and parenting stress have a mutually escalating effect on each other. In a study on the effects of maternal depression on child outcomes, parental warmth and involvement were found to be associated with child externalizing problems (McKee et al., 2008). The same study found that low levels of support, warmth, and involvement interfere with the child's ability to regulate arousal and as a result the child may be less able to consider the consequences of his or her actions and refrain from problematic, acting-out behaviors. These studies suggest the outcomes of parenting stress such as depression or anxiety have a negative effect on child behavior and intervention effectiveness. Thus, intervention developers and implementers must consider the interactions between parents and their children with ASD. More specifically, factors that could impede these interventions and exacerbate ASD symptoms and problematic behaviors should be identified. By improving skills in the symptom areas that affect parenting stress, parents will be better equipped to aide in their child's interventions rather than impede them.

**Stress in parents of children with HFASD.** Unfortunately, there are very few studies that have explored the characteristics associated with stress of parents with children with HFASD. Children with HFASD may differ from children with lower functioning ASD



because they may not have significant speech and language disorders or below normal intellectual functioning. While some might interpret the strengths of children with HFASD as evidence that their parents are less susceptible to experiencing parenting stress, these strengths may in fact lead to stress caused by other factors. Epstein et al. (2008) posit that characteristics unique to children with higher functioning types of ASD may also create stress for parents (e.g., difficulties pursuing a psychological evaluation when the child seems to be functioning well in many domains; fewer/less severe symptoms causing hesitance from the diagnostic professional and a longer diagnostic process).

In the few studies that have examined stress levels of parents with children with HFASD, the results are quite similar to studies examining children across the spectrum. There appears to be sufficient evidence to support the hypothesis that parenting stress levels may vary by the child's HFASD symptomatology. One study examining health related quality of life of parents with children with HFASD found higher levels of anxiety and poorer physical health compared to typically developing children (Allik, Larsson, & Smedje, 2006). In mothers specifically, better mental health was associated with lower scores of parent-rated hyperactivity and conduct problems in the child. Little (2002) found similar results regarding anxiety and levels of stress among parents of children with HFASD. Unfortunately, Little (2002) combined these results with children with a Nonverbal Learning Disability, making it difficult to generalize findings to parents of children with HFASD specifically. Epstein et al. (2008) found that for parents of children with Asperger's syndrome, a significant positive correlation existed between mother's stress and the child's level of impairment in executive dysfunction and sensory difficulties. In a study comparing children with HFASD and children with ASD, children with HFASD were found to have less

secure attachments to their parents and their parents reported more daily hassles from their children (Rutgers et al., 2007). Finally, a study comparing children with higher and lower functioning ASD found the group with normal intelligence displayed more psychiatric symptoms such as oppositional defiant behaviors, obsessions, anxiety, and depression (Gadow et al., 2005). Given the paucity of research on stress levels of parents of children with HFASD, this study will explore effects of the total symptomatology associated with HFASD (social, communication, and repetitive and stereotypical behaviors) on parenting stress. This study will also examine the unique effects that each of the three core autism deficits (social, communication, and repetitive and stereotypical behaviors) have on parenting stress.

### **Summary of Literature Review**

The significant increase in children diagnosed with autism spectrum disorders in the last 20 years has sparked interest in intervention strategies for children with ASD and their families. Children with High Functioning Autism Spectrum Disorders (HFASD) experience difficulties in social skills and with restricted repetitive and stereotyped behaviors, but have normal intellectual functioning and language skills that distinguish them from other children with ASD. Because children with HFASD have relative strengths that often disguise their significant social deficits, parents may in turn experience elevated stress levels associated with finding and qualifying for services.

Extensive research has shown that compared to parents of children with and without disabilities, parents of children with ASD experience far more negative outcomes, such as depression, anxiety, increased somatic complaints, and parenting stress. Parents of children with HFASD also experience higher levels of anxiety, poorer physical health, and more

psychiatric symptoms. Several studies suggest psychological distress among parents of children with ASD varies by the characteristics associated with the child's condition and the severity of those characteristics. The struggle to find and maintain support services for their child, in addition to the effects of the child's HFASD symptomatology, may increase parents' stress levels.

### **Statement of the Problem**

**Purpose of the study and research questions.** This study explored the relationships between stress levels of parents with children with High Functioning Autism Spectrum Disorders (HFASD) and the symptomatology of HFASD. While the main questions of the study pertain to child symptoms of HFASD, parent social support and child behavior problems were also assessed because they have been shown to affect parenting stress and could therefore serve as moderators of parental stress levels. Potential factors were measured through parent self-report (parenting stress, social support), and parent report of the child (difficulties with: social skills; communication; restricted, repetitive, and/or stereotyped behaviors, interests, and activities; and behavior problems). This study sought to ask seven main questions relating to the stress levels of parents of children with HFASD.

**Question One:** Do parents of children with HFASD experience higher levels of parenting stress than the normative population (normative population from Parenting Stress Index (PSI), see description of this population in the measures section).

Studies clearly show that parents of children with ASD experience more psychological distress including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic symptoms, compared to parents of children with intellectual or other developmental disabilities (Baker et al., 2003; Bristol & Schopler,

1984; Donovan, 1988; Dumas et al., 1991; Higgins et al., 2005; Sivberg, 2006; Weiss, 2002; Yirmiya & Shaked, 2005). While an abundance of research exists on parenting stress and negative outcomes for parents of children with autism spectrum disorders more generally (i.e., Autism), very few studies have examined outcomes specifically for parents of children with HFASD. Examining parents of children with HFASD specifically is essential due to the unique stressors they suffer related to the higher functioning nature of their child's disorder. It is possible that levels of parenting stress could increase due to difficulty accessing resources. Parents are faced with the arduous process of pursuing a psychological evaluation and a clear diagnosis when their child appears to be functioning well in many domains or have negative interactions with a diagnostic professional who hesitates to give a diagnosis because the symptoms associated with HFASD may appear less severe (Epstein et al., 2008). The few studies focusing on parents of children with HFASD suggest they experience more frequent negative outcomes often associated with stress, such as anxiety and poor physical health, supporting the hypothesis that they also experience high levels of parenting stress (Allik, Larsson, & Smedje, 2006; Little, 2002). It is important to note however, that although these studies investigated negative outcomes that are often associated with stress such as depression and anxiety, they did not address parenting stress specifically, nor did they examine the possible child characteristics that affect levels of parenting stress. Only one study was found that examined parenting stress among parents of children with HFASD. Epstein et al. (2008) found that 75% of the parents in their sample reported high levels of stress. While these findings suggest that parents of children with higher functioning autism spectrum disorders do indeed experience elevated stress levels, the findings are limited by the sample being exclusively parents of children with Asperger's syndrome. In order to address

this issue, the current study included parents of children with Asperger's syndrome as well as parents of children with Autistic Disorder or PDD-NOS and normal intelligence (HFASD). The inclusion of these three disorders in this study mirrors the intervention design of current researchers who target the overlapping core deficits observed in children with HFASD (LeGoff, 2004; Solomon et al., 2004). Given the research findings linking parents of children with ASD to high levels of stress, the emergence of negative outcomes experienced by parents of children with higher functioning types of ASD, and the difficulty accessing resources unique to parents of HFASD, the current study hypothesized high levels of parenting stress would be found among parents of children with HFASD.

***Hypothesis One:*** Parents of children with HFASD experience higher levels of parenting stress than the normative population.

***Question Two:*** Are behavior problems of children with HFASD a significant predictor of parenting stress, after controlling for parental social support?

Significant evidence exists supporting the relationship between child behavior problems and high levels of parenting stress among children with and without disabilities (Bromley, Hare, Davison, & Emerson, 2004; Hastings et al., 2005; Lecavalier et al., 2006; Long, Gurka, & Blackman, 2008). While behavior problems, such as aggression or impulsivity, are not one of the core deficits associated with autism spectrum disorders, they are commonly observed in these children (Baker et al., 2003; Brereton, Tonge, & Einfeld, 2006; Gadow et al., 2005). One study comparing children with higher and lower functioning ASD found the group with normal intelligence displayed more psychiatric symptoms such as oppositional defiant behaviors, obsessions, anxiety, and depression (Gadow et al., 2005). Researchers have established significant support for the relationship between parenting stress

and child behavior problems in children with ASD (Bromley, Hare, Davison, & Emerson, 2004; Hastings et al., 2005; Lecavalier et al., 2006). Few studies have been conducted that examine levels of parenting stress in parents of children with both normal intelligence and ASD (HFASD). These studies have found a relationship between high levels of parental anxiety and poor physical health to be associated with child behavior problems, hyperactivity, and conduct problems (Allik, Larsson, Smedje, 2006; Little, 2002). However, Little combined these results with children with a Nonverbal Learning Disability, making it difficult to generalize findings specifically to parents of children with HFASD. Epstein et al. (2008) found that for parents of children with Asperger's syndrome, there was a significant positive correlation between mother's stress and the child's level of impairment in executive dysfunction and sensory difficulties. These impairments may result in a child acting out or expressing external behaviors out of frustration and therefore impact parenting stress. These findings suggest a significant relationship between parenting stress and behavior problems among children with ASD. Assessing this relationship, in addition to the effects of ASD core symptoms, is especially important to aid intervention developers in targeting the characteristics of children with HFASD that are most stressful for parents.

***Hypothesis Two:*** Behavior problems of children with HFASD are a significant predictor of higher parenting stress.

***Question Three:*** Do the social difficulties of children with HFASD predict higher parenting stress after controlling for behavior problems and parental social support?

Social skills, one of the core areas of difficulty associated with children with ASD, have been found to be a consistent predictor of parenting stress in the general ASD population (Kasari & Sigman, 1997; Ornstein-Davis & Carter, 2008). However, this

relationship remains untested for parents of children with HFASD. A child's level of social skills may affect levels of parenting stress because social skills such as empathy or cooperation may affect the quality of a parent-child relationship. If a child is missing these skills, the parents may feel frustration or a feeling of being unfulfilled or appreciated by their children and that may in turn, affect levels of parenting stress. Given the promising findings in the literature for parents of children with ASD, it was hypothesized in this study that the relationship between difficulties with social skills and higher levels of parenting stress would remain true for children with HFASD.

***Hypothesis Three:*** The social difficulties of children with HFASD are a significant predictor of higher parenting stress.

***Question Four:*** Do the communication difficulties of children with HFASD predict higher parenting stress after controlling for behavior problems and parental social support?

For parents of children with ASD, some studies have found that difficulties with communication (such as verbal expression) are one of the most stressful features of the child's disability for both mothers and fathers (Bebko et al., 1987). However, contradicting evidence suggests communication skills are not salient predictors of parenting stress for mothers, but are associated with fathers' perceptions of child difficulty (Konstantareas et al., 1991; Ornstein-Davis & Carter, 2008). Ornstein-Davis and Carter (2008) proposed the parents in their ASD sample may not have attributed their stress to their child's difficulties in communication for two reasons: (a) as a parent of a young child they may have unclear expectations for appropriate language development; or (b) they may experience optimism about their child's language development due to their child's inclusion in early intervention services with a strong emphasis on language development. Taking these theories further, it

may be possible that parents of children with HFASD experience high levels of stress because of their child's relative strengths in communication. These unique stressors could originate from the misperceptions of teachers, family members, or the community that the child has a normal IQ and should therefore be able to function similarly to a child without a disability.

***Hypothesis Four:*** The communication difficulties of children with HFASD are a significant predictor of high parenting stress.

***Question Five:*** Do the restricted, repetitive, and/or stereotyped behaviors, interests, and activities of children with HFASD predict higher parenting stress after controlling for behavior problems and parental social support?

Theories of parenting stress suggest that one of the most stressful factors associated with parenting a child with ASD is the poor acceptance of the child's autistic behaviors by society and even by other family members (Sharpley et al., 1997). The majority of research studies agree that stress levels of parents with children with ASD are positively correlated with the severity and frequency of restricted, repetitive and stereotyped patterns of behavior, interests, and activities characteristic of children with ASD (Konstantareas et al., 1991; Tzoy et al., 2007). In contrast, some studies have found that although restricted, repetitive and stereotyped behaviors are positively correlated with parenting stress, these behaviors are not as stressful for parents as other child characteristics such as conduct problems, lack of prosocial behaviors, social difficulties, language difficulties, and cognitive impairments (Bebko et al., 1987; Lecavalier et al., 2006). There are no studies investigating the relationship between parenting stress and restricted, repetitive and stereotyped behaviors among children with HFASD. Given that children with HFASD display restricted, repetitive



and stereotyped behaviors at the same rate and severity as children with ASD, it is likely that these behaviors will impact parenting stress similarly for parents of children with HFASD (Cuccaro et al., 2007).

***Hypothesis Five:*** The restricted, repetitive, and/or stereotyped behaviors, interests, and activities of children with HFASD are a significant predictor of high parenting stress.

***Question Six:*** Is the total HFASD symptomatology (combined difficulties in social, communication, and restricted, repetitive, and/or stereotyped behaviors, interests, and activities) of children with HFASD a significant predictor of high parenting stress after controlling for behavior problems and parental social support?

Researchers have examined ASD symptomatology for the individual characteristics common among children with ASD (difficulties in social, communication, and restricted, repetitive, and/or stereotyped behaviors) as well as the impact of a child's total ASD symptomatology. Researchers studying the impact of the total ASD symptomatology found that the overall severity of the child's autism (the sum of all symptom ratings) was related to the parents' degree of stress (Bebko et al., 1987). A number of studies on children with ASD separately examined each of the three subdomains of dysfunction associated with ASD to identify potential areas of intervention (Konstantareas & Homatidis, 1992; Lecavalier et al., 2006; Ornstein-Davis & Carter, 2008; Twoy et al., 2007). Conversely, some researchers suggest the symptoms of ASD are part of a singular underlying factor encompassing the three criterion domains for all autism spectrum disorders (Constantino & Gruber, 2004). The current study therefore utilized the notion that the symptoms of ASD are part of a single factor and examined total ASD symptomatology as a predictor of parenting stress.

***Hypothesis Six:*** The total HFASD symptomatology of children with HFASD is a significant predictor of higher parenting stress.

***Question Seven:*** Does social support moderate the relationship between child characteristics and parenting stress?

Many studies have found social support to be a moderating variable for parenting stress with children with many disabilities including ASD (Pakenham, Sofronoff, & Samios, 2004; Plant & Sanders, 2007; Pottie & Ingram, 2008). Research on parenting stress and social support suggests that two primary stressful factors associated with parenting a child with ASD are poor familial and societal acceptance of autistic behaviors and low levels of social support received by parents (Sharpley et al., 1997). Parents without access to family members providing child care report higher levels of depression, anxiety, and frequency of being stretched beyond their limits (Sharpley et al., 1997). Not only does social support negatively affect levels of parenting stress, it has also been found to buffer against stress (Bailey, Wolfe, & Wolfe, 1994; Bristol & Schopler, 1983; Goode et al. 1998). This dissertation hypothesized there would be an interaction (moderating) effect between child characteristics (i.e., HFASD symptomatology, behavior problems) and social support on parenting stress, given previous findings linking social support and parenting stress (Holmbeck, 1997; Baron & Kenny, 1986).

***Hypothesis Seven:*** Parental social support moderates the relationship between child characteristics and parenting stress.

## **Chapter Three:**

### **Method**

#### **Participants**

**Demographics.** The participants for the study included children ages 8 to 12 years old with HFASD and one of their parents. Parent-child dyads were recruited from central North Carolina using flyers sent to school counselors in Wake, Chatham, Chapel Hill/Carrboro, Johnston, and Durham County School Systems, the North Carolina Autism Society, and the offices of pediatricians in Wake County, North Carolina. The parent who completed the eligibility questionnaires was asked to be the primary informant for the duration of the study. This study included both mothers and fathers as the primary respondent (one parent per child). Sixteen percent of families participating in the study had a total household income between \$25,000 and \$50,000, 15% had a total household income between \$50,001 and \$75,000, 29% had a total household income between \$75,001 and \$100,000, and 40% had a total household income above \$100,000. In this study, 41% of children had a diagnosis of Autism (High Functioning), 39% had a diagnosis of Asperger's syndrome, 17% had a diagnosis of PDD-NOS, and 4% had a different diagnosis (one participant). The one participant without a Pervasive Developmental Disorder diagnosis was admitted to the study because he/she was undergoing an evaluation to confirm or rule out an autism spectrum disorder. Child participants in this study had an average WISC-IV Verbal Composite Score of 107.98 (SD=15.42). Forty-three percent of child participants had a WISC-IV Verbal Composite Score between 85 and 100. Fifty-seven percent of child

participants had WISC-IV Verbal Composite Score above 100. Data were collected on several other child and family demographic factors including gender of parent and child, race/ethnicity of parent and child, parental education, and marital status of parents.

Distribution of these variables among the participants is displayed in Table 1.

Table 1.

*Participant Demographic Variables*

Demographic Variables	Child (n = 55)		Mother (n = 49)		Father (n = 6)	
Gender						
Male	98.2%	(54)			10.9%	(6)
Female	1.8%	(1)	89.1%	(49)		
Ethnicity						
Hispanic or Latino	0%	(0)	1.8%	(1)	1.9%	(1)
American Indian/Alaska Native	1.8%	(1)	1.8%	(1)	0%	(0)
Asian	3.6%	(2)	3.6%	(2)	3.7%	(2)
Black or African American	1.8%	(1)	1.8%	(1)	1.9%	(1)
White	92.7%	(51)	90.9%	(50)	94.4%	(52)
No Response					5.6%	(3)
Level of Parental Education						
HS graduate or equivalency exam			3.6%	(2)	7.3%	(4)
Some college			12.7%	(7)	9.1%	(5)
Associate degree			5.5%	(3)	5.5%	(3)
College graduate			41.8%	(23)	32.7%	(18)
Some graduate school			9.1%	(5)	5.5%	(3)
Graduate professional degree			27.3%	(15)	36.4%	(20)
No Response					3.6%	(2)

*Note.* The gender category represents the make-up of the parents who were the primary respondent for the study. The other categories indicate characteristics of the child’s parents regardless of the parents’ participation in this study.

**Procedures**

The present study was conducted using data from a larger study directed by the 3-C Institute for Social Development in Cary, North Carolina. The larger project was a clinic-based study of the effectiveness of a social skills group intervention for children with high functioning autism spectrum disorders ages 8 to 12 years. The following procedures were conducted prior to the current investigation.

**Inclusion procedures.** To be considered for inclusion in the larger study, children had to meet several conditions. First, the child must have had a parent-reported diagnosis of Autism (high functioning), Asperger's syndrome, or high functioning Pervasive Developmental Disorder Not Otherwise Specified. Second, the child must have had normative intellectual functioning as reported by a parent.

To determine a child's eligibility for the study, parents completed three eligibility measures to corroborate the reported high functioning autism spectrum disorder diagnosis: (a) the Social Communication Questionnaire (SCQ), (b) the High Functioning Autism Spectrum Screening Questionnaire (ASSQ), and (c) the Childhood Asperger Syndrome Test (CAST). This method of determining diagnosis was based on research by Ouellette-Kuntz et al. (2006), in which they sought a method for confirming an ASD diagnosis that would be more feasible in large epidemiological studies than giving the gold-standard diagnostic assessments of the Autism Diagnostic Interview-Revised (ADI-R) or the Autism Diagnostic Observation Schedule-Generic (ADOS-G). They found that when all three of these measures were given, the reliability of an accurate identification of a child with ASD was 100%. Following the methodology suggested by this research, children that met the parent reported cut-off scores on any one of the three screeners were scheduled for an individual assessment session to measure the child's ability to comprehend verbal information presented in the intervention and to rule out behavior problems that would negatively affect group functioning. Children with a Verbal Comprehension Index (VCI) score greater than or equal to 85 on the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV) and a T score of less than or equal to 70 on the Aggression Scale of the Child Behavior Checklist (CBCL) were included in the trial. Families that did not meet criteria for the study were

given a list of alternate resources in central North Carolina that offer group or individual services for those in need of social skills or autism related services.

**Data collection procedure.** Once eligibility was established, parent-child dyads were invited to attend a two-hour assessment session. With the assistance of trained research assistants, children completed a measure of social skills. Simultaneously in a separate room, parents completed measures of their child's social problem-solving abilities and social skills, as well as measures of their own stress levels, social support, and demographic information.

### **Measures**

**Inclusion measure.** The Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) is a 40-item yes-or-no instrument, previously known as the Autism Screening Questionnaire (ASQ). It is used to evaluate a child's communication skills, level of social functioning, and the presence of autistic mannerisms (Ehlers, Gillberg, & Wing, 1999). The SCQ was completed by a parent or primary caregiver and required less than 10 minutes to complete. It is based on the more comprehensive Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and has been found to have good validity in its initial validation study (Sensitivity=0.85; Specificity=0.75; Berument, Rutter, Lord, Pickles, & Bailey, 1999) and in a more recent follow-up validation study (Sensitivity=0.88 and Specificity=0.72; Chandler et al., 2007). Each item is scored 0 or 1, with 1 being the score endorsing each symptom of autism (Charman et al., 2007). The SCQ measures the three core deficits of autism: Social Interaction, Communication/Abnormal Language, and Stereotyped Behavior. As reported by Berument et al. (1999), the alpha reliability coefficient for the total scale was 0.90, 0.91 for the Social Interaction domain, 0.71 for the Communication/Abnormal Language factor, and 0.67 for the Stereotyped Behavior factor.

Cronbach's alpha for the SCQ total scale in the current sample was 0.73. This questionnaire was used as one of the three screeners of ASD. In the present study, a cutoff score of 15 was utilized to determine the child's eligibility as suggested by Ouellette-Kuntz et al. (2006). The SCQ subscale scores (Communication/Abnormal Language, and Stereotyped Behavior) were also used as independent variables for the core deficits of ASD.

**Inclusion measure.** The High Functioning Autism Spectrum Screening Questionnaire (ASSQ) is a 27-item questionnaire used to identify children and adolescents with higher-functioning ASDs (i.e., children with normal intelligence or mild mental retardation). In the present study, this questionnaire was used as one of the three eligibility screeners to identify children with possible HFASD. The ASSQ measures parent reported child social interaction, communication problems, and restricted and repetitive behaviors. Parents rated items on a 3-point scale ranging from 0 (indicating normality), 1 (indicating some abnormality), and 2 (indicating definite abnormality; Ehlers et al., 1999). In epidemiologic studies conducted in the United States, scores of 15 or higher are typically used for parental responses to identify children with high functioning autism spectrum disorders. The ASSQ has good test-retest reliability for parent report,  $r = .96$ , interrater reliability,  $r = .77$ , and concurrent validity for identifying children with high functioning autism spectrum disorder (Ehlers et al., 1999). In the current sample, Cronbach's alpha was 0.81.

**Inclusion measure.** The Childhood Asperger Syndrome Test (CAST) is a 37-item parental self-completion questionnaire designed to screen for high functioning autism spectrum disorders in epidemiological research. This was the third measure used to determine eligibility of children with symptoms of ASD in the study. The CAST has

previously demonstrated good accuracy for use as a screening test, with high sensitivity in studies with primary school aged children. A score of 15 or higher was used in this study to determine a diagnosis of an autism spectrum disorder, as suggested by Scott, Baron-Cohen, Bolton, and Brayne (2002). The CAST has demonstrated moderate test-retest reliability within a two month period, with a kappa of 0.41, and 74% of children receiving the same diagnostic identification (Allison et al., 2007). Cronbach's alpha for the CAST in the current sample was 0.66.

**Inclusion measure.** The Verbal Comprehension Index (VCI) of the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV; Wechsler 2003) was used to obtain a measure of verbal intelligence as part of the eligibility screening process. The three subtests administered were Similarities, Vocabulary, and Comprehension. The VCI is a measure of word knowledge and retrieval, verbal concepts and reasoning, and social knowledge and awareness. The composite score derived from the VCI has an internal consistency reliability of .94 (Williams, Weiss, & Rolfhus, 2003). For the purpose of the study conducted by the 3-C Institute for Social Development, from which these data were taken, children must have received a VCI score of equal to or above 85 for study inclusion. This cutoff was set to one standard deviation below the mean due to the highly verbal nature of the intervention being tested in the larger study.

**Inclusion measure.** The Child Behavior Checklist Parent Form (CBCL) is a 140-item measure designed for children in Elementary, Middle, and High school (Achenbach, 2001). It measures children's behavior problems and competencies, as well as behavior changes over time or after treatment. It is designed to be completed by the parent or caregiver of the child. Subtest/scores include: Aggressive Behavior, Anxious/Depressed,



Attention Problems, Delinquent Rule-Breaking Behavior, Social Problems, Somatic Complaints, Thought Problems, Withdrawn, Externalizing, Internalizing, Total Problems, plus DSM-oriented scales. The CBCL takes 15 minutes to complete. This scale has test-retest reliability of .90 and an alpha coefficient of .94. The Aggressive Behavior scale was used to exclude children with significant behavior problems that would affect the ability to participate in the intervention being tested in the larger study. Children who received a T score of 70 and above were excluded from the study.

**Measure of parenting stress.** The Parenting Stress Index-Third Edition (PSI; Abidin 1995) was used as an outcome variable in this study. This 120-item scale is used in early identification of dysfunctional parent-child systems, identification of areas for prevention programs aimed at reducing stress, identification of areas needing intervention and treatment planning in high stress areas, family functioning and parenting skills, child-abuse risk, and forensic evaluation for child custody. Parents responded to statements on a 5-point Likert-type scale (strongly agree, agree, not sure, disagree, or strongly disagree). The PSI can be completed in approximately 20 to 30 minutes (Loyd & Abidin, 1985). The Total Stress, Child Domain, and Parent Domain scores of the PSI were used as the dependent variables in this study. The Total Stress score is calculated by adding the raw scores of the Child Domain and the Parent Domain. The subscales that comprise the Child Domain are Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. The subscales that make up the Parent Domain are Competence, Isolation, Attachment, Health, Role Restriction, Depression, and Spouse. Reported coefficient alpha reliability coefficients are .93 for the Parent Domain, Child Domain .90, and Total Stress .95 (Loyd & Abidin, 1985). Cronbach's alpha for the current sample on the Total Stress scale

was .87. The PSI has been empirically validated to predict observed parenting behavior and children's current and future behavioral and emotional adjustment (Abidin, 1995), not only in a variety of U.S. populations, but also in a variety of international populations.

**Measure of social skills and problem behaviors.** The Social Skills Rating System (SSRS; Elementary Level; Gresham & Elliott, 1990) can be used to assess parent, teacher, and child report of the child's social skills. The SSRS is a standardized measure that assesses the perceived frequency with which certain social skills and behaviors are exhibited in the home and community. The SSRS generates scores in five social domains: Cooperation (e.g., helping, sharing), Assertion (e.g., initiating, responding to others), Responsibility (e.g., communication with adults, regard for property), Empathy (e.g., concern and respect for others), and Self-Control (e.g., turn-taking, responses to conflicts). The SSRS also has a Problem Behaviors domain that assesses Internalizing problems, Externalizing problems, and Hyperactivity. The SSRS has been found to have acceptable internal consistency, test-retest and inter-rater reliability, and content, construct, discriminant, and criterion-related validity (Gresham & Elliott, 1990). Internal consistency ratings for the parent report of the Social Skills domain are .87 to .90. Internal consistency for the Problem Behaviors domain is .73 to .87 for parent report. Test-retest reliability for the Social Skills domain is 0.87 for the parent report. The test-retest reliability for the Problem Behaviors domain for the parent report is .65 (Gresham & Elliott, 1990). In this study, parents rated the frequency of behaviors on a 3-point scale (Never, Sometimes, and Very Often), which correspond to scores of zero, one, and two respectively. Raw scores for each subscale were acquired by summing the scores for each item in that subscale. Each relevant subscale was summed to find the Total raw score for each domain. Comparisons were made using the standard scores and percentile rankings

for the “Social Skills” and “Problem Behaviors” scales, based on the Total raw scores for these domains (Gresham & Elliot, 1990).

**Measure of social support.** The Family Support Scale (Dunst, Trivette, & Jenkins, 1986) is a measure of parents’ satisfaction with the support they receive in raising a child. It consists of 18 items covering sources of support such as immediate family, relatives, friends, and others in the family’s social network, social organizations, and specialized and generic professional activities. Parents rate each existing source of support on a 5-point Likert scale ranging from not at all helpful (1) to extremely helpful (5). The FSS takes approximately 10 minutes to complete. The reported internal consistency reliability coefficient alpha is .77, split half reliability is .75, and test-retest reliability (1 month interval) is .75 for the average correlation of the 18 items and .91 for the total scale scores. Cronbach’s alpha for the FSS in the current sample is .76. This measure was used to identify areas of support for the family.

Table 2

*Measurement Information*

	Variable Description	Score Range	Scoring	Normative Value
<b>Eligibility</b>				
SCQ total	ASD screener	0-40	Sum (cutoff 15)	10.8
ASSQ total	ASD screener	0-81	Sum (cutoff 15)	6.56
CAST total	ASD screener	0-37	Sum (cutoff 15)	4.73
WISC-IV VCI	Verbal IQ	40-160	Composite	100
<b>Dependent Variable</b>				
PSI total stress	Total stress level	0-600	Sum	213.25
<b>Independent Variables</b>				
SSRS social skill	Total social skills	1-114	Sum	52
SCQ communication/abnormal language	ASD related communication difficulties	0-13	Sum	NA
SCQ stereotyped behavior	Restricted, repetitive, and/or stereotyped behaviors, interests)	0-8	Sum	NA
SSRS problem behaviors	Externalizing, Internalizing, Hyperactivity	1-51	Sum	13
<b>Moderator</b>				

### Data Analysis Plan

Data were analyzed using version 15.0 of the SPSS-PC statistical package.

**Question one.** Do parents of children with HFASD experience higher levels of parenting stress compared to the general population (normative population from PSI)? To address the first question, raw scores from the Parenting Stress Index (PSI) – Third Edition were used (Abidin, 1995). Descriptive statistics (e.g., mean, median, standard deviation, range, percent of scores in the normal range [15<sup>th</sup> to 80<sup>th</sup> percentile = normal range], and percent of scores in the high range [scores at or above the 85<sup>th</sup> percentile = high]) were reported. A  $z$ -test was calculated to assess whether the mean level of parenting stress found in this sample was statistically different from the level of parenting stress found in the normative population. All PSI total scores, domain scores, and subscale scores were compared to the published norms as cited in the PSI manual (Abidin, 1995).

Forty-one percent of the norm group for the PSI norms was recruited from well-child-care pediatric clinics in Central Virginia, while 20% were from public school day care centers in Virginia, 10% from a health maintenance program in Massachusetts, 12% from private and public pediatric clinics in New York City, 7% from private pediatric practices in North Carolina, 6% from private and public pediatric clinics in Georgia, and 4% from public schools in Wisconsin. The normative sample also included 3.6% children who had been referred to the clinics for diagnostic services related to behavioral or chronic health problems such as diabetes. The total sample size of the normative sample was 2,633 mothers ranging in age from 16 to 61 (Mean age = 30.9). Ethnic group composition was 76% White, 11%

African American, 10% Hispanic, and 2% Asian. The children of the parent sample ranged in age from 1 to 12 years of age with a mean age of 4.9 years (SD=3.1).

**Predicting Parenting Stress with Child Symptomatology.** To address questions two through six, hierarchical linear regression was conducted to determine the most reliable and robust prediction of parenting stress using child HFASD symptomatology. Parental social support and child behavior problems were included in the first block of the model to control for their effects. Block two included the variables for social difficulties, communication difficulties, and restricted, repetitive, and/or stereotyped behaviors, interests, and activities. Because there is no clear theoretical or causal reason to input one of these symptoms before another, these three variables were entered simultaneously. Raw scores from the Parenting Stress Index-Third Edition (PSI), the Family Support Scale (FSS), the Social Communication Questionnaire (SCQ), and the Social Skills Rating System (SSRS; parent report) were used in these analyses.

**Question two.** Are behavior problems of children with HFASD a significant predictor of parenting stress after controlling for parental social support?

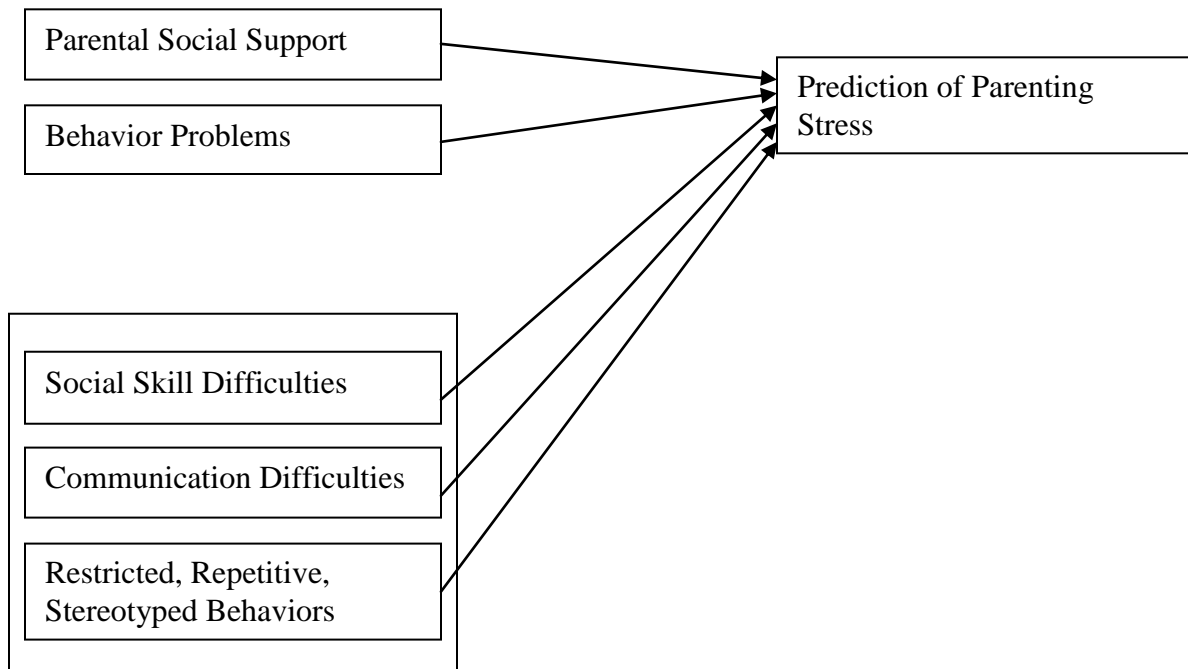
**Question three.** Do the social difficulties of children with HFASD predict higher parenting stress after controlling for behavior problems and parental social support?

**Question four.** Do the communication difficulties of children with HFASD predict higher parenting stress after controlling for behavior problems and parental social support?

**Question five.** Do the restricted, repetitive, and/or stereotyped behaviors, interests, and activities of children with HFASD predict higher parenting stress after controlling for behavior problems and parental social support?

**Question six.** Is the total HFASD symptomatology (combined difficulties in social, communication, and restricted, repetitive, and/or stereotyped behaviors, interests, and activities) of children with HFASD a significant predictor of high parenting stress after controlling for behavior problems and parental social support?

Figure 1. *Model for Questions Two through Six*

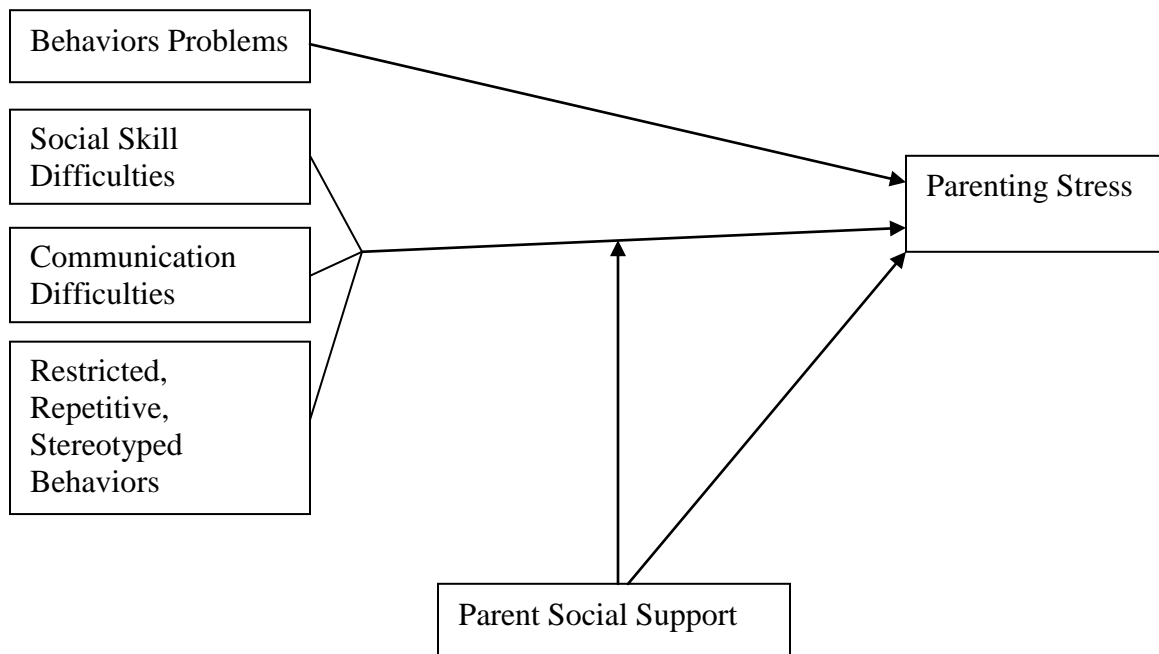


**Moderation of HFASD Symptom’s Relationship with Parenting Stress by Parental Social Support.** To address question seven, hierarchical linear regression was conducted to determine the moderating effect of social support on the various HFASD symptoms’ relationships with parenting stress (Holmbeck, 1997). Interaction terms were created for each of the three HFASD symptoms. Social support, behavior problems, and the three HFASD symptoms were entered in the first model, followed by the interactions terms in the second model. Raw scores from the Parenting Stress Index-Third Edition (PSI), the

Family Support Scale (FSS), the Social Communication Questionnaire (SCQ; Communication/Abnormal Language and Stereotyped Behavior scales), and the Social Skills Rating System (SSRS; Social Skills and Problem Behaviors scales) were included in this analysis.

**Question seven.** Does social support moderate the relationship between child characteristics and parenting stress?

Figure 2. *Model for Question Seven*



## **Chapter Four:**

### **Results**

#### **Preliminary Analyses**

**Missing data.** In the first stage of data analysis, the data were screened for missing data, normality, multicollinearity, outliers, and errors. Missing data were identified by inspecting frequency tables. For the SCQ Total Score, data were complete for 84% of the cases. For the SCQ Stereotyped Behavior domain, data were complete for 93% of the cases. For the SCQ Communication/Abnormal Language domain, data were complete for 95% of the cases. For the PSI Total Raw score, data were complete for 96% of the cases. For the SSRS Social Skills domain, data were complete for 98% of the cases. For the SSRS Problem Behaviors domain, data were complete for 98% of the cases. For the FSS, data were complete for 95% of the cases.

The values of the missing data were estimated using the expected maximization (EM) algorithm for the maximum likelihood (ML) estimation in SPSS version 15.0. Step one of the EM algorithm computed the expected value of the complete data log likelihood given the current parameter values. The second step substituted the expected values for the missing data calculated in step one and maximized the expected log likelihood to get the new parameter estimates. As suggested in Allison (2003), steps one and two were repeated until convergence was obtained. Allison (2003) states that “the probability that data are missing on Y may depend on the value of X, but does not depend on the value of Y, holding X



constant". The EM algorithm for the ML estimation assumes missing values are missing at random (MAR; Allison, 2003, Potthoff, Tudor, Pieper, & Hasselblad, 2006). To test the assumption that data were missing completely at random (MCAR), a chi-square test was used to compare the participants with incomplete data to those participate with complete data. Little's MCAR test was not significant and the data was therefore assumed to be MCAR. EM is advantageous because it avoids impossible matrices, avoids overfitting, and produces realistic estimates of variance. Listwise deletion was not the preferred method because it leads to a decrease in power and possibly biased results.

**Testing assumptions and for problems with the data.** Next, data were screened for multicollinearity. Variance Inflation Factor (VIF) for each variable was examined for overly high correlation among the independent variables. All VIFs were less than four, indicating multicollinearity was not overly problematic with respect to the stability of the regression coefficients.

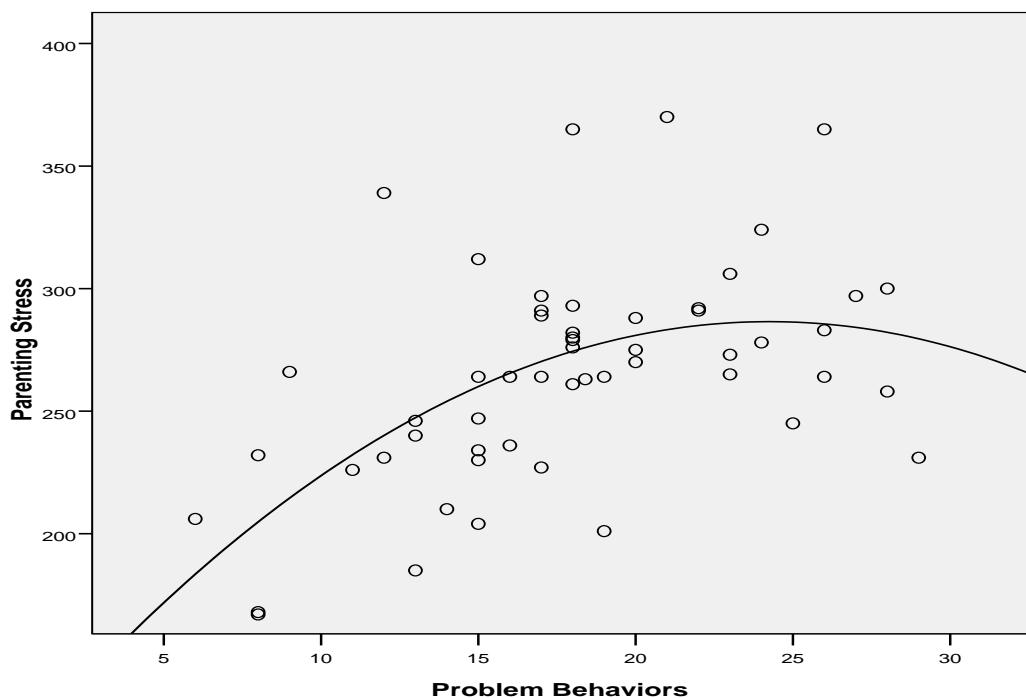
Normality was assessed to ensure residuals were normally distributed and were of constant variance over the independent variables. This was done by examining a histogram of the residuals, a normal probability plot, and a scatterplot between predicted scores and residuals. Both independent and dependent variables were examined for univariate and multivariate outliers using histograms and normality plots. Mahalanobis distance was calculated and no multivariate outliers were found with  $p < .001$ . Multivariate outliers were analyzed with respect to influence using Cook's Distance (Tabachnick & Fidell, 2001). Cook's Distance was calculated for each of the data points in the set and an index plot was created using these values. The index plot was then examined and all values were found to be within tolerable range. One outlier was found to have Cook's Distance greater than one.

Inspection of the data revealed that this participant had failed to complete numerous measurements, so this case was excluded from analysis.

Multivariate linearity was examined using residual plots and scatterplots of the dependent variable plotted against each independent variable. A nonlinear relationship between Problem Behaviors and Total Parenting Stress was detected. In order to address this issue, a quadratic term was created by squaring the Problem Behaviors variable. The inclusion of this variable was found to be significant,  $p < .05$ .

Figure 3.

*Problem Behaviors and Total Parenting Stress Plot*



The assumption of homoscedasticity was examined to minimize biased significance levels through scatterplots of the residuals. None of the scatterplots revealed significant heteroscedasticity. Data were also screened to ensure that errors of predication were independent of one another. The Durbin-Watson test of autocorrelation was used to check

the assumption that errors of prediction were independent of one another (Tabachnick & Fidell, 2001). The Durbin-Watson coefficient was 1.9 and in the acceptable range, indicating independent observations.

### **Descriptive Analyses**

Descriptive statistics were calculated for the data from each measure. The first measure analyzed was the Parenting Stress Index. The mean parent stress level for parents of children in this sample was 265.1 with a standard deviation of 44.2. The ratio of skewness to its standard error was .39 and the ratio of kurtosis to its standard error was .78. These ratios suggest that the data are somewhat normally distributed.

Table 3

#### *Descriptive Statistics for Dependent Variable*

Variable	Current Sample						Normative Sample	
	Mean	SD	Median	Mode	Range	% of scores above 85 <sup>th</sup> %	Mean	SD
PSI Total Stress	265.10	44.20	264.86	264.00	203.00	62.10	213.25	35.0
Life Stress	6.30	6.04	5.50	0.00	27.00	13.10	7.8	6.2
Parent Domain	126.48	27.44	122.50	109.00	151.00	17.00	123.1	24.4
Competence	27.83	6.57	27.00	26.00	32.00	15.00	29.1	6.0
Isolation	16.25	11.44	14.00	14.00	86.34	24.20	12.6	3.7
Attachment	13.46	9.84	11.00	11.00	73.00	16.90	12.7	3.2
Health	13.32	9.81	12.00	10.00	75.00	18.70	11.7	3.4
Role Restriction	19.41	9.30	17.50	16.00	67.00	48.30	18.9	5.3
Depression	20.67	7.08	20.00	17.0	46.00	11.40	20.3	5.5
Spouse	20.20	10.88	18.97	22.00	82.00	33.50	16.9	5.1
Child Domain	136.48	21.95	137.50	161.00	106.00	83.80	99.7	18.8
Distractibility/ Hyperactivity	28.70	5.33	28.50	23.00	22.00	38.90	24.7	4.8

Adaptability	34.81	6.43	35.00	34.00	32.00	77.80	24.9	5.7
Reinforces Parent	14.20	4.22	14.00	12.00	21.00	76.00	9.4	2.9
Demandingness	25.82	6.79	27.00	29.00	25.00	68.70	18.3	4.6
Mood	13.91	3.77	14.00	11.00	16.00	67.7	9.7	2.9
Acceptability	18.96	3.75	19.00	18.00	17.00	85.3	12.6	3.5

\*N = 2633, \*\*n = 54 from current study

Next, the total score from the SCQ and the SCQ subscale scores were analyzed using descriptive statistics. As seen in table 4, the mean for the SCQ Total scores on the measure was 15.82. The means for the Communication/Abnormal Language and Stereotyped Behavior subscales were 5.26 and 4.46, respectively. The skewness and kurtosis ratios for the SCQ Total score and both subscales were less than one in all cases.

Table 4

*Descriptive Statistics from SCQ*

SCQ scale	Mean	SD	Median	Range
SCQ Total	15.82	4.81	15.82	23
SCQ Communication/Abnormal Language	5.26	2.1	5	8
SCQ Stereotyped Behavior	4.46	2.1	4.45	8

Scores for behavior problems and social skills were derived from the Social Skills Rating System (SSRS). The mean score for the Social Skills subscale was 33.89 with a standard deviation of 9.1. The skewness ratio for the Social Skills subscale was 1.96 indicating significant positive skewness. However, the robust nature of the general linear model provides reasonably unbiased and accurate inferential statistics for data with this level of skewness (Tabachnick & Fidell, 2001). The kurtosis ratio was .09. The mean score for the Problem Behaviors domain was 18.02 with a standard deviation of 5.58. The skewness ratio for the Problem Behaviors domain was 0 and the kurtosis ratio was -.67.

Table 5

*Descriptive Statistics from SSRS*

Domain	Mean	SD	Median
Social Skills	33.89	9.06	33.00
Problem Behaviors	18.02	5.58	18

The mean score for the Family Support Scale was 36.28 with a standard deviation of 11.23. The median was 36.34. The skewness ratio for the Family Support Scale was 1.66 indicating slight positive skewness. Again, the robust nature of the general linear model provides reasonably unbiased and accurate inferential statistics on data with this level of skewness (Tabachnick & Fidell, 2001). The kurtosis ratio was .79.

**Results for Question One**

Research question one asked if parents of children with HFASD experience higher levels of parenting stress compared to the general population (normative population from PSI). A *z*-test was calculated to assess whether the mean level of parenting stress found in the sample was statistically different from the level of parenting stress found in the normative population. PSI total scores and the Child Domain scores were compared to the published norms cited in the PSI manual (Abidin, 1995).

The mean score for the normative population for the PSI Total Score was 213.25. The mean for the sample was 265.1 for the PSI Total Score. There was a significant difference in the Total Stress scores between parents in this sample and the normative population,  $z = 10.78, p < .001$ . The effect size measure of the difference between this sample and the normative population on the PSI Total Score was very large,  $d = 1.47$ . For the Child Domain, there was a significant difference in scores between parents in this sample and the normative population,  $z = 14.42, p < .001$ . The effect size measuring the difference

between this group of parents of children with HFASD and the normative population on the Child Domain was again very large,  $d = 1.96$ . Therefore, parents in this study show significantly higher levels of overall parenting stress than parents in the normative population. Because the scores on the Child Domain for these two groups were significantly different, it appears that the difference in overall parenting stress can be attributed to characteristics of children with HFASD. These results support Hypothesis One: parents of children with HFASD experience higher levels of parenting stress than the normative population.

### **Results for Question Two**

Question two asked if the behavior problems of children with HFASD are a significant predictor of parenting stress after controlling for parental social support. In order to investigate the relationship between behavior problems and stress in parents of children with HFASD, a linear regression analysis was conducted using data from the SSRS Problem Behaviors domain to predict parenting stress as measured by the Total Stress score from the Parenting Stress Index (Abidin, 1995). When the scatterplot for these two variables was examined, it revealed a nonlinear relationship. Therefore, polynomial regression was used to extend the linear regression model to allow for the fitting of a nonlinear relationship. The shape of the data in the scatterplot suggested a quadratic model would provide the best fit while retaining interpretability. In order to facilitate interpretation, the data on the problem behaviors variable were mean-centered. The data for the problem behaviors variable were then squared to create the quadratic term.

A hierarchical regression analysis was conducted to predict the overall parenting stress from the HFASD symptomatology of the child and the child's problem behaviors,

while controlling for social support. The following analysis was used to answer questions two through six. In order to partial out the effects of social support on parenting stress, the parental social support variable was entered into the model first by itself. By itself, social support explained almost none of the variance in parenting stress,  $R^2 = .005$ ,  $F(1,52) = .24$ ,  $p = .63$ .

The next model contained the social support variable and the problem behaviors variable. The increment in  $R^2$  showed that problem behaviors explained a significant amount of the variance in parenting stress, above and beyond the variance explained by social support,  $sr^2 = .23$ ,  $F(1,51) = 15.61$ ,  $p < .001$ . Then, the quadratic term was added to the model in step three. Like the linear problem behaviors variable, the quadratic term explained a significant amount of the variance in parenting stress above and beyond the other variables in the model,  $sr^2 = .07$ ,  $F(1, 50) = 5.1$ ,  $p = .03$ , supporting the decision to include it. In order to determine the total amount of variance explained by problem behaviors, the linear and quadratic terms were combined into a set and the semi-partial squared multiple correlation was determined. Together, the linear and quadratic behavior problems variables explained 30.39% of the variance in parent stress,  $sr^2 = .30$ ,  $F(2,51) = 10.99$ ,  $p < .001$ .

The equation including the quadratic term was as follows:  $\hat{Y} = 274.6 + 3.86X_1 - 0.31X_1^2$ . Written a different way, the equation looks like this:  $\hat{Y} = 274.6 + (3.86 - 0.31X_1)X_1$ . This equation indicates that the effect of problem behaviors on parenting stress depends on its level. At lower levels, small increases in problem behaviors predict larger increases in parenting stress than they do at high levels. Cudeck and du Toit (2002) suggested an alternative parameterization of this model that allows for substantive interpretation of the parameters. In this model, an alternative form is given by:

$\hat{Y} = \alpha_0 - (\alpha_Y - \alpha_0) \left[ \frac{X}{\alpha_X} - 1 \right]^2$ . The parameters in this equation may be interpreted as such:

$\alpha_0$  is the predicted value of Y when X=0;  $\alpha_X$  is the maximum value of  $\hat{Y}$ ;  $\alpha_X$  is the value of X when  $\hat{Y}$  is at its maximum. The parameters can be derived using the following equations:

$\alpha_0 = B_0$ ;  $\alpha_Y = B_0 - \frac{B_1^2}{4B_2}$ ;  $\alpha_X = \frac{-B_1}{2B_2}$ . In this case, the parameter of interest is  $\alpha_X$  as it

indicates the level of problem behaviors at which parenting stress is no longer predicted to increase. In this case, that value is 6.21 above the mean, or 24.23. Additionally, because the data were centered, the coefficient  $B_1$  may be interpreted to mean that the slope of the line when X is at its mean is 3.86, meaning that a one unit increase in problem behaviors for someone at this level ( $\mu=18.02$ ) would predict a 3.86 unit increase in parenting stress.

### **Results for Question Three**

Questions three through six were investigated through the hierarchical linear regression analysis referred to in question two. Parental social support and child behavior problems were included in the first block of the model to control for their effects. Block two included the variables for social difficulties, communication difficulties, and restricted, repetitive, and/or stereotyped behaviors, interests, and activities.

Question three asked if the social difficulties of children with HFASD predict higher parenting stress. Table 6 shows that the social skills variable is significant, explaining 10% of the total variance in the parenting stress variable. The beta weight for social skills shows that a one standard deviation increase in social skills difficulties predicts a .38 standard deviation decrease in parenting stress, after controlling for parental social support and behavior problems.



### **Results for Question Four**

Question four asked whether the communication difficulties of children with HFASD predict higher parenting stress. The communication/abnormal language variable explained two percent of the variance, above and beyond parental social support, behavior problem (linear), behavior problems (quadratic), and social skills. Table 6 shows that a standard deviation increase in communication/abnormal language predicts a .16 standard deviation increase in parenting stress, holding all other variables constant. However, this beta weight is not significantly different from zero.

### **Results for Question Five**

Question five asked if the restricted, repetitive, and/or stereotyped behaviors, interests, and activities of children with HFASD predict higher parenting stress. The stereotyped behavior variable explained three percent of the variance respectively, above and beyond parental social support, behavior problem (linear), behavior problems (quadratic), social skills, and communication difficulties. Table 6 shows that a standard deviation increase in stereotyped behavior predicts a .18 standard deviation decrease in parental stress, holding all other variables constant. However, this beta weight is not significantly different from zero.

### **Results for Question Six**

Question six asked if the total HFASD symptomatology (combined difficulties in social skills, communication skills, and restricted, repetitive, and/or stereotyped behaviors, interests, and activities) of children with HFASD is a significant predictor of parenting stress. The semi-partial squared multiple correlation for the set showed that the general symptomatology for HFASD was a significant predictor of parenting stress,  $sr^2 = .21$ ,  $F(3,47)$

= 6.93,  $p < .001$ . While the set as a whole explained a significant amount of the variance in parenting stress, not all of the individual symptom variables were significant predictors.

Table 6

*MLR Predicting Parenting Stress*

Predictor	B	$\beta$	$t$	p	$sr^2$
Intercept	274.1	0	10.83	<.001	n/a
Social Support	-.03	-.03	-.25	.81	<.001
Behavior (Linear)	3.27	.34	2.96	.005	.23
Behavior (Quadratic)	-.3	-.27	-2.57	.01	.07
Social Skills	-2.13	-.38	-3.2	.003	.10
Communication/Abnormal Language	2.89	.16	1.34	.16	.02
Stereotyped Behavior	-3.73	-.18	-1.63	.11	.03

**Results of Question Seven**

In this question, the relationship of interest is the moderating effect of social support on the various HFASD symptoms' relationships with parenting stress. Therefore, three terms were created to carry the interaction with parenting stress: one for each HFASD domain of interest. In order to create these interaction terms, the scores for each subject on the social skills measure, the communication/abnormal language subscale, and the stereotyped behavior subscale were each multiplied by that subject's parental social support score. In order to facilitate interpretation and eliminate problematic multicollinearity effects, all scores in the model were centered (Aiken & West, 1991).

This model contains a total of nine terms that were entered in a two-step hierarchical linear regression. As suggested by Holmbeck (1997) the predictors and moderator's main effects were entered in the regression equation first, followed by the interactions of the predictors and the moderator. In step one, the six terms from the original model [social

support, behavior (linear), behavior (quadratic), social skills, communication/abnormal language, and stereotyped behavior] were entered to partial out their effects on parenting stress (see Table 6). In the second model, the interaction terms were added and their unique effects examined.

The original model, shown in Table 6, explained 52% of the variance in parenting stress. With the addition of the interaction terms, 57.8% of the variance was explained by the new model. However, this increase in the amount of variance explained was not significantly different from zero,  $sR^2 = .057$ ,  $F(3, 44) = 1.99$ ,  $p = .13$ . Predictably, the individual regression coefficients are also not significantly different from zero.

Table 7

*Interaction Terms*

	$\beta$	$t$	p	$sr^2$
Parental Social Support-Social Skills Interaction	-.15	-1.28	.21	.02
Parental Social Support-Communication Interaction	-.14	-1.21	.23	.01
Parental Social Support-Stereotyped Behavior Interaction	-.13	-1.12	.27	.01

**Supplemental Statistical Analysis**

In order to rule out alternative explanations for the results presented here, one additional analysis was run. The supplemental analysis employed here compares the results of the scale utilized in this study to measure children’s social skills (SSRS–Social Skills domain) with a similar measure utilized as part of the screening process (SCQ–Social Interaction subscale). The results from both measures were input into separate simple linear regression equations to compare their ability to explain variance in parenting stress. The results from the analysis utilizing the Social Interaction subscale of the SCQ as a predictor of parenting stress showed that the amount of variance explained by this measure was not

significantly different from zero,  $sr^2 = .06$ ,  $F(1,53) = 3.27$ ,  $p = .08$ . The results from the equation utilizing the SSRS social skills scale, on the other hand, showed that it was able to explain a portion of the variance significantly greater than zero,  $sr^2 = .35$ ,  $F(1,53) = 28.11$ ,  $p < .0001$ .

## **Chapter Summary**

This chapter explored a number of questions regarding stress in parents of children with HFASD. The research questions investigated in this dissertation are as follows: (1) Do parents of children with HFASD experience higher levels of parenting stress than the normative population? (2) Do the social difficulties of children with HFASD predict higher parenting stress? (3) Do the communication difficulties of children with HFASD predict higher parenting stress? (4) Do the restricted, repetitive, and/or stereotyped behaviors, interests, and activities of children with HFASD predict higher parenting stress? (5) Is the total HFASD symptomatology of children with HFASD a significant predictor of parenting stress? (6) Are behavior problems of children with HFASD a significant predictor of parenting stress? (7) Does social support moderate the relationship between child characteristics and parenting stress?

This study consisted of 55 children with HFASD and one of their parents. Parents completed self-report measures on parental stress levels and social support as well as measures on child characteristics related to behavior and the symptomatology of autism spectrum disorders. Scores on these measures were used as variables in hierarchical linear regression models.

The results of these analyses suggest that: (1) parents of children with HFASD experience higher stress levels than parents in the normative population (2) greater

difficulties with social skills and behavior problems among children with HFASD are associated with higher parenting stress (3) communication difficulties and stereotyped behavior do not predict higher parenting stress (4) higher levels of total HFASD symptomatology are associated with increased parenting stress (5) social support does not moderate any of the other variables' effects on parenting stress.

## **Chapter Six:**

### **Discussion**

This study examined the relationship between social support, child symptomatology, and levels of parenting stress. More specifically, the study investigated the effects of children's behavior problems, communication skills, social skills, and restricted, repetitive, stereotyped behaviors on levels of stress among parents of children with HFASD. Furthermore, the study examined whether social support moderated these relationships. The findings and implications are discussed in detail below.

#### **Parent Stress Levels**

While numerous research studies have documented that parents of children with ASD have the highest stress levels of parents of children with disabilities, there is a gap in our knowledge for parents of children with ASD and intellectual levels in the average range or higher. More specifically, the paucity of research exists for parents of children with HFASD in two areas: (a) stress levels of parents of children with HFASD, and (b) if stress levels are higher, the factors contribute to the elevation of those levels.

Overall, the present findings provide empirical support for the hypothesis that parents of children with HFASD experience significantly higher stress levels than parents in the normative population. Parents in this sample had children between the ages of eight and 12 with diagnoses of Autism, Asperger's syndrome, or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). These children also had a Verbal Intellectual Quotient of 85 or greater. The stress levels of parents in this sample were compared to the normative

population provided by the Parenting Stress Index manual (PSI; Abidin, 1995). The stress levels of parents in this sample were significantly higher than the stress levels of parents in the normative population, supporting the hypothesis that, like parents of children with autism, parents of children with HFASD have higher stress levels than parents in the general population.

In order to ensure that child characteristics and not an extraneous variable accompanying the parenting of a child with HFASD were to blame for higher parenting stress, both the overall level of parenting stress and the child domain were examined. While the difference between parents in this sample and parents in the general population was large for overall levels of stress, there was an even greater difference between the two populations when only the child domain was examined. This suggests that characteristics associated with the child such as the child's lack of adaptability, demandingness, and inability to fully reinforce the parent were responsible for a majority of the stress associated with parenting a child with HFASD. These findings extend the work of Little (2002), who found that children with either a Nonverbal Learning Disability or HFASD had parents with higher stress levels than the general population. In the present study, though, only children with forms of HFASD were studied, allowing claims to be made regarding that population alone.

Because children with HFASD have average or higher cognitive abilities and adequate verbal abilities, it may be tempting for practitioners and clinicians to believe that parents in this population do not suffer from elevated stress levels due to their children's diagnoses. However, these data suggest that this conclusion would be erroneous. Studies of children with autism have shown that higher parenting stress levels can be associated with fewer gains through interventions (Gabriels et al., 2001; Osborne et al., 2008). Moreover,

high levels of parenting stress and maladaptive behaviors in children have been found to create a negative feedback loop, causing increases in both stress and problem behaviors (Baker et al., 2003). It seems not only possible but likely that these outcomes would hold true for the population in question here, given the results of the current study. Therefore, those working with both children with HFASD and their parents have cogent reasons to focus on reducing or eliminating parenting stress as part of treatment for both parents and children.

### **Child Characteristics Associated with Parenting Stress**

For the population of interest in this study, little was known regarding sources of stress for these parents. Beck et al. (2004) found that a combination of behavior and poor social skills in children with autism predicted higher levels of parenting stress. The present study found both of these factors to be associated with parenting stress in children with HFASD as well.

It was hypothesized that higher levels of problem behaviors would predict higher levels of parenting stress in this sample. The data supported this hypothesis, finding problem behaviors to explain a significant portion of the variance in parenting stress. However, the relationship between problem behaviors and parenting stress was not found to be a straightforward linear relationship. At low levels, smaller increases in behavior problems predicted greater increases in parenting stress than at higher levels. For example, the parent of a child scoring 14.23 on the problem behaviors scale is predicted to have a score of 205 on the PSI, while the parent of a child scoring a 15.23 on the problem behaviors scale is predicted to have a score of 214.75, a difference of 9.75. In contrast, the parent of a child scoring 29.23 on the problem behaviors scale is predicted to have a score of 286.15 on the PSI, while the parent of a child scoring 30.23 on the problem behaviors scale is predicted to



have a score of 286.6, a difference of only .45. Although in both cases, the difference in scores on the PSI was one, the predicted difference differed dramatically, depending on the level of problem behaviors in the child.

One possible explanation for these findings is that problem behaviors cause parents' stress only up to a certain point. After this point, parents have reached a stress level that is near their maximum, precluding further large increases. Another possible reason for these results could be that parents begin to seek out resources that contribute to resilience only when behavior problems reach a certain point. Because these parents have more protective factors, their stress levels may not continue to increase as they did when behavior problems were more manageable. This study's data suggest that social support was not a factor in this manner, making the former explanation more likely than the latter. However, future studies may be conducted using qualitative methods such as interviews, observations, and focus groups to determine if either of these explanations is plausible.

This study also sought to prove that the symptomatology of children with HFASD (difficulties with social skills, communication skills, and repetitive/stereotyped behaviors) contributed to parenting stress, above and beyond the effects of behavior problems. In order to accomplish this, the HFASD characteristics of interest were studied both as a group and individually. The data supported the hypothesis that the overall HFASD symptomatology was associated with increased parenting stress as this set of variables explained a significant amount of the variance in parenting stress. This finding is concurrent with research on parents of children with autism that found autism symptomatology to be highly associated with parenting stress (Freeman et al., 1991; Hastings & Johnson, 2001; Kasari & Sigman, 1997; Konstantareas & Homatidis, 1989).

The data suggest that lower levels of social skills are highly correlated with parenting stress while difficulties with communication and stereotyped/repetitive behaviors were not. This result supports the finding of Ornstein-Davis and Carter (2008), who found that social skills deficits were the single greatest predictor of stress for parents of children with ASD. This relationship was hypothesized to exist because the parent/child relationship hinges on social skills such as empathy, cooperation, and self-control. The absence of these skills in the child can cause parents frustration and a feeling of being unfulfilled by their children. This relationship may be especially important in parents of children with HFASD versus parents of children with ASD because of the subtle nature of the social deficits found in HFASD. The difficulties with reciprocity are more obvious among children with autism and low intellectual functioning. Reciprocity is an example of a social skill that is more subtle in children with HFASD that may leave parents feeling unsuccessful in bonding with their child. The findings here support this hypothesis, as there was a strong relationship between low levels of social skills in children and increased parenting stress.

However, it was also hypothesized that difficulties with communication and problems with stereotyped/repetitive behaviors would be significant predictors of parenting stress. Neither of these hypotheses was supported by the data. There are a number of reasons why significant relationships may not have been found by this study.

Some of the reasons involve the methodology employed here. This study utilized data from a larger study examining the efficacy of a social skills intervention for children with HFASD. The measure utilized to gather data on communication and stereotyped/repetitive behaviors was part of the screening process and as such, the range on this measure was restricted to those scoring in the range to become participants in this study.

Although this measure was not the only screening tool, the results from this measure and the other screeners were highly correlated. Cohen, Cohen, West, and Aiken (2003) note that restriction of range in this manner causes a reduction in variance and, therefore, a subsequent reduction in covariance. This reduction could be partially responsible for the fact that these predictors' regression weights were nonsignificant.

Another related issue is that these variables were measured using subscales of a larger measure, the SCQ. As such, they contained fewer items and therefore provided less opportunity for variance. For example, the possible range of scores on the Problem Behaviors domain of the SSRS was from 0 to 36 while the range on the Abnormal Language/Communication subscale of the SCQ only had a possible range of 0 to 9. The small range of scores on the individual subscales could be one reason for the nonsignificant findings with respect to these two variables.

While the last two explanations for the data's failure to bear out the hypotheses dealt with methodological reasons, there are also possible explanations related to the substantive nature of the subject under investigation. One such explanation is that communication difficulties and stereotyped, repetitive behaviors are no longer the deficit of focus for parents of children this age. It is likely that parents of young children with HFASD are highly concerned and consequently stressed by their child's poor communication skills and the highly atypical nature of their repetitive behaviors when they begin to see these difficulties as developmentally abnormal. As these children grow closer to middle childhood and adolescence, parents may become more desensitized to their children's difficulties in communication and repetitive behaviors. During this developmental period, children with HFASD are often teased because of their social naiveté and unusual style of relating

(Ozonoff et al., 2002). In addition, their perspective on friendships is different from those found in the more complex social structure emerging among typically developing children during middle childhood. Children with HFASD value friends who are nice and who have similar interests rather than valuing friendships in which they experience companionship and a deeper social connection like typically developing children at this age. Children with HFASD report feeling sad that they do not have many friends or when friends do not want to play with them. Despite these experiences, the child's lack of ability or motivation to compromise in these social situations can be extremely frustrating for parents (Ozonoff et al., 2002). Because of the significant changes in social structure occurring for all children during middle childhood and the subtlety of the social deficits, poor social skills may become highly concerning to parents.

Another possibility is that the effects of communication difficulties and issues with stereotyped repetitive behaviors on parenting stress may be moderated by variables beyond the scope of this study and population. For example, at low levels of cognitive functioning, children's repetitive/stereotyped behaviors may become a larger cause of stress, acting as the proverbial straw on the camel's back. However, because children with HFASD do not suffer from low cognitive functioning, their repetitive and stereotyped behaviors do not cause a significant amount of stress for parents.

Another issue that is specific to communication deals with verbal intelligence. General cognitive deficits in children with ASD often contribute to difficulties with both expressive and receptive language. In this study, none of the children suffered from severe deficits in verbal IQ, ensuring that they have better expressive and receptive language capabilities than children with ASD. Communication difficulties, in turn, are not as severe in

this sample of children. It is possible that the relationship between communication difficulties and parenting stress is curvilinear with greater communication difficulties predicting higher and higher levels of parenting stress as the difficulties become more severe. Because this population suffers from less severe communication difficulties, the linear relationship between this variable and parenting stress is not significantly different from zero.

Some past research has found that mothers do not perceive communication difficulties to be a source of stress while fathers do (Orenstein-Davis & Carter, 2008). The sample in this study predominantly consisted of mothers. If mothers do, in fact, perceive communication difficulties to be less stressful, then it would be expected for them to be a poor predictor of parenting stress, as was found in this study.

Although the methodological issues outlined previously suggest that these results should be interpreted cautiously, the findings that communication difficulties and repetitive/stereotyped behaviors are not significant predictors of parenting stress suggest some important things for practitioners and clinicians working with children with HFASD and their parents. Specifically, when interventions for this population of children are being designed with one of the goals being to reduce their parents' stress, they should focus more heavily on reducing behavior problems and teaching social skills than they should on teaching communication skills and reducing repetitive/stereotyped behaviors.

### **The Role of Social Support as a Moderator**

Research has shown social support to act as a buffer against parenting stress for families of children with ASD (Sharpley et al., 1997). Therefore, it was hypothesized that social support would moderate the negative effects of the other variables on parenting stress. However, the data did not support this hypothesis. No significant interactions were found

between social support and any other variable. Moreover, social support by itself did not appear to have a significant relationship with parenting stress.

One possible explanation for this finding is that the small sample size in this study ( $N=54$ ) and the large number of variables included in the final model ( $k=9$ ) caused a loss in power to detect differences. However, the extremely small effect sizes associated with these variables suggest the relationships would not be substantively meaningful (range of  $sr^2$ : .001 - .02). Therefore, while a larger sample size may have yielded different results, it seems that this would be unlikely.

Another possible explanation for social support's lack of a relationship with parenting stress deals with the unique features that separate children in this sample from children with ASD and a cognitive impairment. That is, the stressors that uniquely affect parents of children with ASD, but that do not affect parents of children with HFASD, may be ameliorated by increased levels of social support while the ones associated with HFASD may not. For example, communication difficulties have been found to be a significant predictor of stress in parents of children with ASD (Bebko et al., 1987). However, this study has not found communication to be a significant predictor of parenting stress. If social support is an effective way of reducing stress when the source of stress is communication difficulties, then it would have no effect on parents whose stress originates from other sources.

Differences between the demographic characteristics of this sample and that of samples in other studies may also explain social support's lack of a role in explaining variance in parenting stress. In past research investigating the relationship of parental social support and parenting stress, the sample's demographic characteristics have not been revealed (Sharpley et al., 1997). It is possible that participants in that study came from a

wide variety of socioeconomic classes and situations. Rutter (2006) has noted that protective factors like social support can function as such for one group in one situation but not for other groups in other situations. This phenomenon may be occurring here. The sample under consideration in this study comes from largely middle and upper class backgrounds. Therefore, additional stressors associated with poverty may not affect them. Without these additional stressors in play, the range of social support levels across the sample may not act as a protective factor.

### **Study Limitations**

Several methodological limitations of this study should be mentioned. First, the sample used in this study does not necessarily reflect the full demographic population of parents of children with HFASD. Therefore, the results of this study should be applied with caution to parents who do not fit the demographic profile of parents in this study. For example, almost all parents in this study were middle class and white. Practitioners and researchers working with Black, Hispanic, or Asian families or families living in poverty may not find similar predictors of parenting stress. The caution should especially be applied to the finding regarding social support. It seems a strong possibility that, for parents experiencing greater stress for reasons other than their child, social support may be a crucial protective factor in spite of the fact that it was found to be nonsignificant for the sample of parents in this study. It should be noted that the sample from this study was pulled from a unique area of North Carolina with a higher median household income and a higher level of completed education than the rest of the state. In 2004, the Raleigh-Durham-Chapel Hill median family income was \$69,800 and in 2008, 44% of people living in the same area had attained an associate, bachelors, or graduate/professional degree (Office of State Budget and

Management, 2000). This area houses three research universities and eight other colleges and universities and has numerous organizations researching, treating, or supporting families of children with ASD. Given the unique features of this sample, generalization of this study's findings to all families of children with HFASD should be cautioned.

Similarly, the sample utilized in this study does not represent the entire population of children with HFASD. Because of the restrictions of this study's sample from the larger study, children with an IQ below 85 were excluded. Therefore, generalizations regarding parents of children with HFASD who have IQ's less than 85 should be made with great caution. Children with severe aggressive behaviors were also excluded from this study (score  $\geq 70$  on the Aggression Scale of the CBCL). This could have affected the results of this study in that children with more severe aggressive behaviors may be associated with higher levels of parenting stress; however this is unlikely because of the curvilinear relationship between child behavior problems and parenting stress. In addition, caution should be used when generalizing the results found in this study to parents of children with HFASD and severely aggressive behaviors.

Another limitation regarding the demographic make-up of this sample is the low number of female child participants. The average prevalence rate of children with ASD indicates males are more likely to be affected than females, with an average prevalence ratio of 4.3 males to one female (CDC, 2007). However in this sample, the ratio was 54 males to one female. Possible reasons for this ratio may be associated with the goal of the larger study from which this data was collected. The larger study intended to test the efficacy of a social skills intervention targeting children with HFASD. It is possible that parents of females with HFASD are more motivated to seek resources that will allow them to have contact with other



females and avoid social skill interventions that include mostly males. It is also possible that parents of females with HFASD between the ages of 8 and 12 years old are spending their time and energy pursuing interventions targeting deficits other than social skills. In order to generalize these findings to the population of parents of children with HFASD, studies should be conducted to explore the relationship between the characteristics of females with HFASD and levels of parenting stress.

Another demographic factor to consider in this study's sample is the large proportion of White participants. Approximately ninety percent of participants in this sample were White, while other studies have found more congruent prevalence rates for Black and White children (CDC, 2007). In 2006, North Carolina's proportion of White, non-Hispanic children with ASD was 12.2 per 1,000 and the proportion of Black, non-Hispanic children with ASD was 7.5 per 1,000 (CDC, 2009). In that same study, data were collected from eleven states in the US and the proportion of White, non-Hispanic children with ASD in North Carolina (12.1 per 1,000) was higher than the average across all eleven states (9.7 per 1,000; CDC, 2009). It is possible that the large number of White children in this dissertation sample is partially a product of the state's high proportion of White children with ASD. Practitioners and researchers should use caution when generalizing the findings from this study to more racially diverse populations.

It is important to note with this study, as with all studies using a correlational design, that causation cannot be proved using the results. However, some traditional threats to internal validity can be ruled out. It is extremely unlikely that reverse causation and reciprocal causation are issues here, given that ASD's causes appear to be physiological in nature. It is possible, although again unlikely, that there is some third-variable causation in

effect. A genetic cause of ASD could also be associated with increased stress levels in adults. However, it seems more logical that the behaviors and symptomatology examined here are at fault as they have been shown to be causes of stress in other populations as well (Beck et al., 2004).

Still, HFASD symptomatology and behavior issues are complicated and often interrelated. While this study has treated the variables as if they are independent of each other, they may not act as such to the families and children involved. It is possible, for example, that a child's difficulties with communication and social skills translate to frustration for the child. The child may then express this frustration through behavior problems. Therefore, although the results of this study suggest that communication is not a significant predictor of parenting stress, it may in fact be so because of its contribution to other variables' levels.

An issue that is tied to this is the operationalization and subsequent measurement of the variables studied here. Aside from being highly interrelated conceptually, they can also be difficult to clearly define in ways that are consistent across families and measures. In order to gain an idea of how this is so, simple regression equations were set up using the social interaction subscale of the SCQ and the social skills domain of the SSRS. While the subscale of the SCQ failed to be a significant predictor of parenting stress, the social skills measure of the SSRS was a significant predictor of parenting stress and had a significantly greater effect size as well. Both of these measures have excellent reliability and provide data that are valid for making claims of the nature found in this study. It is possible that their slightly different operationalization and measurement of the variable in question, social skills, is the reason for the findings in this study. The social skills scale of the SSRS

measures five positive social behaviors: cooperation, empathy, assertion, self-control, and responsibility. These social skills are rated according to the perceived frequency of each skill. The social interaction component of the SCQ evaluates social functioning in children who may have an ASD. Because the SCQ was designed to be a screener, it taps social behaviors that are specific to the diagnosis of an ASD (e.g., eye to eye gaze, enjoyment sharing), while the SSRS seems to target behaviors that are expected for typically developing children (e.g., gives compliments, responds appropriately to teasing). It is possible that the slightly different goals of the measures and the operationalization of social skills illustrate the difficulties in measuring the various constructs at play in this study.

Another limitation related to measurement in this study was the use of only one rater for all the variables. Although parents are generally accepted as a reliable source of child's behavior, some researchers may prefer to have more than one source of information for behaviors that often require observation of children in social settings to avoid any bias that may be introduced by the parent. Similarly, some researchers have shown that mothers and fathers experience parenting stress differently (Dabrowska & Pisula, 2010). However, in this study, mothers and fathers were treated as members of a single population: parents. Also, because mothers were predominantly sampled, there were not enough fathers in the study to conduct robust statistical analyses. Future research in the area of stressors for parents of children with HFASD may look at treating mothers and fathers separately to gain a better understanding of the similarities and differences between them.

Third, the independent variables depicting child characteristics that were predicted to increase parenting stress levels may not be the only variables that affect parenting stress. In order to add a more comprehensive set of variables to the equations, a much larger sample

would need to be used. Although utilizing a sample of this size was prohibitive in the case of this study, future studies, especially those national in size and scope, could introduce more variables to the regression equations, thereby providing a more complete picture of those factors that contribute to parenting stress in this population.

In addition, there could be other factors that negatively or positively affect parenting stress that were not captured in this study. For example, IQ or comorbid issues such as seizures or tic disorders could have profound effects on parenting stress. It is also possible that parents feel a sense of loss because their child is not the typically developing child they pictured when planning a family. Parents with children with HFASD who were diagnosed later in life may have difficulty reconciling the image they had of their child as academically gifted and awkward versus having a social disorder. These factors could have major implications for determining the level of stress experienced by parents of children with HFASD. Again, though, the size of the sample in this study precluded adding such variables as their inclusion would have reduced the study's power to detect the predictors of interest.

Finally, this study utilized normative data from the PSI and data from a sample of parents of children with HFASD. It is not certain that the PSI population is void of variables that could affect parenting stress. This limits generalizability to the population of parents of children with HFASD. Future research should consider comparing parents of children with HFASD to a control group in order to rule out other possible factors related to parenting stress.

## **Future Research**

Based on the study limitations, several recommendations can be made for future research. First, future studies should survey parents of children with ASD and IQs greater than 70, to more accurately represent the population of parents of children with HFASD. Second, future research should utilize a comparison group of children with ASD and cognitive impairments to compare the stress levels of parents as well as possible child characteristics that affect these levels. Third, data on child characteristics should be acquired from multiple sources. Studies that use multiple raters of child characteristics could provide more reliable results as well as uncover important variations in variables predicting parenting stress. Fourth, future studies should seek to obtain a more economically diverse sample of parents of children with HFASD. It is possible that social support would moderate the effects of HFASD symptomatology on parenting stress for parents at the poverty level.

As future studies begin to accurately identify variables that sufficiently predict higher levels of parenting stress for parents of children with HFASD, those variables should be further investigated using qualitative methods. The question of *why* the predicting variables relate to higher levels of parenting stress could lead to more effective interventions for those characteristics.

Additionally, factors not accounted for in this study that are specific to parents of children with HFASD should be assessed as possible predictors of parenting stress. The higher functioning nature of children with HFASD may be related to a delay in diagnosis and intervention. Studies should examine the effect of a child's age at the time of diagnosis or the time elapsed between a parents' first indication of a problem and the time the diagnosis is given.

Finally, future research should examine the varying time points at which certain HFASD symptomatology or behavior problems predict higher levels of parenting stress. Parents of children with HFASD could be assessed during early childhood, middle childhood, and adolescence for the effects of the development stages on parenting stress.

In conclusion, results from this study support the relationship between parenting stress, child behavior problems, and social skills. The present findings extend previous research by demonstrating the predicting power of social skills and behavior problems on stress levels of parents with children with HFASD. In addition, this study provides preliminary evidence that parents of children with HFASD experience higher stress levels than parents of typically developing children. Future research should continue to examine the child characteristics that relate to high levels of parenting stress, especially those characteristics that are specific to ASD and HFASD.

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